Carers and Social Inclusion

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Abbreviations

ABS	Australian Bureau of Statistics
ADHC	Ageing, Disability and Home Care
ALOs	Aboriginal Liaison Officers
B-SEM	Bristol Social Exclusion Matrix
CALD	Culturally and linguistically diverse
CCS	Canadian Caregiver Strategy
CDC	Consumer Directed Care
Census	Census of Population and Housing
COAG	Council of Australian Governments
CSN	Carer Support Network
CtG	Closing the Gap
FACS	Department of Family and Community Services
FT	Full-time
GPs	General Practitioners
HILDA	Household, Income and Labour Dynamics in Australia
HVWA	Helping Children with Autism
LGA	Local Government Area
NDIS	National Disability Insurance Scheme
NEET	Not in employment, education or training
NSQ	Non-school qualification
NSW	New South Wales
NZ	New Zealand
OID	Overcoming Indigenous Disadvantage
PT	Part-time
SA	South Australia
SDAC	Survey of Disability, Ageing and Carers
TAFE	Technical and further education
TIA	Transient ischemic attack
UK	United Kingdom
UNSW	University of New South Wales
WAVE	Wirreanda Adaptive Vocational Education
YACs	Young adult carers

Executive Summary

Carers make enormous contributions to society and experience significant challenges. This report focuses on how we might understand and measure the social inclusion of carers.

Care is a profound and fundamental relational practice of providing appropriate support and assistance to people with needs that may arise from disability, mental health issues, chronic illness, frailty due to ageing, or alcohol and other drug dependencies. People become carers, most often because of a pre-existing relationship, and an event or condition that arises which may change the nature of that relationship. In such cases, new needs emerge that require a level of support. Any person can become a carer, and most people will provide, and all will receive, care at some point over their life course.

Carers are also citizens within their society and their activities and relationships are framed and facilitated by their society's social, economic and political structures and institutions. Citizens become visible as carers when they take on care responsibilities that impact on their capacity to meet their other idealised social, economic and political citizenship roles and responsibilities: to contribute economically and aim to be financially self-reliant; to be unencumbered workers who can focus exclusively at times on their paid employment; to be effective learners as students; to be available, attentive and empathetic friends; and to be contributors to the broader community.

Social inclusion is a broad and contested concept that seeks to identify the basis for social membership in a society and the capacity to participate in normatively defined activities within that society. As a policy frame, the concept of social inclusion is related to the concept of social exclusion. These concepts differ in that the former aims to outline policy goals for participation or inclusion and the latter is used to describe groups that are identified as socially excluded or disadvantaged with respect to some forms of participation. In academic discourse the concepts of social inclusion and social exclusion are the subject of debates about:

- the nature of those who are 'excluded' and 'included'

- the underlying explanation for exclusion or inclusion

- the types of measures that can identify the 'excluded' or 'included'

- the extent to which the concepts can be useful in assessing social disadvantage and promoting policies that seek a more inclusive and just society.

To date, research has documented carers' situations with respect to conventional measures of disadvantage or exclusion. The research in this project sought to address a number of gaps in our knowledge:

- What does an inclusive society mean for carers themselves?

- What aspects of life are most important or challenging for carers?

- What does existing data tell us about carers' social inclusion?

- What indicators of social inclusion are needed that make carers' exclusion or inclusion more visible and relevant to carers' lives and experiences?

- How is care and social inclusion perceived in Aboriginal and Torres Strait Islander communities in Australia?

- What policies might support carers' social inclusion and what lessons can we learn about policies in specific national contexts from countries such as England?

The research sought to address these gaps through employing qualitative and quantitative methods and policy analysis across three interconnected themes:

- Theme 1 Reconceptualising social inclusion

    - Review of concepts and measures of social inclusion and theories of social care and ethics of care in literature and policies.

    - Focus groups were conducted with carers at different points in the life course (young adult carers aged 18–25 years, mid-age carers aged 25–64 years, older carers aged 65 years and older) and service providers in South Australia (SA) and New South Wales (NSW) in metropolitan and non-metropolitan locations.

    - Analysis of the social inclusion and social exclusion of carers in Australia using the *Australian Bureau of Statistics (ABS) Census of Population and Housing* (Census) data for 2006 and 2011 and the *Household, Income and Labour Dynamics in Australia (HILDA) Survey* (2005–2013).

- Theme 2 Care and social inclusion in Indigenous communities

    - Review of research and policies in Australia, New Zealand and Canada about the concepts, meanings, and experiences of informal care and social inclusion in Indigenous communities.

    - Two 'yarning circles' held in SA to explore the meanings and experiences of informal care and social inclusion for Aboriginal and Torres Strait Islander Australians in urban and regional communities.

- Theme 3 Care and social inclusion in Australia and England

    - Review of policy similarities and differences in Australia and England to identify any policy lessons for Australia.

    - Analysis of the censuses from Australia and England to assess the relative rates of social inclusion in each country.

Key findings of the research are:

Theme 1 Reconceptualising social inclusion

While the concept of social inclusion provides a framework for examining the role and place of unpaid carers in society, it needs revising to account for carers' lives and relationships. This can be achieved by applying the lens of a relational approach to social inclusion. This approach enables an analysis of structural inequalities and shifts the focus from those designated as excluded or outsiders onto the excluders and the included, as well as the terms of inclusion.

A relational approach to care and social inclusion facilitates a focus on care roles, relationships and responsibilities:

- Carers' roles can be understood in relation to the broader health, aged and disability care systems in different ways: as resources, co-workers, co-clients or carers whose role can be superseded. Each approach has different implications for policies to support carers' social inclusion: whether the primary policy focus is on sustaining the caregiving relationship and/or whether carers are viewed as having needs and a life of their own.

- The elements of care relationships highlighted by the ethics of care literature allows for a broader understanding of the histories, complexities, obligations and responsibilities of care relationships and how this might affect carers' social inclusion.

- A relational approach to social inclusion brings attention to the allocation of responsibility to care and the distribution of care in society. It provides the opportunity to focus on both those who provide unpaid care and those who do not and the implications for policy.

Explanations for social exclusion include those that:

- focus on individual deficits

- assume inclusion through any form of paid work

- examine distributional issues and structural inequalities.

The distinctions between different explanations for the causes of exclusion are important for understanding how carers may be perceived in a social inclusion framework and for the assumptions underpinning proposed policy remedies to address carers' inclusion.

Measuring social inclusion

Existing measures of social inclusion are not adequate to account for carers lives. They do not take into account the contributions of carers in their roles, the complexity of their relationships, and their multiple responsibilities. To date, concepts and measures of social inclusion are limited in that they:

- Primarily only focus on participation in public sphere activities (employment, education, etc.), so care is only seen as a disadvantage or risk factor on these measures.

- Occasionally identify care as an indicator of inclusion, but an adequate indicator to measure it in this way is lacking. Thus they do not sufficiently recognise and value the economic contributions and the social connectedness provided by informal care relationships in private or community settings.

- Neglect the potential contradictions of being socially included in multiple spheres, for example, how combining caring and paid employment can negatively impact on social participation and the long-term health of carers.

- Do not address the terms of inclusion, or the quality of participation in caring or any other social roles.

Carers across the life course

Focus groups conducted with carers at different points in the life course and also with service providers outlined the contributions of carers and challenges for carers' social inclusion.

- Carers' entry into caring varied and resulted from a dramatic event or a slow deterioration of their relatives' health over time. Older carers, often, had spent many years in their caring roles, with multiple and simultaneous caring responsibilities.

- Carers provided vital support to their children, siblings, spouses, parents and/or grandparents, which allows those being cared for to remain at home and connected to their communities.

- Carers in all age groups prioritised the needs of their relatives over their own needs and often sacrificed their own social inclusion in order to support the social inclusion of their relatives.

- Although carers found providing support to their loved ones a rewarding experience, which gave them a broader perspective on life, they wanted recognition that their caring role saved governments money, often at the expense of their participation in other aspects of life, such as education and training, employment, leisure and social life.

- Disengagement from employment, education and social activities, together with the unpredictable and often constant demands of caring, meant that carers could not plan ahead and experienced time pressure, poor health and financial insecurity over the short and long-term.

- Access to information and appropriate, high-quality support for their relatives and respite services for themselves, as well as flexible working conditions, were essential to sustain their social and economic participation.

Young adult carers (YACs)

- YACs faced many challenges completing school, studying at university or TAFE or finding work that accommodated their caring responsibilities.

- YACs' future choices and transition to adulthood often were constrained by their caring responsibilities and potentially set them on a pathway to disadvantage and social exclusion.

- Access to information, individualised and flexible support services and carer-friendly educational structures and employment conditions ameliorated YACs' disadvantage and enhanced their social inclusion.

Mid-age carers

- Many mid-age carers experienced structural barriers to accessing appropriate services to support their relatives and themselves in their caring role. Years struggling with the service system often left them exhausted, both mentally and physically, and concerned about the future.

- Carers living in areas where the National Disability Insurance Scheme (NDIS) had been implemented noted that, although support to their relatives had, for the most

part improved, access to respite services had been minimised and they could now only access a form of respite indirectly through services for the care recipient.

Older carers

- Some older carers had provided care to their relatives for extensive periods of time without help, unaware that support services were available, or that they were eligible for services, as they did not identify as carers.

- Providing care over time had a cumulative impact on older carers' health, social life and financial security. Many expressed concerns about the future when they could no longer provide support to their relatives.

- Access to a support network, flexible and high-quality respite services and accessible public spaces facilitated older carers' social inclusion.

Stakeholders

- Barriers to carers' social inclusion included a lack of awareness about available services, and the eligibility criteria for services and income support, especially when carers did not recognise themselves as carers.

- Carers experienced guilt in relation to asking for help, due to family or cultural expectations about caring for their relatives, which has ramifications on the mental and physical health of the carers.

- Possible risks to carers' social inclusion are associated with the implementation of policies that redirect support away from carers in their own right.

New indicators of social inclusion for carers

Based on discussions with these groups, key additional indicators of social inclusion relevant to carers' lives (outlined in section 3.5) include the domains of:

- Recognition and respect
- Quality of participation
- Opportunities for choice
- Spillover effects
- Effects over time

Care and social inclusion in Australia

An analysis of indicators of social inclusion and exclusion for carers in the ABS *Census of Population and Housing* showed that:

- Overall, carers were less likely to participate in employment and have lower secondary education achievement.

- Female carers experienced a greater negative impact on their capacity to participate in education and employment, suggesting that the impact of disability or elder care responsibilities may be compounded by child care responsibilities,

gender norms within households, and in social expectations around managing work and care:

- For young women, the disadvantage is most apparent in education and being not in employment, education or training (NEET).
- Female carers aged 25–44 years were the most disadvantaged group compared to their peers in terms of education and employment, particularly carers without non-school qualifications.
- Female carers of working age are more likely than male carers to live in jobless households.

- Overall, younger carers were more disadvantaged with respect to household income, home ownership or purchasing, access to a motor vehicle, and access to the internet. These consistent findings of disadvantage in resources highlight the impact of caring at early stages in the life course.

In Aboriginal and Torres Strait Islander communities:

- Young carers (aged 15–24 years) experienced education and employment disadvantages compared to their non-carer peers, and these disadvantages increased between 2006 and 2011.

- Young male carers showed greater levels of disadvantage with respect to being in the NEET group, and male carers aged under 45 years were more disadvantaged with respect to employment.

- Resource indicators showed that young male carers were more disadvantaged with respect to access to the internet and income.

Among carers from culturally and linguistically diverse (CALD) backgrounds:

- Young women were more disadvantaged with regard to Year 12 completion.

- Female carers aged 25–44 years and male carers aged over 45 years were more disadvantaged with respect to employment participation.

Data on carers' social exclusion, analysed by Local Government Areas (LGAs) for New South Wales (NSW) and South Australia (SA), identified that:

- Young carers were less likely than non-carers to complete Year 12 education in over two-thirds of LGAs for which there was reliable data. Disadvantage for young carers was more pronounced in regional areas in NSW and SA.

- Carers were disadvantaged in nearly all LGAs in NSW and SA with regard to employment, especially carers without a non-school qualification.

- Carers in regional areas in NSW and SA were most disadvantaged with respect to having low incomes.

These findings suggest that location matters for carers' social inclusion outcomes, particularly with regard to education, employment and as a consequence, income. It highlights the key role of education in protecting carers' participation in employment.

Additional indicators of social inclusion and changes over time were explored in the *Household Income and Labour Dynamics in Australia (HILDA) Survey* between 2005 and 2013. Key findings for the participation, resource and quality of life indicators are:

- After 2009, carers were more likely than non-carers to report wanting to work but being unable to do so (being marginally attached).

- In all years considered, carers were more likely than non-carers to be working long hours (over 40 hours per week), but only in 2013 were carers who were employed full-time more likely than non-carers to report that they wanted to work fewer hours.

- Key differences in reported job characteristics between the two groups were that carers reported higher levels of stress and lack of time to do everything in their job.

- Carers were more likely than non-carers to report low levels of social participation in all years.

- Carers had higher rates of poverty and financial stress. The latter finding is most likely to be a result of the combination of low incomes and additional costs of disability and care.

- Compared to their non-carer peers, female carers were more likely to say that they were poor and also unable to save.

- Carers, were however, less likely to have high levels of debt compared to non-carers, which may be due to the older age of carers.

- Compared to non-carers, carers, particularly carers aged 25–44 years, lacked social support.

- Carers had lower average scores for physical and mental health, with young carers (both men and women) and female carers aged 25–44 years most disadvantaged.

- Females carers aged under 45 years reported the highest levels of stress.

- Overall, carers report lower levels of personal efficacy.

Additional indicators based on those proposed in the indicators developed from the literature review and focus groups were also examined and showed that:

- Carers experience a greater sense of time pressure than non-carers.

- Female carers who are also parents may have higher levels of work-family conflict and male carers report lower levels of work-family facilitation than their non-carer parent peers.

Theme 2 Care and social inclusion in Indigenous communities

The policies of social inclusion in Australia, New Zealand and Canada focus on opportunity and wellbeing and contain reference to the uniqueness and circumstances of peoples in Indigenous communities. While the social inclusion policies in all these countries recognise the need to address disadvantages experienced by Indigenous peoples, the particular circumstances of carers and how their inclusion might be supported are not explicitly mentioned.

New Zealand has an overarching national carer strategy, and in Australia, there are state-based strategies. All the strategies in Australia have been developed within the framework of respective Carer Recognition Acts and provide for explicit recognition of the circumstances of Aboriginal and Torres Strait Islander carers, although they differ in how they approach

the implementation of the principles within the Acts. The New Zealand Carer Strategy also recognises the unique position and information needs of Māori carers.

In Australia, New Zealand and Canada, the literature suggests that:

- Love, commitment, obligation and sense of family responsibility are key factors that underpin caring in Indigenous communities and that Indigenous carers fulfil an important role.

- Caring is diverse in nature and facilitates more than just practical aspects of care.

- Defining care as an individual practice, where one person cares for another, risks narrowing the activity of caring in ways that may exclude Indigenous practices of care. While considering the role that individual Indigenous people play as carers, it is also helpful to consider Indigenous caring as 'networks of care' or 'landscapes of care'.

- Considering 'carers' as part of a network – that extends through and beyond family, friends and community and interacts with the state (e.g. hospitals, specialists, government services) – may allow for innovation in policy responses for carers that can support them as part of a network, a family or a community.

Indigenous carers' experiences of services vary. However, the literature review suggests some broad aspects that are common to Indigenous carers in Australia, New Zealand and Canada:

- The need for access to culturally appropriate and timely information.

- The need for culturally safe services.

- Recognition by health and disability systems and broader society of the contributions of Indigenous carers.

- Support for carers to identify as carers.

- Communication and coordination among service providers, communities and caregivers.

The capacity of carers to offer care and support is affected by socio-economic disadvantage, carers' own health problems, family dynamics and employment. Care includes financial burdens for the carer and, as such, there is a need for adequate financial support. Many carers may have chronic illnesses which affect their capacity to care. Carers require support in terms of:

- access to respite

- a job that enables them to balance cultural and caregiving obligations

- community housing

- training and education.

Dispossession and earlier government policies have impacted on the cohesion and connections of family and communities. The literature suggests that supporting and strengthening communities and community participation has benefits for carers.

Stakeholder consultations

In the 'yarning circles', the carers indicated that:

- caring for family members is just something that carers 'naturally' did, or is part of Aboriginal 'culture' and 'way of life' as Aboriginal people.

- Indigenous carers became carers through a mix of wanting to care, out of obligations and responsibilities to culture and family, and limited choices, opportunities and alternatives.

- Aboriginal carers do not always identify with the term carer. Recognition as a carer usually occurs through a facilitator.

- caring arrangements can be complex and may be reciprocal. Aboriginal carers play a large number of roles.

Being an Aboriginal carer is both rewarding and challenging. Rewarding aspects included spending time and getting to know the people they care for, and passing on and receiving cultural knowledge. Challenges included managing school, employment, and family conflict and complexity. Advocating and negotiating with services caused stress.

Aboriginal carers indicated that they had limited opportunities to do things outside of their caring roles. Many participated in support groups which provided them with opportunities to meet with other Aboriginal carers, to hear about changes to carer and disability policy, services and funding, and share some of the great things about being a carer.

Many Aboriginal carers get practical and emotional support from families, friends and neighbours, and the people they are caring for, as well as support from government and other service providers. However, some carers indicated that they received no support.

Suggestions for governments included:

- recognition for carers and their cost-saving role.

- human rights should be upheld and respected.

- on-going and continuous funding for Aboriginal carers support groups and services.

- support in their caring roles and opportunities to engage in activities outside of their caring roles.

- financial support for carers located in regional and remote locations.

- advocates for Aboriginal carers.

- affordable health and dental services.

- access to information about changes to policies, services and funding.

- listening to carers about the impact of policies and programs.

- support for volunteering in Aboriginal communities.

- setting the relationship right between Indigenous and non-Indigenous peoples in Australia.

> ## New indicators of social inclusion for Aboriginal and Torres Strait islander carers (see section 9)
>
> Indicators of social inclusion relevant to Indigenous carers included the domains of:
>
> - Recognition
> - Health and wellbeing
> - Culture and heritage
> - Services
> - Education and employment
> - Resourcing

Theme 3 Care and social inclusion in Australia and England

Comparative policy analysis

Social inclusion is also specific to the national context. England has a longer history than Australia of legislation and policies that might support genuine choice for carers to participate in multiple roles, yet also faces different challenges to Australia Policies that support carers were identified through reviewing key literature and policy documents in Australia and England to identify any policy lessons for the Australian context. As well as national level policies, States and Territories in Australia have legislation and policies to recognise and support carers. The focus of this study is on national level legislation and policies and

differences. In comparing policies across countries, a useful conceptualisation is to ask whether the logic of carer policy in each country follows either a 'carer as a co-producer' model, or a 'carer as a co-client' model. In the former case, the carer is perceived to be a resource, while in the latter they are perceived as having a life of their own.

What are the key social policy systems for carers in Australia and England that might enable carers to not only to sustain their caregiving obligations, but also to combine employment and care, and social inclusion and care in sustainable and fulfilling ways?

- Income support that is adequate and flexible: In both Australia and England, the proportions of income support benefit recipients who are also able to be in the labour force is low and the financial penalty of care is evident for those who must rely on benefits.

- Carer recognition and rights legislation, which carries entitlements for carers to be assessed for services (in their own right as co-clients) as in the United Kingdom (UK). However, the corollary needs to be sufficient government funding and provision of appropriate caregiver support policies. In Australia, the Carer Recognition Act 2010 does not carry entitlement for carers to be assessed as co-clients with respect to their service needs.

- Workplace and labour force measures that provide right to request flexible employment arrangements for all employees with caregiving responsibilities, including paid leave. This is essential to effectively mitigate for carers the difficulty of combining employment and care and with that the financial penalties imposed by caregiving.

In Australia and England, all of these policy domains under analysis are interconnected with respect to their future effects on the capacity and opportunity for carers to maintain, enter or re-enter employment and engage in other modes of social inclusion. The domains of income support policies, rights and recognition legislation, workplace flexibility and paid leave arrangements, and the right to be assessed for dedicated carer-specific services (following the carer as co-client logic), need to be addressed if carers who aspire and struggle to combine care and employment and other forms of social inclusion are to achieve their legitimate aspirations.

Social inclusion outcomes for carers in England and Australia

Overall, analysis of Census data for England and Australia identify many similarities in the social inclusion outcomes for carers in Australia and England. However, there are also salient differences.

- Young carers in Australia, particularly females, experienced more educational disadvantage than young carers in England in 2011. The disadvantage in Year 12 completion rates for young women who are carers has reduced in both countries over time, but especially in England.

- The gendered disadvantage of caring in education is reinforced in the finding that young female carers have the highest rates of NEET. Although this has lowered over the time periods considered in both countries, in 2011, one in five young women with caring responsibilities did not participate in education, training or employment.

- Carers in England had slightly higher rates of paid employment and full-time employment compared to Australia in 2011.

- In both countries, women who are carers in the 25–44 years age group are most disadvantaged when compared with their peers.

- Employment rates for carers stayed fairly constant over the time periods in each country, with slight increases for female carers.

- Young carers in both countries are more disadvantaged in terms of access to resources than older carers, reflecting pathways into caring and opportunities to accumulated resources at different points in the life course.

- The national differences in the structure of the housing market are evident in the differences in rates of private and public rental for carers in Australia and England. A further question to be explored is the significance of the quality of housing and security of tenure for renters on other aspects of their social inclusion in Australia and England.

1   Introduction

Carers make enormous contributions to society and experience significant challenges. This report focuses on how we might understand and measure the social inclusion of carers. We begin by exploring the nature of care and caring relationships, ideal images of citizens that underpin rights and entitlements, and the valued activities and basis for membership in a society.

1.1   Background

Care is a profound and fundamental relational practice of providing appropriate support and assistance to people with needs that may arise from disability, mental health issues, chronic illness, frailty due to ageing, or alcohol or other drug dependencies. People become carers, most often because of a pre-existing relationship, and an event or condition that arises which may change the nature of that relationship. In such cases, new needs emerge that require a level of support to be met by one or both parties. Any person can become a carer, and most people will provide, and all will receive, care at some point over their life course.

Carers are also citizens within their society and their activities and relationships are framed and facilitated by their society's social, economic and political structures and institutions. Citizens become visible as carers when they take on care responsibilities that impact on their capacity to meet their other idealised social, economic and political citizenship roles and responsibilities: to contribute economically and aim to be financially self-reliant; to be unencumbered workers who can focus exclusively at times on their paid employment roles; to be effective learners as students; to be available, attentive and empathetic friends; and to be contributors to the broader community.

Social inclusion is a broad and contested concept that has emerged in recent decades in academic and policy discourse and seeks to identify the basis for social membership in a society and the capacity to participate in normatively defined activities within that society (Silver, 2010, 2015). As a policy frame, the concept of social inclusion is related to the concept of social exclusion. These concepts are different in that the former aims to outline policy goals for participation or inclusion and the latter is used to describe groups of people that are identified as socially excluded or disadvantaged with respect to some forms of participation. In academic discourse the concept of social inclusion has been, and continues to be, the subject of many debates about the nature of, and the types of measures that can identify, those who are 'included' and 'excluded', the explanation for exclusion/inclusion and the extent to which it can be useful in assessing social disadvantage and promoting policies that seek a more inclusive and just society.

Research to date has documented carers' situations with respect to conventional measures of disadvantage that include:

- exclusion from economic participation in employment, with a consequent lack of economic resources
- lack of access to education and training
- lack of capacity to engage in social and community activities
- lack of access to services
- poor health outcomes.

All might be regarded as conventional measures of social inclusion – encompassing participation, resources and quality of life. In all these assessments, care is perceived as a negative, a risk factor for different types of exclusion, and a barrier to inclusion in what is seen as important. This perception of care as primarily a burden exists within social inclusion/exclusion discourse, despite the recognition that informal carers maintain the social connection of many people through care in the community, make a substantial economic contribution through unpaid work, and are essential partners and supports for the disability, health and aged care systems in any society.

To date, research has not explored what an inclusive society might mean for carers themselves, or what aspects of advantage and disadvantage they perceive as most salient to their lives and care relationships. Specifically, the research has not asked carers what they value and what they miss out on, how they balance or manage their competing roles, or what they would say to governments about how their inclusion could be supported. Research has not comprehensively explored how indicators of social inclusion could make carers' exclusion or inclusion more visible and relevant to their lives and experiences, and whether the data exists to undertake such an analysis. Research is also yet to fully explore the existing data to document what might be known to date about carers' social inclusion.

In the Australian context, researchers have been critical of the concept of social exclusion/inclusion with respect to Aboriginal and Torres Strait Islander communities due to the lack of critical engagement with issues of cultural diversity and cultural maintenance (Hunter, 2009; Taylor, 2008). Issues of care, disability and what social inclusion might mean are yet to be fully explored in Aboriginal and Torres Strait Islander communities.

Social inclusion is also specific to the national context. For example, policy initiatives since 1995 in the UK relating to work-life balance, welfare reform, education, pensions, children, and health and social care, have been underpinned by government expectations that managing both work and care will be a part of the lives of many citizens (Cass & Yeandle, 2009). The UK has a longer history than Australia in developing policies that might support genuine choice for carers to participate in multiple spheres. As well as overarching carers' strategies, carers in the UK have gained rights through legislation (Yeandle et al., 2007b). The policies have envisaged carers as individuals with multiple roles: partners in social care, employees, services users, and partners in health services (Yeandle et al., 2007b). Such policy directions have been challenged by the impact of the Global Financial Crisis and the subsequent austerity measures, resulting in rhetoric and legislation that may not be able to be accompanied or matched by resources. Research in the UK is yet to examine, however, whether such policies have enhanced carers' social inclusion and what lessons such policy developments might hold for Australia.

In Australia, despite bipartisan rhetorical support for carers at the federal level, policies supporting carers' participation in multiple spheres have been more limited, giving no more than nominal recognition of carers as having needs in their own right. While there have been some developments towards greater carer recognition through the National Carer Recognition Framework, the reforms of the aged care, disability and health systems mean that specific supports targeting carers are in a state of transition and flux. Policies to support carers in Australia are complicated by the national/state arrangements and governments: state governments may have carer strategies and policies for their domains of responsibility that result in geographical location being important for carers' outcomes. Research to date has also not mapped changes in policies that might support carers' social inclusion in Australia.

1.2   Carers and social inclusion project

This project aimed to address these gaps through three interconnected themes. The project had four overarching aims, which sought to:

- document carers' social exclusion

- reconceptualise social inclusion to take account of the contradictions in carers' lives

- provide better evidence to inform policies which seek to support carers from culturally diverse backgrounds to engage in multiple life domains

- develop indicators of social inclusion most relevant to carers and Aboriginal and Torres Strait Islander carers.

Each theme had an independent set of aims, as described below.

Theme 1: Reconceptualising social inclusion to acknowledge informal care

1. Develop a framework for understanding the potential contradictory status of informal care in social inclusion theories, empirical analyses and policies.

2. Develop indicators of social inclusion most relevant to carers.

3. Analyse and map the spatial distribution of aspects of social exclusion for carers in Australia using the Australian Bureau of Statistics (ABS) *Census of Population and Housing 2006 and 2011* (Census).

Theme 2: Care and social inclusion in Aboriginal and Torres Strait Islander communities

1. Undertake a comparative analysis of research, policies and programs about carers and indicators of social inclusion in Indigenous communities in Australia, New Zealand and Canada to identify theoretical frameworks and policy lessons.

2. Explore the concepts, meanings, and experiences of informal care and social inclusion for Aboriginal and Torres Strait Islander Australians in urban and regional communities.

3. Develop indicators of social inclusion for Indigenous carers and identify their policy implications.

Theme 3: Care and social inclusion in Australia and England

1. Review policies aimed at supporting carers in Australia and England.

2. Compare social exclusion outcomes for carers in Australia and England.

This report provides an overview of findings from the research, with the structure of the report aligning with the themes outlined above. The methods undertaken for the research are described in the Appendix.

2 Reconceptualising Social Inclusion to Take Account of Care
Trish Hill and Cathy Thomson

2.1 Social inclusion

Social inclusion is a key concept in academic and policy discourse that is employed with different interpretations in various contexts (e.g. Daly & Silver 2008; Levitas, 1998, 2003; Silver, 2010, 2015; Australian Government, 2009). Definitions of social inclusion address the processes that facilitate participation and recognition for differently situated individuals. For example, Silver proposes a working definition of social inclusion/exclusion as:

> a multi-dimensional, relational process of increasing opportunities for social participation, enhancing capabilities to fulfil normatively prescribed social roles, broadening social ties of respect and recognition, and at the collective level, enhancing social bonds, cohesion, integration, or solidarity. Social inclusion may refer to a process encouraging social interaction between people with different socially relevant attributes or an impersonal institutional mechanism of opening up access to participation in all spheres of social life (2015:2–3).

Key elements within definitions of social inclusion are the relational aspects of social bonds, the multidimensional nature of participation and disadvantage, and the individual and institutional processes that can create exclusion or inclusion (Silver, 2010).

The concept of social inclusion is connected to the term social exclusion, however there are important differences. As a concept and policy frame, the focus has tended to be on the 'excluded' and to target policies to, and sometimes stigmatise, particular groups viewed as 'problems' outside the mainstream (Levitas, 1998; Daly & Silver, 2008). In such cases, the term 'social exclusion' is used. In some academic and policy literature, the concepts of social inclusion and social exclusion are used interchangeably, separated by a slash, or perceived to represent opposite ends of a continuum (Hayes et al., 2008; Silver, 2010). However, other approaches have emphasised that "the mechanisms, motivations and agents" of social inclusion and social exclusion are different (Silver, 2010:193; Daly & Silver, 2008; Levitas, 2003). For some, social inclusion is differentiated from social exclusion, in that it focuses on a goal or social objectives, rather than a problem. That is, it is a term that explores what is necessary for inclusion or social membership (Silver 2010; Daly & Silver, 2008).

Importantly, in the research on both social inclusion and social exclusion, academic critiques have shifted the focus from those designated as excluded or outsiders onto the excluders and the included, as well as the terms of inclusion (e.g. Daly & Silver, 2008; Levitas, 1998; Veit-Wilson, 1998). These types of relational approaches to social inclusion enable an analysis of structural inequalities and potentially invite 'a critique of "mainstream" values and practices' (Marston & Dee, 2015:127).

Thus the concept of social inclusion also has the potential to raise fundamental questions about which activities are deemed as valuable modes of participation in any society at

any point in time, and what might be the features of an inclusive society (Levitas, 1998, 2003). Levitas notes that "the idea of an inclusive society potentially forces onto the agenda this larger question of what kind of society we want to live in…" (2003:9). The concept of social inclusion, thus, has the potential to bring to the foreground the structures, mechanisms, and practices which generate inequalities and opportunities for participation in a society (Levitas, 1998, 2003; Lister, 2010; Silver, 2010).

2.2 Understanding care and social inclusion: a relational approach

The concept of social inclusion provides a framework for examining the role and place of unpaid carers in society and to explore ways in which social inclusion, currently or potentially, accounts for caring relationships. Highlighting the structures, mechanisms and practices that affect carers' participation in any society, draws attention to:

- the social value placed on caring activities and relationships and the ways in which these activities are distributed and materially and symbolically recompensed

- the ways in which care is recognised and the extent to which carers are included within other activities within society

- how care functions as a category generating structures of social, political and economic inequalities

- the mechanisms through which inequalities generated by care provision can be and are, prevented, mitigated or compensated

- the day-to-day practices in the health, aged and disability care systems that contest or reinforce inequalities generated by the social and economic structures of informal caring.

As well as providing a framework to illuminate social structures of inequality, the social inclusion and care literature also emphasises the issue of relationality. A relational approach to care and social inclusion enables a focus on roles, relationships and responsibilities, as outlined below. The relational approach also permits consideration of the terms of inclusion and goes beyond the simple dichotomy of inclusion/exclusion to acknowledge the possibility of inequalities among the included and inclusion on unfavourable terms (Levitas, 1998; Sen, 2000). A focus on the terms of inclusion can bring to the foreground the ways in which carers' opportunities to engage in non-caring activities, such as employment, education, and social and political participation, are mitigated or enhanced by structures, mechanism or practices outlined below.

Acknowledging the relational nature of care demonstrates the different ways in which the social roles of carers can be understood in relation to the broader health, aged and disability care systems and how carers' social inclusion is conceptualised and addressed in policy. As outlined by Twigg and Atkin (1994), unpaid carers can be perceived as:

1. a resource (a support to be drawn on by services)

2. a co-worker (working in partnership with service providers)

3. a co-client (in need of support from services themselves)

4. a superseded carer (the point at which carers' support is no longer required either

due to services provided to the person with disability to increase their independence to a level where the carer is no longer needed or through concern for the carer and supporting a decision to relinquish the caring role).

Each of these roles for carers has different implications for how carers' social inclusion could be conceptualised and achieved. The first three approaches aim to support the continuation of caregiving responsibilities but the policy focus for each would be different. For the first two approaches the aim of social inclusion approach would focus on sustaining the role of carer, while the third and fourth cases would focus more on the needs of the carers in their own right.

A relational approach to understanding social inclusion, informed by an ethics of care, also provides an opportunity to focus on the characteristics and elements of care relationships and what we might consider as the basis for socially inclusive relationships. Academic discussions around the specific characteristics of caring relationships have described key elements that have implications for how we understand individuals and their social relationships. Rather than perceiving individuals as rational, self-interested, autonomous economic actors, an ethics of care approach assumes that individuals exist within interdependent relationships and multiple responsibilities to self and others (e.g. Sevenhuijsen, 1998, 2000). This concept of the individual has implications for how we understand the citizen who is to be included in any society: their interests, motivations, decisions and actions. A citizen carer is thus situated in relationships that go beyond that of consumer and employee.

The literature on caring also describes qualitative elements of good care relationships, such as attentiveness, responsibility, competence, responsiveness and trust (Sevenhuijsen, 1998; Tronto, 2013). Such relational qualities go beyond notions of self-interested individuals to recognise the histories, complexities, obligations and responsibilities individuals have with each other. These qualities help illuminate what is important in an assessment or measure of the quality of care and other relationships. They also speak to the complexity of decision-making and choices in carers' lives.

A relational approach to social inclusion and the literature on caring both bring attention to the allocation of responsibility to care and the distribution of care. It provides the opportunity to focus on both those who provide unpaid care in society and those who do not or have socially sanctioned justifications for opting out of care responsibilities (Tronto, 2013). The question of how responsibilities for care are allocated in a society is an important consideration for equity and for framing policy responses, as will be discussed below. As Tronto argues:

> Making care a central value in democratic life will require a rethinking of many existing social institutions, political institutions, and practices. Not only will money need to be redistributed and the relationship of work and care rethought, there will also be a need to reconsider how citizens spend their time (Tronto, 2013:178–9).

2.3 Explanations and policies

Explanations and policy responses to the question of carers' social inclusion are also based on perceptions of who should be responsible for care and the place of care in society.

Explanations for social exclusion frame exclusion and inclusion differently, with some approaches focusing on individual deficits, others assuming inclusion through any form of paid work, and others examining distributional issues and structural inequalities (Levitas, 1998, 2003).

The distinctions between different explanations for the causes of exclusion are important for understanding how carers may be perceived in a social inclusion framework and for the assumptions underpinning proposed policy remedies to address carers' inclusion. For example, if responsibility for care is assumed to reside within families or citizens/individuals then policies would focus on providing minimal health and welfare support. If individual carers or carer citizens were regarded as having a primary responsibility to engage in paid work, then care would be considered an impediment to employment, and carers would be assumed to take on caring roles because of a preference for care over employment. The policy focus would emphasise carers' employability, or promote mechanisms to reconcile work and care. If society, as a whole, is regarded as having a responsibility for care, then the policy focus would be on providing high quality and accessible formal care services to people with care needs and the carers themselves. The social structures and social policies would focus on creating an inclusive society in which care responsibilities are equally distributed by providing opportunities for carers to have a life of their own as well as attend to their caring relationships with minimal penalties in other aspects of their life.

2.4 Assessing social inclusion

One way to monitor how well a society meets its care responsibilities and how equitably care responsibilities are distributed across society is to measure carers' social inclusion. This requires that concepts and measures of social inclusion are adequate to recognise and assess what it is that carers' value and what they miss out on and the place of carers in society.

Along with the multiple definitions of, and policy approaches to, social inclusion, there is no consensus about which indicators should be used to measure social exclusion or social inclusion. The development of indicators has focussed predominantly on indicators of social exclusion rather than inclusion. A number of key studies have developed conceptual frameworks and indicators of social exclusion. These include:

- Bristol Social Exclusion Matrix (B-SEM) (Levitas et al., 2007)
- Multidimensional Framework for Identifying Socio-Economic Disadvantage (Scutella, Wilkins and Horn, 2009)
- Poverty and Social Exclusion in UK (Aldridge et al., 2012)
- Left out and Missing Out Study (Saunders et al., 2007).

Table 2.1 outlines the key domains used in each study. Each study uses slightly different indicators of social inclusion, except for Scutella et al. (2009), where the indicators were designed to map to those used in the B-SEM. The provision of care is not adequately captured in these of indicators developed to date. Although 'unpaid work and care of others' is included in the employment domain within the conceptual framework, there is no specific indicator to measure care as an indicator of social inclusion.

Table 2.1 Indicators used in key studies

Area	Levitas et al., 2007	Scutella et al., 2009	Saunders et al., 2007	Aldridge et al., 2012
	Domain	Domains	Categories	Topic
Resources	Material/economic resources	Material resources	Economic exclusion	Low income Child Poverty targets
	Access to public and private services	Community	Service exclusion	
	Social resources	Social	Disengagement	
Participation	Economic participation	Employment	Economic exclusion	Work
	Social participation	Social	Disengagement	
	Culture, education and skills	Education and skills	Economic exclusion	Education
	Political and civic participation	Community	Disengagement	
Quality of life	Health and wellbeing	Health and disability	Service exclusion	Sickness and disability
	Living environment	Community		Housing
	Crime, harm and criminalisation	Personal safety		

Currently, informal care is both largely overlooked and has a contradictory status within existing concepts and policies of social inclusion. Concepts of social inclusion and policies promoting social inclusion primarily focus on participation in public sphere activities, and the social roles of employee, student or trainee, consumer, service user, and community or political actor. Some empirical measures of social inclusion only recognise a limited range of activities. The roles in the private sphere of carer, parent and domestic work are not often recognised. When care is included in assessments of social inclusion, care is most often empirically measured as a risk factor for exclusion. Occasionally care is conceptually identified as an indicator of inclusion, but an adequate indictor to measure it in this way is lacking.

Thus, current concepts of social inclusion do not adequately recognise and value the economic contributions and the social connectedness provided by informal care relationships in private or community settings. When social support outside public sphere activities is recognised in existing measures it is conceived and measured as a resource possessed or accessed by an individual rather than a relationship with associated histories and obligations. While measures of social participation are often included in social inclusion indicators, these are often assessing the number of social activities rather than the quality and complexity of such relationships. Finally, concepts and measures of social inclusion also neglect the potential contradictions of being socially included in multiple spheres, for example, how combining caring and paid employment can negatively impact on social participation and the long-term health of carers.

2.5 Barriers and facilitators of social inclusion

Within existing social arrangements, different structures, mechanisms and practices facilitate or create barriers to carers' social inclusion. A concept of social inclusion that aims to illuminate carers' advantages and disadvantages needs to recognise these elements.

Structures include legislative, regulatory and normative frameworks in which the possibilities of, and opportunities for, participation are defined and ideal participants are described. For example, for carers this will include:

- legal recognition and rights – carer recognition, antidiscrimination

- nature of economic opportunities for those negotiating care and work – laws, labour markets, education and training

- codification of rights and entitlements for carers in welfare system

- human rights - conventions that refer to the right to family life and to balance work and family responsibilities

- eligibility criteria and resources available for services within the health, disability and aged care systems

- the gendered assumptions in all of these legal and regulatory frameworks about entitlements and responsibilities

- the social support and resources available for carers

- availability of social and cultural activities for carers and those they care for (e.g. accessibility and costs), and

- geographical inequalities in access to services and support.

Mechanisms encompass institutional arrangements that enable or impede social inclusion. For example:

- recognition, acknowledgement and accommodation of needs and difference/ discrimination and inclusion on unfavourable terms

- provision of information and training/lack of or inadequate information or communication

- provision of alternative care and services/lack of quality services and denial of access through eligibility criteria, rationing, prohibitive cost, lack of time, distance

- inclusion through provision of social and material resources – in kind or cash

- exclusion through coercion or obligation – use of power or threats or withdrawal of entitlements to restrict choice or exert authority.

Practices are the day-to-day interactions of paid and unpaid carers, services and administrators within the structures and mechanisms, such as the provision of relevant and timely information and advocacy by individual service providers that assist carers to negotiate challenges and support them to recognise and take up opportunities. Against these positive practices, however, can be services or administrative practices that can be confusing, obscure opportunities, or present impediments to carers being able to access support.

2.6 Summary

This section has outlined the theoretical discussions within the care and social inclusion literature that might help broaden the assessment of social inclusion to account for the role and place of carers in society.

This research project conducted a range of consultations with carers and stakeholders to explore how carers feel about how their experiences are recognised and valued in society, and what, among these structures, mechanisms, and practices, helps and hinders their participation. The next chapter reports on the findings from the consultation and their implications for how we might measure social inclusion.

3 Social Inclusion Across the Life Course
Cathy Thomson and Trish Hill

To explore the issues outlined in Section 2 further, focus groups were conducted with carers at different points in the life course, and also with services providers, to consider their perspectives on a range of questions:

- What activities do carers do and what do they miss out on?
- What helps them to take part in different activities and what makes it difficult?
- What is the impact of caring on different parts of their lives?
- What should we measure to assess if carers are socially included?
- What should policy makers do to support carers' social inclusion?

The following three sections summarise the main findings from the focus groups with carers that were conducted in SA and NSW in metropolitan and non-metropolitan locations (see Appendix A for further methodological details).

3.1 Young adult carers[16]

> You're trying to help someone else live their life at the same time as, you sort of, sacrifice your own life … to make sure that someone else's life is not a nursing home.

Overview of the caring situations

Young adult carers (YACs) entered their caring roles along different pathways. Some had grown up providing care, whereas others had become a carer after a life event that changed their family situation. The support provided by YACs varied considerably: it encompassed physical, emotional and practical support, as well as monitoring.

For many YACs the support they provided to their relatives was an integral part of their daily routine within the family; they thought all young people provided care. Some were primary carers for a grandparent, parent or child, while others helped their parents care for a sibling. Although some carers had entered their caring role abruptly, they still considered the support they provided to their relatives as a normal part of family life. Some YACs commented that they had little choice about taking on caring roles, given complex family dynamics and other family members opting out of providing support:

> I have older brothers … we all lived with mum … before everything happened. Now they're all off on their own. They don't see mum now because they don't like to see mum as the way she is … which is upsetting to me because I have to deal with it daily where they choose not to, and they choose not to support my carer role. (Carer of parent)

16 This research focuses on young adult carers who are young carers aged 18-25 years. As this group does not include all young carers, we refer to them as young adult carers.

YACs wanted recognition of their caring responsibilities and to be appreciated for the work they did. They wanted acknowledgement of the difficulties they had to overcome to finish school, take part in social activities and/or paid work while also providing care. Identification of being a 'carer' often resulted from YACs coming in contact with services, although when asked, most YACs were unsure how they first became involved with services. YACs also sought recognition of their knowledge, skills and expertise in their caring role from health professionals and other service providers:

> A big issue I am facing right now is basically being treated as a minor instead of being treated as an adult. We care and still medical practitioners treat us like we know nothing about what's going on. We are with our loved ones 24/7 and know them the best but still get the run around. (Carer of child)

Participation in different activities

Some YACs viewed providing support to family members and also engaging in other activities was a normal part of everyday life:

> Yeah it's just been part of life, I don't feel like I have to juggle things, it's just how I've grown up with it, you know, it doesn't feel like it's out of the normal routine or anything. It's just been what I've done. (Carer of parent)

Generally, the YACs' ability to participate in other activities, such as social activities, paid work, education and employment, was restricted by their caring responsibilities. The young people talked about having to choose between different parts of their lives, whereas continuing to provide care was taken as a given:

> …I doubt whether you'll find many carers that can do more than one thing. So you choose between your education, working or a social life. (Carer of parent)

The degree to which caring responsibilities impacted on YACs participating in different types of activities varied and depended on the characteristics of the YACs, the intensity of the support given, and the amount of help provided by other family members and services.

Access to services provided the YACs with support in their caring role and connections to other young carers through support groups, social activities and retreats. These activities reduced the young people's feelings of isolation by providing them with a chance to meet other young people who understood their situation, and gave them a break from caring and something to look forward to:

> I've just had so much going on in life at the moment and I'm so stressed out. You don't even know why you just feel like crying … And knowing that I've got the retreat next week … So I'm, like, 'Yay, I've got something to look forward to'. I know I'm having a night out. (Carer of parent)

Caring made it difficult for some YACs to study at TAFE or university. For a number of young people, their caring responsibilities had also made it hard to complete high school due to a lack of understanding and flexibility from teaching staff:

> One of my teachers pretty much told me I had to choose 'school or your family. You can't have both'. So I ended up dropping out of school. (Carer of parent and grandparent)

Many YACs found it challenging finding a job after they finished school due to a lack of experience and limited job opportunities, particularly for those living in non-metropolitan areas:

> Finishing high school, trying to find the job isn't easy. You know, it's who you know, not what you know, that's how I got my job from [name of organisation]. I knew the manager there … If I could go back three years ago I would have gone for all those jobs that I didn't want to do, so I could have a bit of experience. (Carer of sibling)

The constraint of caring responsibilities made it doubly hard for YACs to find paid work. Competition was fierce for the available positions and securing a job required persistence and some luck. Some YACs opted to take whatever position that was offered, just to get some experience. Most worked part-time and one YAC had two part-time jobs to cover expenses:

> I'm working full-time hours this year, two jobs, to sustain myself, and I'm studying part-time as well. I've found it's pretty difficult emotionally and physically. Like today I was up at 4.30, started at 6.00 at my job at the [shop] to 2.30, and then 3.00 to 6.00, so I'm a Nanny in [name of town], and then I usually go home after that and I'll help cook, and I'll help bath the little ones. (Carer of sibling)

Use of social media is a common way for young people to engage socially. Access to social media provided some YACs with an opportunity to assume a different persona and connect with other young people without talking about their caring experiences. However, many YACs found the postings on social media concerned trivial matters and could not relate to the discussions, given the problems they faced at home:

> Which isn't the worst part … but yeah, the biggest problem is the people that go on there [social media] and have a massive whinge about something so minor. (Carer of parent)

Factors that help young adult carers to participate

Access to flexible and supportive services, such as Carer Support Services, Raw Energy and the WAVE programs, facilitated YACs' social inclusion. Carer support services gave YACs financial assistance (e.g. paying for gym memberships and car registration) and emotional support. Carer support services also organised support groups and retreats, which gave them time to themselves, respite from caring and a social outlet. These types of support were vital for YACs to sustain their caring roles.

A common experience for the YACs was that once in contact with the carer support service system they were well supported with individualised and flexible support:

> I think Carer Support for me, like, is more emotional support. I mean, I get a lot of financial support from them too … If I'm having a really bad day I know I can call up and talk to someone because … I don't have much family support at all … A lot of friends don't understand, especially at our age. (Carer of parent)

Other factors that assisted YACs to participate in different activities included: access to adequate support for their relative; support from other family and friends; flexible and supportive learning environments, such as distance learning and special consideration provisions at school and university; and flexible and supportive employment conditions:

> When I first started caring I was in this group through my high school … called WAVE which was probably the best experience ever … They actually got me a few courses … things that I could attend. So I ended up getting my Community Service Cert II … So at the moment I'm studying my Diploma of Nursing. (Carer of parent)

Access to transport also assisted YACs to participate in other activities. Once the YACs gained their driver's licence it gave them independence but it also enabled them to expand the support they gave to their families:

> And now we have a small car I can say 'Mum, I'll go and do the grocery shopping, don't worry about packing all the kids in the car and putting [name] in the hoist and then trying to walk him around the shopping centre for an hour and a half'. Yeah, it's so much easier now driving. (Carer of sibling)

Many YACs did not have enough time or money to attend to their health needs. Access to a gym membership through a carer support service helped to improve YACs' mental and physical fitness. One YAC commented:

> Yeah. Carer support is amazing… I can't even explain how many breakdowns I would have had if I didn't have this programme. They signed me up for a gym membership, so that's making me, like, really really good and making my lifestyle healthy. It's a 24-hour gym so I can go there any time I need to for a stress reliever. (Carer of parent)

Access to support from family and friends was also essential to YACs' participation:

> Just my other brothers and sisters, they were really supportive of me and my friends and people here at Carer's Link. (Carer of sibling)

Challenges for young adult carers' participation

A number of service characteristics made it difficult for YACs to participate in different activities. These characteristics include a lack of information, ad hoc entry into the service system and a lack of access to high quality, appropriate and affordable respite. A common experience for YACs was to stumble into services:

> I'm not sure how but I found a programme called Raw Energy and I was joined up with that until I think 18 or 16. I can't remember when the programme was cut off. Then I had no support at all and mum saw this [YAC Carer Support] programme. (Carer of parent and grandparent)

Also a lack of experienced and trained paid care workers made it difficult for carers to feel confident that the person would be well cared when they left the house:

> Yeah, that's hard isn't it because if you can't leave the house confident that the person that you're leaving [her] with is trained and knows how to deal with it, it's hard to relax isn't it? (Carer of sibling)

Some YACs in the study lived in areas that were more disadvantaged in terms of socio-economic status and access to services than other areas. Respite services were particularly limited in these areas:

> I think that the easier the life is of the person that you're caring for, the easier the caring role is … I don't know, but yeah, say if there was more funding or more

> services … then it might not decrease my caring role but it would certainly increase my wellbeing. (Carer of sibling)

Also, the YACs living in these disadvantaged areas often experienced difficulties accessing transport and this was compounded by difficulties getting their driving licence. Some YACs did not have an adult available to log the necessary hours of supervised driving:

> I have my Ls, I've had my Ls for over two years, it was just hard with him … he was always tired or something. (Carer of sibling)

Many carers experienced mental exhaustion and anxiety from constantly worrying about the person being supported. Many YACs talked about not being able to switch off from their caring responsibilities:

> I suppose, like, you're – although you're caring for, you know, who you're caring for, but you're also trying to live your life as well. So you're doing literally 101 things at a time. So your brain's just always on. It just keeps on going. (Parent caring for child)

A range of factors made it difficult for YACs to participate in education and training, including unsupportive learning environments, the costs associated with studying, and inflexible study timetables:

> I have a four-week placement that's supposed to start in three weeks that I am not going on because I – I'm not going to have that respite … Then at the end of my year I've got six more weeks, like, that I have to get respite for … It's [the placement] not flexible. But you can't go in and say, 'Well, I'll do two weeks, two days a week for the next however long'. They don't offer that. (Carer of parent)

Also, a lack of understanding and flexibility from teachers and/or employers made it difficult for carers to balance school/university and/or paid work and caring responsibilities.

Impact of caring on different parts of young adult carers' lives

It was evident from the discussions that providing care came at a cost to the young people. Many of the YACs were aware that they were sacrificing their economic and social participation in order to safeguard the social inclusion of their parent, child or sibling:

> I was told while I was pregnant … this is what the outcome's going to be … I will take whatever happens and I will just figure it out … So from that … moment I kind of sacrificed life to get my child. (Parent caring for child)

YACs talked about the lack of spontaneity in their lives due to caring responsibilities. Most of the YACs' social lives were restricted or non-existent. Many of the young people found that their friendships fell off because friends did not understand their situation or the YACs found it difficult to relate to people of their age:

> My social life is kind of non-existent at the moment … So that's been difficult because there's no other real way I've been able to engage apart from my workmates which is fine because I'm so busy all weekend. (Carer of sibling)

Many of the YACs focused on the needs of their relatives rather than own needs. Some experienced health issues because they put off their own health checks:

> Mental health can be a big result and then it just goes around in a circle because that then impacts your caring role, which then impacts your mental health. And it's hard sometimes because you don't know how to support yourself in that stuff, as well, because you're so busy trying to care for someone who needs care. (Carer of sibling)

Caring responsibilities influenced the YACs' current and future choices, such as post-school options, employment and moving out of home. The YACs took account of their caring responsibilities when making decisions about the transition to independent living. Caring responsibilities made it impossible for some to consider moving out of home:

> I'd love to get my own place and then just enjoy that … but I'd be constantly at my mum's and my grandma's. So I just wouldn't have the time to get there. (Carer of parent and grandparent)

In contrast, one YAC had moved out of home. Her caring responsibilities now predominantly involved monitoring and checking on her mother. Despite being independent and having her own life, the YAC's mother was constantly in the back of her mind. She commented:

> I'm fairly independent but I just have to make sure that her shopping's done and her washing and all the kind of house chores. But I go out and have my own life and do my own things, but in the back of my mind I'm always worrying, like, is she okay? (Carer of parent)

While many of the impacts of care that YACs identified were negative, some YACs felt that their caring role provided them with useful life skills, maturity and a different perspective on life:

> But at the end of the day I learnt how to get over stuff a lot easier than a lot of people do. So I mean in a way it helped me at the end. (Carer of parent)

However, for other young people the impact of providing support had a long-term impact on other aspects of their lives and, as one YAC said, "it puts you behind in life". This can be especially hard when significant events occur simultaneously, such as finishing studying and trying to find a job. Coping with these events can be difficult at this vulnerable time in the young people's lives as they transition to independent living or from studying to paid work, given their additional caring responsibilities. This can have a cumulative impact on their future.

Indicators to measure social inclusion suggested by YACs

The YACs were asked how we should measure their social inclusion and their suggestions included:

Multiple activities

- Percentage of YACs who are doing more than one activity at a time in addition to caring.

- Percentage of YACs who have to choose between participating in education, paid work or social activities.

- The amount of time allocated to different activities (minimum time in all or balance between different activities).

Social activities

- Amount of time and how often YACs can get away from their caring responsibilities.

- Types of activities YACs are involved in when they are not caring.

Health

- Ratings of physical health and mental health.

Services and support

- YACs' satisfaction with their access to respite services.

- Percentage of YACs who access support groups.

- Percentage of YACs with access to family support.

Transport

- Percentage of YACs who have a driving licence.

- YACs' access to transport – public and private.

Employment and education

- Percentage of YACs studying their preferred course.

- How easy or difficult it was for YACs to find paid work.

- Percentage of YACs accessing on-the-job training.

YACs' suggestions to policy makers and service providers

Finances

- Review the eligibility criteria for young adult carers who are seeking to transition to Youth Allowance. To be considered independent for Youth Allowance requires an 18 month work history of 30 hours per week. Currently, young adult carers aged less than 22 years must provide 'constant care' to qualify for Carer Payment, which has a limit on work or study of 25 hours per week (including travel). Therefore, they cannot be working towards meeting the independence criteria for Youth Allowance.

Social and family support

- More support groups for 18–25 year olds, with more regular days to get together.

- More flexible age limits on support groups as it is problematic when they have to move between age ranges.

- Access to enjoyable family activities.

Services

- Better support for care recipients; carers want to know that their relatives are getting all supports that they need.

- Improved access to flexible respite services.

- Access to adequate respite to cover the work hours of employed YACs.

- Increased support for early intervention services for care recipients and additional support for people with emotional and cognitive disabilities.

Health

- Access to affordable gym memberships for YACs through financial support or discounted membership.

- Improved access to mental health support and counselling for YACs and their families using a holistic approach.

Transitions

- Increased support, such as case management or advocacy for YACs, through key transitions periods e.g.. from school to work/study and from studying to paid work.

Education

- Access to a place to 'chill out' and focus while at school.

- Assistance to access face-to-face training and education rather than remote learning.

Employment

- Increased employment opportunities.

- Access to flexible employment conditions.

- Designated positions for YACs.

Rural areas

- Increased transport options.

- A scheme to help YACs buy a car. For example, pay a gap fee similar to Medicare. It could be called 'Medicar' and provide financial help and support to get a driving licence.

3.2 Mid-aged carers

We want them to be as independent as possible and every day of that 18 years that I've spent with my son has been towards that. That's what we are working towards. It might not be the same as an 18 year old who was in his class last year but he will eventually be able to do all these things but unless there's supports underneath him, he just won't.

Caring situation

For some mid-age carers, entry into caring was via a dramatic event, whereas for others it was from the birth of a child or due to a slow deterioration of the health of their relative:

You've just kind of stepped into this role, whereas we've gradually been weaned all the way, because our children were born with it. (Parent caring for child)

Mid-age carers provided physical, emotional and organisational support to children, siblings, spouses, parents and grandparents, in addition to caring for other family members without disabilities:

I have two children. My eldest … has autism … but I am also undertaking full-time care of my grandmother who is at the end stage of her life. I care for my husband, so he has physical and cognitive issues. (Parent caring for a child, parent and spouse)

Many carers only realised they were a 'carer' once they entered the service system after numerous years of providing support. For others, recognition occurred after their child, spouse or parent received a confirmed diagnosis of their condition.

Carers had a sense of responsibility and loyalty to their relatives which was encompassed with love. However, even though carers provided help to their relatives out of love, they wanted recognition and acknowledgement that the support they provided equated to cost-savings for the government:

> If we weren't caring for the people in our lives, you just think how much would that cost the government? We do it because we love them obviously, but it would be good to get some sort of recognition. (Parent caring for child)

What other activities are mid-age carers able to do?

Carers were involved in a variety of activities apart from caring, including paid work, education, social activities and volunteering:

> I focus on helping other people. I work a lot, I really love it. I love running my own program … I love being around so many autistic kids and seeing the different variation in them. I like to see [their] progress. (Parent caring for children)

Many carers felt guilty about doing things for themselves, although they realised that outside activities were important so as not to burn out. However, carers' other activities were often restricted by their caring role:

> I do distance education because I just cannot do it on campus anymore because [of] my husband … I suppose I'd maybe be able to now, but even when he is at supported employment I'll get a phone call from him at least once a day … even though they are supposed to be supporting him. (Spouse carer)

Factors that help mid-age carers to participate

Public awareness of disability and caring facilitated carers' and their relatives' social inclusion and enhanced their sense of belonging to a community. For example, one parent carer and his child had recently joined a local group. The group had accepted them both without judgement. Initially, he was concerned that he and his child would be excluded, but the concern was unfounded. The father felt empowered by this positive experience and it inspired him to try other activities with his child. He said:

> We're being included and that's a really good empowering feeling; you feel normal again. It was really encouraging. (Parent caring for child)

Access to information about services was another key factor in assisting carers to participate socially and economically. Centralised information provided carers with a gateway to services, such as Carer Support Services in SA. High quality and flexible services that catered for individual needs were essential for economic and social participation of carers and their relatives, as were professionally qualified paid workers:

> We are under NDIS. I get great support from carers, as in paid carers, to come and help … I've gone back one day a week to work in the last six months. (Spouse carer)

Most carers whose relatives were eligible for the NDIS had a positive experience with the process of accessing services and the level of support provided.

Carers spoke about developing 'service literacy', which involved gaining an understanding of the eligibility criteria to access support. Information was gained through asking the 'right' questions. Also carers found accessing support was often more successful if forms were completed in a way that portrayed the true extent of their relatives' needs, that is, if they were not available to assist them:

> Because my husband has various health professionals, they always say, 'You have to think about what he is like on his worst day and that's what you have to tell them'. And I think it is hard because when you see him, you will not think he has a disability because he can present himself quite well. (Spouse carer)

Flexible employment conditions, such as working part-time and an understanding and supportive management, assisted carers to maintain employment. Working gave carers a sense of satisfaction and a break from their caring role:

> I started going back to work late last year just on weekends because my [spouse] doesn't work on weekends … So it is, that working time, even though it is work, but it is my own time. It is really good. (Parent caring for child)

Time away from their caring role in the form of retreats or respite services facilitated social connections to other carers, gave them access to essential information and time for themselves.

In addition, access to a Companion Card helped carers and their relatives to be involved in recreational activities. It encouraged them to attend sporting events or concerts together because of the reduced costs. This was especially important for those on limited income.

Challenges for mid-age carers' participation

Many carers lacked awareness of services and struggled for years without help. Carers from culturally and linguistically diverse (CALD) backgrounds experienced some difficulties accessing culturally appropriate services. Often carers reached a crisis before accessing services:

> I don't use any services at all … I sort of tend to do a lot of things on my own now and I think there's probably a lot of carers that are the same, and I think from when I was in high school … and there was nothing. I was never asked 'how was I?', if I needed any help or anything. (Carer of parent)

The complex and bureaucratic systems of support often made it difficult for carers to access services. Carers felt that they had to 'jump through hoops' to gain support. They often found the questions on assessment forms unclear and seemed designed to prevent them from accessing support. They noted that questions on the forms were framed around the level of need of their relatives on their 'best day' rather than what they are like on every other day. The carers felt that if they answered the questions based on their relatives' best day they would not get the help they needed:

> It just seems to be this game where you have to go and basically beg or work around

> and figure and mess with your head until you can work the system. They think for them to throw you a crumb you're just going to be grateful. (Parent caring for child)

Service characteristics, such as lack of availability, long waiting lists, restrictive respite hours and lack of quality respite services, inhibited carers' participation. Area disadvantage also impacted on the availability and quality of services.

As noted earlier, carers whose relatives were eligible for the NDIS had accessed a range of services. In their discussions with NDIS assessors, carers were made aware by service providers that their relatives were the target group for support. Previous access to respite for carers in their own right was not available under the NDIS. Carers could now only indirectly access respite through the provision of specific support services to the person needing support, for example physical therapy or social activities:

> Well he wasn't getting anything before the NDIS. He was on a waiting list for some program with ADHC or something, but the waiting list was just really long … With the NDIS, we only got very limited hours of support for him and we are struggling with that. (Spouse carer)

Carers' participation in other activities was limited by a lack of suitably trained paid care workers. Carers found that the variable quality of some paid care workers made it difficult to feel confident that their relatives would be well cared for when they went out:

> Even when they are good one day, they are not the next and balancing all of that I have a few carers that are in their early 20s. I feel like I've got more teenagers in my house and I'm sort of cleaning up after them. (Spouse carer)

Carers often felt disadvantaged in the labour market when competing for jobs against other people without caring responsibilities. Many found it difficult to combine paid work and care responsibilities due to the unpredictable nature of some illnesses and disabilities and a lack of respite services that cover the working hours of full-time or part-time employees:

> Well, in terms of work, is there any full-time care available? No. That's a measure – there is nothing I can get in my area that will give a nine to five care. I've got a nine pick up, but a three o'clock return. (Carer of parent)

Carers were often interrupted at work or called away to deal with a crisis and felt that this reflected poorly on them as workers. Some took positions below their level of qualifications to fit in with their caring responsibilities. Inflexible work arrangements, insecure working conditions, and unsympathetic managers and co-workers made it impossible for many to remain in employment:

> I used to find a doctor's certificate with my son's name on it wasn't sufficient … They wouldn't give me my sick leave pay because my name wasn't on the certificate … I would have a 20 year old tell me, 'You do realise you are a number'. I'm like, 'Seriously, I can't come into work, my son is in hospital'. That used to make me feel so small and I was scared to ring in sick. (Parent caring for child)

Carers receiving the Carer Payment commented that the limit of 25 hours per week of work (paid work, volunteer work, studying or training) including travel time to be eligible for the payment restricted their employment options. Also, it created a disincentive for carers to increase their hours of work, as they would lose their carer status.

Many carers prioritised their relatives' health and social needs at the expense of their own. The constant demands of caring meant carers often found it difficult to concentrate when participating in other activities. Many were on high alert and worried constantly about their relatives and what needed to be done to support them:

> Switching the brain off is the other hard one, even when you're at work, you know, it's like 'Oh, I haven't made that appointment', 'I haven't been to the chemist'. (Carer of parent)

Many carers felt that they have no life of their own:

> We drop everything else to be that carer and then how do you pick the pieces back up? I think it is like sacrificing 95 per cent of who you are in the first 10 years that I remember, and it is trying to find who you are after that. (Parent caring for child)

Limited income and the expenses associated with supporting their relatives restricted carers' social participation. Carers noted that the Carer Payment was less than minimum wage. Also, they often had to pay for private health services because the waiting lists in the public system were too long. After paying for disability-related expenses and household bills carers were often left with nothing to spend on outings or other activities:

> All the expenses add up and then there's no money left to do anything. (Spouse carer)

Many carers had to adjust their vision of the future:

> That vision's shattered. Yeah, you can't reset that. I was never going to be on a disability pension or a carer's pension or whatever, there was no way. I was going to make it work. It didn't happen. (Parent caring for child)

Impact of caring on different parts of mid-age carers' lives

Providing care over the life course to a child, spouse or parent affected many aspects of carers' lives: their health, their relationships, their labour force participation, and their current and future economic security. These effects could build up over time.

For many carers there was a cumulative impact of caring on their health – both mental and physical. Carers often spoke about being stressed and exhausted from responding to the constant demands of their caring responsibilities while navigating through a complex system to locate information about services and their eligibility criteria:

> I've been only doing it for 16 years … and I'm bitter and twisted now. So I'm over it and I say what I say and I don't care whether you like me or not because … I don't have the time or the energy. (Parent caring for child)

> I just don't want to have to fight for everything. (Parent caring for child)

Caring also placed a strain on relationships with family and friends. Carers often could not attend social events at the last minute or arrived late due to the unpredictable nature of their relatives' needs. Family members or friends found it difficult to understand their circumstances and over time invitations to events or social occasions dropped off.

Carers also found it difficult to sustain relationships with family and friends. Carers often were worn out and did not have enough time or energy to participate in social activities. Carers

who managed to attend social functions often spoke about feeling isolated and as if they were living in a parallel universe:

> You don't have much left … to give other people. I think it gets to such a point where you're sick of your own voice saying how difficult it's been … Things haven't changed, they haven't gotten any better, in fact they are worse and you feel like when somebody else might be complaining about something else that you would find so mundane. (Parent caring for child)

As discussed, providing support to a relative with a disability, chronic illness, fragility due to ageing often made it impossible for carers to remain employed due to unpredictable or high levels of needs of their relatives. Carers who had left the workforce lost valuable skills and confidence. Carers also missed the social aspect of work, in addition to the income it generated.

The damaging effect of caring responsibilities on carers' current level of income and future retirement income was evident. The expenses relating to their relatives' medical appointments, medications, equipment and services restricted their ability to participate in social events and prevented them from paying for services that could improve their mental and physical health, such as counselling services and gym memberships:

> It is like you have to save up to do any social things. And anything I do, all the things for my husband, because the medical stuff you can't get reimbursed so the CPAP machine, that's over $1000 and I had to buy that … so I don't have the money to do social things even if I wanted to. (Spouse carer)

The impact of caring extended into the future; many carers were concerned about the welfare of their relatives, when they could no longer support them:

> You've got to think future too, it is hard for us to think future but when we are not around they are going to get thrown into something. (Parent caring for child)

Despite the challenges faced by carers they found providing support to their children, siblings, spouses, parents and grandparents rewarding. Providing care made them better people. Some had developed new skills and worked in areas that they would not have considered prior to taking on a caring role. Through their experiences of caring, others had established valuable friendships, developed patience and compassion and an appreciation of the diversity of life:

> It's all subjective…but I think I'm a better person and it's guided me into areas that I didn't think I'd be going, like being a support worker and I really get a lot out of it, I love working with [people with disabilities] and to me there're a light in the world compared to everything you see on the news. (Parent caring for child)

Indicators to measure social inclusion suggested by mid-age carers

Health

- Percentage of carers taking anti-depressants.
- Percentage of carers suffering from mental and physical isolation.
- Percentage of carers who attend to their own health needs.

Social activities

- Number of people in the carers' support network.

- How often carers go out socially.

Relationships

- Percentage of relationship breakdowns e.g. single-parent carers.

Services

- Percentage of carers who need additional respite services.

- Percentage of carers who access training for their caring role.

Employment

- Percentage of carers who have restricted job choices.

- Percentage of carers who access training to re-enter the workforce.

- Percentage of carers with access to flexible employment conditions, such as job sharing.

Mid-age carers' suggestions to policy makers and service providers

Awareness

- Increased awareness of caring roles, disability and mental illness through TV and social media.

- Better advertising and promotion of available services.

- One-stop-shop for information about available support and/or a 'show bag' of information for carers.

- Training for health care professional about disability and the important role of the carer.

- A facilitated forum where carers can tell their stories to politicians and service providers.

Access to services

- Availability and access to training for carers, such as how to deal with the stress associated with caring, lifting and handling techniques.

- Increased support for GPs so that they can be be a key access point to services.

- Access to counselling or support workers to assist with mental health issues and the stress associated with caring.

- Programs to help carers have the opportunity for exercise, such as gym membership.

- Greater access to services that target different needs i.e. different types of support groups, appropriate services for care recipients which encompass things that they like and enjoy.

- Increased access to culturally appropriate services.

- Increased access to high quality respite services (planned and emergency) (even though the relatives of some carers are better off under the NDIS, increased access is still needed).

Paid care staff

- Increased training and improved conditions for paid workers.

Employment

- Increased access to flexible employment conditions, such as job sharing.

- A carers' subsidy for employers as an incentive to employ carers, particularly those who have been out of the workforce and felt they lacked the necessary skills to re-enter the workforce.

- Increased cap on the number of hours carers are allowed to work while receiving the Carer Payment.

- Allow carers on Carer Payment to access support through employment agencies and training courses similar to recipients of the New Start Allowance.

- Availability and access to workplace training for carers re-entering the workforce.

3.3 Older carers

> I was the sole carer and doing everything and brought [my child] up to a position where she can now make a contribution rather than a drain on society; yes I can do more now that she has got some help. I have broken my hip twice so therefore I can't go out and just do a manual job … but that doesn't mean to say I don't want to make a contribution and there's the area of volunteering which I would like to do more in … but we are tired, we are exhausted and we are not given credit for that.

Caring situation

The caring situations of older carers varied, however, most had provided support to their spouse, parent or child for many years. Carers often had multiple caring responsibilities over time which entailed caring at both ends of life. Other carers had simultaneous caring responsibilities, for example caring for a spouse and an ageing parent, or their child and grandchild:

> I cared for her on my own until two and a half years ago … and the last 10, 15 years I have also been caring for my parents. (Parent caring for child and own parent)

Some had cared for extensive periods of time before they found out about services or income support for carers. One couple of a child with disability had cared him for over 50 years without help:

> So we've been looking after him for 59 years and it was probably not up until three years ago that our solicitor friend said that we should put in for being a carer because as we are getting older we don't know what's going to happen to him when we are not around. (Parent caring for child)

Some carers felt that they were wearing multiple 'hats' and oscillated between being a

carer and a partner, parent or grandparent. Carers also discussed the reciprocal nature of the caring relationship where each person provided care for the other at different times throughout their lives:

> Sometimes I'm the carer and sometimes he's the carer, if I've had surgery … because you're both together it's − the role changes at times. (Parent caring for child)

Carers felt that there was a lack of understanding of the caring role and a need for increased public awareness of their contribution:

> We are doing this for nothing and we are not getting any recognition for it. (Grandparent caring for grandchildren)

Caring was viewed as a normal part of a relationship and despite providing additional support to their child, parent or spouse was difficult, carers did not view it was a burden:

> I think carer is just a word, you know. I still accept it's just a word because obviously when you've been married for many years, as long as I have, you know, it's the normal thing to look after your wife or your wife would look after me. (Spouse carer)

Many carers were unaware that they were carers until they stopped working and applied for income support. Also carers only found out about services when they identified as a carer:

> It almost comes accidentally that you're a carer. I don't think you're very aware of what facilities are available for you … I think I was probably more aware of it because when I gave up work, because I had to, and my wife was sort of caring for me then for a fair while … When I got better, she got worse, so I sort of just took over that role. (Spouse carer)

What other activities are older carers able to do?

Activities that carers were involved in other than providing support included paid work, social activities and volunteering. However, many of these activities were fitted around their caring responsibilities. Also, many carers took on additional roles that the care recipient used to have responsibility for. A wife caring for her husband with a degenerative disease commented:

> I had to work out how to be a mechanic. I mean, I had some basic knowledge because I've come off a farm and I'm really glad because I've got good grandsons now who can take over all that. I'm always having to shift or change something on a wheelchair. (Spouse carer)

The support provided by carers helped their relatives negotiate and understand the world. In some cases they helped them to maintain relationships with others and assisted them to be socially included. Carers drove their relatives to social activities and or/and encouraged them to participate in different activities. For example, a mother encouraged/cajoled her child with a disability to go to supported employment:

> Now it's because he works [in supported employment] … five days a week … I make him go … It's the only interaction he has with people. (Parent caring for child)

Factors that help older carers to participate

Access to flexible and high-quality respite assisted carers to participate in other activities, such as volunteering, but also enabled their relative to engage socially:

> I have a carer come in two hours a week every week, and in those two hours … I did my shopping one week, and another week I did a little bit of volunteer work at a bookshop – that was two hours. (Spouse carer)

Some families had accessed services through the NDIS. Overall, these carers had positive experiences with the support they received. A couple in their 80s who cared for their son, now aged 59, without any help until three years ago could not speak highly enough of the range of support they received for him through the NDIS. However, carers noted that they were not the focus of the support provided under the NDIS.

Access to a well-developed support networks, such as those found in retirement villages, and support from extended family assisted carers to continue in their caring role:

> When I had my second hip replacement done last August, my daughter flew over from London, with her husband to look after me and look after my son. (Parent caring for child)

Accessibility in public spaces was vital for carers and their relatives to enjoy outings:

> The art gallery and the museums and different places around Australia, have got those lifters now … you have to go somewhere with the attitude, 'Oh, well, he probably won't be able to go upstairs or see this and that'. So if that happens [disability access] it's a bonus, like, that's fantastic. (Spouse carer)

Challenges for older carers' participation

Many carers suffered from mental and physical exhaustion which made it difficult to take part in activities that they previously enjoyed. Carers often ignored their own health needs, which also prevented them from participating:

> I think a lot of the things that you have to give up. I used to be a volunteer … just make cups of tea and that sort of thing … and I loved it. I used to play sport of some sort, did a lot of quilting, but I got to that stage that I couldn't concentrate on it anymore. My blood pressure went up. I had side effects from so many medications, but I wasn't well for 12 months about the same time as [my husband] was at his worst. (Spouse carer)

Carers often found it difficult to plan events in advance due to the unpredictable nature of some illnesses. They were often late to events because the care recipient would take a long time to get ready or change their mind about attending an event. Carers often talked about feeling rushed and pressed for time. Many carers could not switch off, even when having a break, due to being on 'alert 24 hours a day':

> Well, I didn't go out otherwise, but even just the shopping, I would just rush up the street and back home again … I used to just grab what I wanted, and it was always just rush, rush, the whole time. No, we didn't go out. (Spouse carer)

A common theme in the focus groups with older carers was a lack of accessible buildings

and facilities which inhibited social outings. Many carers experienced problems finding and/or using disability toilets or ramps:

> There was a place in [name of resort] with a disabled toilet; a big toilet, it was fantastic. Get the wheelchair in there, can't close the door. There was a car park behind it, he's leaning forward doing a wee in full view of everybody. (Spouse carer)

A number of service characteristics made it difficult for carers to have a break from their caring responsibilities and take part in various activities. Many experienced a lack of information about services or entered the services system in an ad hoc manner often after crisis. Also carers felt that the existing government websites were not user-friendly for older people because they were difficult to navigate and to find relevant information.

Other service characteristics that restricted carers' participation were inadequate support services, especially for young people with high needs, and a lack of flexible respite services, particularly in non-metropolitan areas. The lack of appropriate and safe respite care options, with appropriately trained staff, made it difficult to leave their relatives because they could not be confident that they would well cared for and safe.

Carers also experienced problems accessing services and support for younger people with disabilities during transition periods, as they moved from one age bracket to the next:

> Well, because he's moved up – yes, he's sort of, yeah, the goal posts have moved each time … So then you start the whole role again and you think … my God, you know, another 20 years … I hope to God I live that long so my daughter can have a life with her husband before she has to take over the role of caring. It makes it a bit hard. (Parent caring for child)

Providing support often put a strain on carers' finances and restricted the activities that they could take part in. Some carers went without in order to financially support their relatives:

> My daughter is fiercely independent. She is determined to make her own way … And my finances have been not great, but been really, really drained, not that I ever put any pressure on her. I did without myself, as you would do to help your child, until she eventually went to Centrelink. (Parent caring for child)

Some carers in the focus groups had juggled both caring responsibilities and paid work for many years. However, as the care needs increased or changed it often became impossible for them to continue working.

> But having to leave work, even though I was eligible to retire, I would have liked to have stayed working, but I needed to leave to cope – to look after him and to be there for him because of the mental health issues that arise with intellectual disability. (Parent caring for child)

Impact of caring on different parts of older carers' lives

Many carers experienced strains on their relationships with other family members and friends. Some lost contact with their friends due to the stigma associated with particular conditions, such as dementia. Many carers lived in a constricted world, especially with regards to their social life:

> It would be lovely to go and see … an older sister … you're very restricted and you just sort of accept it … we're planning, you know, to go over to see my daughter … but I'd have to take six months preparing and hope I can get him to walk out the damn door with me, because we've had that before where he wouldn't walk out the door when the taxi's arrived. (Parent caring for child)

Caring responsibilities had a cumulative impact on carers' health (mental and physical) due to the grief over changes in their relationships with their relatives, constant stress and time pressure:

> It's aging me and I'm thinking, another 10 years, what's going to happen? I'm worrying about – I don't want to become withdrawn. I want to still be a person … I don't want to end up … as a psychiatric patient … I don't want to become depressed … But that needs to be assessed … the impact on the carer because it's ongoing. And how long is it going to keep going? Well, it does until you die. (Parent caring for child)

Some carers had relocated to provide support to their relatives and this had led to a disconnection from their established social networks and a strain on their finances:

> I have such reduced finances to help her [daughter] and I had a [stroke] three months ago, I guess from the stress of it all, plus the stress of moving was enormous and I don't have my friends around me. I mean we are in email contact and on the phone … I'm trying to make some friends. (Parent caring for child)

As noted in the quote above, providing care often limited carers' income and many carers expressed concern about their current and future financial security. Carers often left paid work to support their relatives and relied on income support. Carers also incurred costs associated with providing support, such as relocation expenses, medical bills, medications and equipment. Carers' limited income curtailed their participation in social activities as well as being able to go on holidays.

Carers were also concerned about how they pay for the future care needs of themselves and their relatives. Older parents of adult children with disabilities were apprehensive about the future and who would provide support for their children if they were hospitalised or when they could no longer provide care. Ideally, parents wanted access to a range of high-quality group homes or supported accommodation. They wanted their children to have a choice about where and who they lived with, rather than being placed somewhere because there was a vacancy. Parents wanted peace of mind that their children would be well looked after, happy and safe:

> It worries you … I suppose for 38 years I've looked after him … I'm hoping I can live another 20 … I did ask about accommodation because it would be lovely if you had a cottage with his peers … and then still come home and spend some time with me at the weekend. But there's nothing. I was told if anything happened, if it was a crisis, they would find something. Well, by then the shock of losing mum would be horrendous. (Parent caring for child)

Despite the difficulties, carers talked about learning a lot through their caring role, especially how not to be selfish. Providing support to their relatives gave them a different perspective on life. For one carer, who supported her grandson with disabilities, caring responsibilities helped her through the grieving process after her husband's death:

As hard as it is I wouldn't change a thing … it puts you in a different light, you've got to think of somebody else (Parent caring for child)

Indicators to measure social inclusion suggested by older carers

Health

- Rating of carers' health, including weight and sleep deprivation.
- Changes in carers' health over time.
- Ratings of mental health, depression and the number of carers taking anti-depressants.
- Level of carers' stress.

Isolation

- Social isolation of carers.
- Access to social networks.

Finances

- Ratings of financial stress of carers.

Older carers' suggestions to policy makers and service providers

Access to information

- Access to information about services and income support for carers when the person they are caring for is discharged from hospital.
- Development of an information website that caters for the needs of older people.
- Inclusion of older people in the planning and development of website.

Services

- Access to high-quality care that was fun and engaging was viewed as essential for the social inclusion of carers and care recipients.
- Activities that carers and care recipients could attend together.
- More activities that enhance the social participation of younger people with disabilities, such as group activities.
- Increased access to group homes and supported accommodation for adult children with disabilities.
- Improved access to preventative respite and emergency respite.
- Services tailored to the individual needs of carers and people in need of support.
- More support for carers after caring ends.
- Increase CALD-appropriate support for carers and their relatives.
- A reduction in program eligibility gaps for young people with disability as they move from one age bracket for example for young people moving into the NDIS.

3.4 Service providers

Focus groups with key stakeholders

Focus groups with key stakeholder were conducted in SA and NSW. In SA members of the Carer Support Network (CSN), which comprises key organisations supporting carers from across the state (carer support services, advocacy organisations and policy makers), participated in the focus groups. NSW has no such state-wide network of organisations designed to meet the specific needs of carers and therefore a number of separate focus groups were conducted in the metropolitan (2) and the non-metropolitan (1) areas. A broad range of service providers (including health services, primary and community services, mental health services, respite, carer support services, centre-based programs, transport, information and education and training services) and policy representatives participated in the focus groups.

Stakeholders noted that the impact of caring on social inclusion was not linear but increased and decreased as carers moved along their 'caring journey'. The nature of caring and the type of support required to facilitate carers' social inclusion changed over time and depended on where they were on their 'caring journey'. Stakeholders reported that when carers first took on a caring role they did not usually identify as a 'carer', as this often occurred while they were in a state of shock after a dramatic event. At this point in their caring journey carers tended to focus on the needs of their relatives and securing appropriate services for them. As carers moved further along their 'caring journey' they were more likely to recognise themselves as 'carers' and to consider their own needs.

Key stakeholders noted that after carers become more settled into their caring role it was increasingly difficult for them to give up their caring responsibilities, especially as services supplement rather than supplant the support carers provided. Therefore carers do not have a real choice about whether to take on a caring role or not. As one service provider noted:

> I suppose that's what a lot of it comes back to, well, whose role is it to care? … But, you know, my mum, my family they're all in [name of OS country]. When my mum's at the point, you know, that she needs caring for, is it my responsibility to uproot and change my life to care for my mum? Or is it the state's?

Key stakeholders also discussed their concerns about the potential risks to carers' social inclusion associated with Consumer Directed Care (CDC) funding and implementation of the NDIS. Stakeholders discussed how both programs had shifted the focus of service provision away from carers receiving support in their own right and more towards the care recipients and, as a consequence only indirectly to the carer. Key stakeholders were also concerned about the capacity of some carers to self-manage funding. Stakeholders noted that although a whole-of-family approach underpinned the CDC funding model, the care recipient was the focus of service provision. Carers accessed services only through the care recipient satisfying the service eligibility criteria. Also, because funding to support the care recipient and the carer as a unit was finite, stakeholders commented that carers often prioritised the needs of their relatives over their own, and would go without rather than reduce the amount of support available to their relatives.

With respect to the implementation of the NDIS, key stakeholders in SA and NSW were concerned about the possibilities that funding quarantined specifically to support carers, such as respite services, would be re-directed or absorbed into services targeting people with disabilities. Carers would only access a form of respite indirectly when the person with disability was taken out for social activities or provided with in-home support or therapy. Although key stakeholders welcomed funding for individualised and flexible support for people with disabilities, they argued that carers should not be disadvantaged in the process:

> I think from a carer's point … we're not applying the same NDIS model. I don't think they've [the carers] got the right to choose. And so I think here we are living in a world where we're supporting our clients, our participants, in this model … But we're doing the exact opposite with our carers. And we're disempowering them to make choices and to have the right to make these choices.

One service provider had organised workshops to empower carers and to assist them to complete assessment forms so that they could access a form of respite indirectly through the support provided to their relatives with disability. A service provider commented that carers were being told by the planners in the assessment process:

> 'Yeah, it's not about you [the carer] it's about the person [with disability] and your needs are not the issue here' … The workshops we were holding was about helping people understand the language. And to go in there and not say, 'I need respite' but 'the person that I'm caring for needs to have this social activity for four hours'.

A number of barriers to carers' social inclusion were discussed in the focus groups with key stakeholders, such as lack of a concept of caring in some cultures, expectations about who should take on caring roles within the family, a lack of information about services, and the eligibility criteria for services and income support. For example, stakeholders commented that some carers thought they were ineligible to access services if they received the Carer Payment. Participants in the focus groups also noted that some carers felt guilty and put off asking for help until it was too late and the needs of the care recipient were too high to support at home. This also impacted carers' mental and physical health. In other instances the care recipient refused help from services, for example parents with disabilities or a mental illness were often reluctant to seek help due to stigma and concerns that their children would be reported to authorities.

Key stakeholders noted that carers often felt under enormous time and emotional pressure when they juggled the demands of work, caring and other family responsibilities. This pressure had a cumulative impact on carers' health and social participation and they often found it difficult to sustain relationships with friends and other family members.

Older parents of adult children with disabilities were identified by stakeholders as a particularly vulnerable group due to a lack of supported accommodation available for adult children. Some parents wanted their adult children to begin the transition from the family home, in preparation for the time when they could no longer provide care. However, in other cases elderly parents struggled to continue to care for their children, as they did not have any retirement savings due to their life time of caring responsibilities and could not afford to remain at home without their children's income.

Service providers highlighted the importance of developing a trusting relationship with the carers and the family over time so that services to facilitate their inclusion would be accepted. Access to flexible respite was deemed as essential to carers' social inclusion. Flexible respite and a supportive work environment were crucial for employed carers. For example a Carer Support Service in SA had implemented policies designed to further support their employees with caring responsibilities who comprised over 40 per cent of the employees. Carers could access another 10 days leave in addition to their regular carers leave entitlements. This leave could be taken when needed and the only administrative requirement for employees was that carers had to indicate, if possible, when they would return to work. Supervisors' approval was not necessary to access the leave.

Access to centre-based respite also assisted carers of people with lower levels of disability to be socially included. However, service providers noted that working carers found it difficult to access support groups which were held during working hours. Also if carers' income was too high they could not access support services.

Barriers to social inclusion

Service providers outlined the following factors that they perceived as barriers to carers' social inclusion:

Choice

- Carers often felt guilty about asking for help in their caring role.
- Lack of an appropriate level of services that made it possible for carers not to provide support (e.g. carers lack genuine alternative care options).
- Cultural expectations about taking on caring roles.
- Normative (family and/or cultural) expectations about who should provide care and when caring becomes untenable.

Stigma

- Carers may not want to ask for help in their caring role due to feeling guilty about having time off and not looking after their relative.
- Parents of young carers may be reluctant to ask to help due to concerns about notification to Family and Community Services (FACS).

Services

- Lack of information about available support.
- Lack of knowledge about the eligibility for services.
- Access to information was uneven and disjointed in some local areas.
- Access to culturally appropriate services.
- Services working in isolation and families had to repeat their stories to different services.
- Carers do not always receive information about services for the care recipient at discharge from hospital.

- Carers access support only after a crisis occurs.

- Relatives do not want to accept services.

- Inflexible service provision that does not meet clients' needs.

- Waiting lists for services, such as respite.

- Administrative barriers (e.g. accessing the Companion Card).

- Area disadvantage and the 'service postcode lottery'; service availability depends on where carers live.

- Lack of accommodation options for families from regional areas travelling to cities for treatment.

- Cost of services.

- Consumer directed care (CDC) shifts focus on funding away from the carer to the person receiving support.

- Funding for and access to services for different groups varies.

- Lack of services specifically targeting carers' needs, such as counselling and respite.

- Under the NDIS, dedicated funding for carer specific services has been incorporated into the individualised funding and directed towards the person with disability.

Relationships

- Changing nature of relationship between carers and the care recipient and carers and other family members and friends.

- Caring can have a negative impact on carers' social participation and when caring ends and they transition out of the caring role, carers face challenges readjusting and reconnecting to family and friends.

Social life

- Lack of spontaneity as respite organised with a trusted paid care worker.

- Lack of ability to plan ahead due to the unpredictable nature of care.

- Inability to switch off from caring role, even when accessing respite, causes exhaustion in carers.

- Carers relocate to be closer to family and friends needing support and lose their own existing support networks.

Time pressure

- Guilt associated with carers jugging multiple roles and feeling that they cannot devote enough time to each role.

- Impact of time pressure on carers' mental and physical health.

- Lack of time to attend to their own needs.

Employment

- Lack of supportive management.

- Lack of flexible employment conditions.

- Carers working less hours than they want due to lack of access to education and vocational training, particularly important for young carers.

Income

- Lack of income, as many carers relied on income support.

- Carers in disadvantaged areas often live in insecure housing and have limited income.

- Financial impact of disability and care on employment and income.

- Carers of older children with disabilities have been unable to work and therefore do not have any superannuation. When they can no longer care for their children and have to move them into supported accommodation, the parents cannot afford to stay in their homes.

Transport

- Carers living in regional areas lack access to transport.

Access

- Lack of wheelchair and disability accessible buildings and public amenities.

What helps carers to be socially included?

Service providers also outlined examples of how services could assist carers to be socially included:

Developing relationships and connections

- Service providers developing trusting relationships with carers and care recipients over time.

Services

- Providing respite (residential and in-home), so that carers can have a break from caring and remain connected to the community and continue with activities, such as volunteering.

- Referring carers to support groups to establish social connections and to share experiences with people going through similar experiences.

- Organised social outings for carers.

- Identification of carers through an intake process for new clients and the discharge planning process from hospital and referral to relevant services.

- Services taking on an advocacy roll on behalf of the carer to link them to services and ensure referrals are acted on.

Empowerment

- Workshops to encourage carers to look at their own needs and communicate their needs through the assessment process.

Employment

- Access to flexible work arrangements.

- Access to clear information about carer leave entitlements.

Additional indicators of social inclusion

- Compare carers to the general population on all indicators of social inclusion, including economic and community participation.

- Recognition of carers' prior skills are recognised in the process of reconnecting to the labour market.

Services

- Access to transport.

- Access to primary and allied health care services.

- Access to training for carers in their caring role e.g. lifting.

- Access to flexible services.

- Access to preferred types of support.

- Access to high-quality services.

Social life

- Ability to go out on the spur of the moment.

- Impact of time pressure on health and social life.

Health

- Impact of emotional strain on carers' health.

- Mental health of carers.

- Carers attending to their own health and undertaking health check-ups.

Elements of good practice in supporting carers' social inclusion Carer Support model in SA

As noted above, carers for the focus groups in SA were recruited through members of the Carer Support Network (CSN), who also participated in the stakeholder focus group. This gave the researchers the opportunity, in SA only, to gain a unique insight into the specific model of support that facilitates carers' social inclusion, implemented state-wide from the dual perspective of the carers and the services that support them. Further details of the SA Carer Support model are outlined below.

The CSN comprises a number of organisations that provide a range of services specifically designed to support unpaid family carers. The Carer Support model underpins the way in which services are delivered within these organisations. Within the model, the value of caring is recognised, as is the importance of carers receiving support that maintains their wellbeing and a balanced lifestyle. Support is provided by 'walking alongside' carers in order for them to access relevant information to sustain their caring roles and quality of life (see http://www. carersupportsa.org.au/index.php/about-csnsa). The Carer Support model is collaborative,

flexible and carer designed and driven. Carers are members of the board and have input into the way in which services are provided.

The Carer Support model aims to support carers as a group with specific needs in their own right, and facilitate their (re)connection to the community. The service approach is holistic and strengths-based and encompasses the needs of the whole family. Initially support focuses on developing a trusting relationship with the carer by listening to them.

The Carer Support model offers a good practice model of service provision that recognises the valuable role of carers and support designed to meet their specific needs. Participants in the focus groups with carers in SA were recruited through services from the Carer Support Network (CSN). Feedback from carers in the focus groups in SA highlighted the importance of services based on the Carer Support model in facilitating their social inclusion.

Other services mentioned in the focus group with young adult carers as supporting social inclusion were the Raw Energy and WAVE programs. The Raw Energy mentor program is designed to 'provide support, respite opportunities and social engagement for the young carers to take time out and have some fun' (see rawenergy@carersupport.org.au). The Wirreanda Adaptive Vocational Education (WAVE) caters for students who have disengaged or are disengaging from mainstream school. It aims to reconnect students to specialised case management and individually tailored learning and earning activities. Teachers, youth workers, counsellors, case managers and mentors provide support to the students. (see http://dusseldorp.org.au/priorities/alternative-learning/case-studies/wirreanda-adaptive-vocational-education-wave/).

3.5   Implications of focus groups for conceptualising and measuring social inclusion

Reconceptualising social inclusion to take account of care responsibilities

Existing social inclusion frameworks and the indicators used to measure social inclusion do not adequately capture carers' contributions to the social inclusion of others through engagement in volunteering and contact with family and friends. The current frameworks also fail to recognise other unique aspects of caring, such as the complex relationships involved, and the way in which carers' participation in different aspects of their lives overlap and interact.

- How do carers perceive their participation in different aspects of their lives?
- How should we assess the quality of participation for carers?
- How should we measure the positive and/or negative interactions or spillovers between different aspects of carers' lives?

The following section sets out important aspects of carers' lives that are not captured in the current social inclusion frameworks and outlines possible ways to measures these.

Recognition and respect

Many carers do not see themselves as carers. They view the support they provide as part of their role as a spouse, daughter/son, parent, relative or friend. This can result in carers not accessing information and services. All levels of society (carers, family, community, workplaces, services and policy makers) must recognise and respect the important role of carers in supporting the health and social care system if carers are to receive the support they need. Recognition of the caring role can occur at various levels: at the individual carer level; within the family, community and workplace; and policy and service provider levels.

Self-identify as carer

Policy and service providers recognise role

Recognition and respect

Family recognises role

Community and workplace recognises role
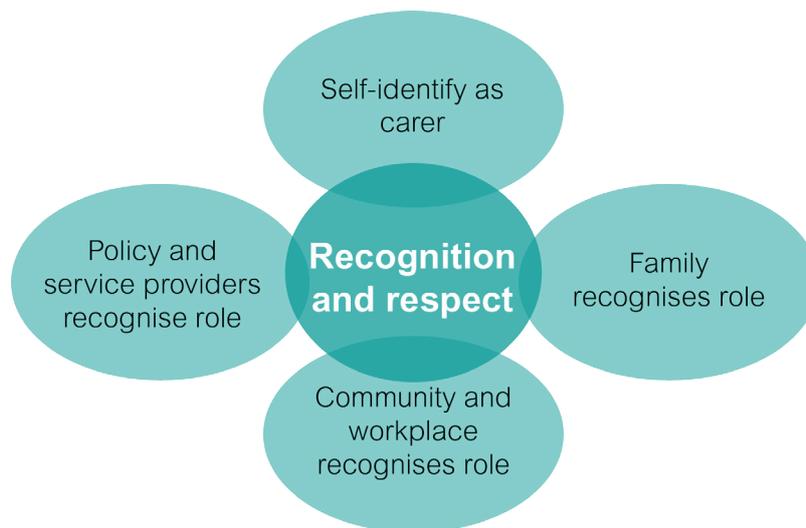
Examples of possible indicators of recognition and respect for the caring role include:

Carers

- Percentage of people who identify themselves as carers.
- Increases in rates of people who identify themselves as carers.

Family

- Percentage of carers who get support from family members in their caring role.
- Percentage of carers who share the care responsibilities within families.

Services

- Percentage of health and community service providers who ask about carers' needs in assessments.
- Percentage of times carers' views and knowledge are taken into account in the assessment process by service providers.

Workplaces

- Percentage of carers who feel comfortable to talk about their caring role at work.
- Percentage of workplaces that have policies to support carers.

Quality of participation

Most of the existing indicators of social inclusion are designed as threshold measures. If a person falls above or below a certain point on a scale, they are categorised as being participating/included or not. These types of measures do not consider the quality of participation or whether being involved in an activity is beneficial or detrimental to general wellbeing. For example, caring responsibilities can limit the type of work carers can do or the hours they can work or the location of their work. This can result in employment conditions that are insecure and poorly paid. Alternatively carers may be employed but they may have little time for themselves and it may be difficult to balance different aspects of their lives. This can also have an impact on the quality of their relationships with family and friends and also the people they support.

Relationships:
satisfaction with relationships
reciprocity in care relationships
indicators of social support
and isolation

Time pressure:
ability to balance
multiple
responsibilities

Quality

Caring situation
access to information,
training, services

Employment
satisfaction with:
job security
job characteristics
balancing work & family

Examples of possible indicators include:

Relationships

- Impact of caring role on relationships with family and friends.

- Changes in relationships with family and friends.

Social support and isolation

- Percentage of carers who can get help from someone when needed.

- Frequency of carers getting together socially with friends or family members not living with them.

Time pressure

- Percentage of carers who always or often feel rushed or pressed for time.

Employment

- Carers' satisfaction with work-family balance.

- Carers' access to flexible work arrangements, such as working from home, flexible start and finish times, carers leave and part-time work.

Caring situation

- Percentage of carers with unmet need for services.

- Percentage of carers with access to information and training about their caring role.

Opportunities for choice

Some carers take on the caring role because there is no other alternative. This lack of choice can have negative impacts on other parts of life, such as entering or keeping a job, education and training, community involvement or spending time with friends.

Another aspect of carers' social inclusion that is not considered in current frameworks and measures is whether they feel they have a choice in taking on their caring role. If carers take on the role of caring because of a lack of alternative sources of support, then they do not have access to the resources and opportunities to exercise agency; a key aspect of social inclusion. This lack of choice in taking on the caring role can have negative implications for other parts of their lives, such as furthering their education and training, community involvement or spending time with friends.
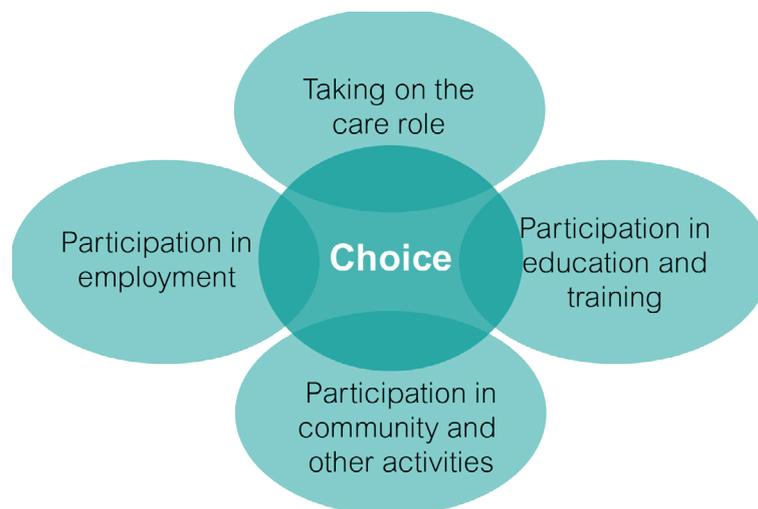
Examples of possible indicators include:

- Percentage of carers who took on the caring role because there were no alternative arrangements available.

- Percentage of carers who have choices about the services they can access to support their caring role.

- Percentage of carers who changed jobs since taking on the caring role.

- Percentage of people who would like to be employed while caring but are not due to a lack of alternative arrangements.

- Percentage of carers who had to leave work or reduce the hours of their employment due to caring.

- Percentage of carers who cannot participate in social or community activities due to caring.

Spillover effects

Many carers are employed and do voluntary work as well as providing help. Participating in a number of activities can have spillover effects. These effects can be both negative and positive. For example, providing care can have a negative impact on paid work. However, being employed can give carers more income and provide a break from their caring role.
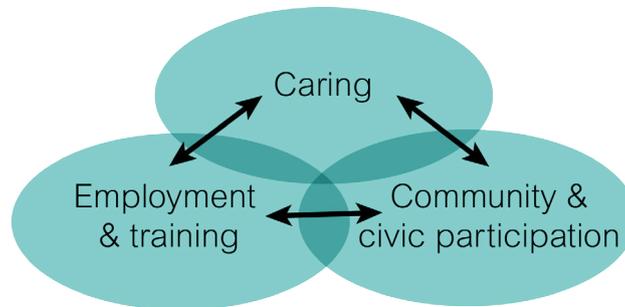
Examples of possible indicators include:

Positive

- Percentage of carers who feel that having both work and caring responsibilities makes them a well-rounded person.
- Percentage of carers who feel that working makes them a better carer.

Negative

- Percentage of carers who worry about what goes on with the person they care for while they are at work.
- Percentage of carers who feel that because of their caring responsibilities, they have to turn down work activities or opportunities that they would prefer to take on.
- Percentage of carers who do not have access to further vocational training.
- Percentage of carers who feel that working leaves them with too little time or energy to be the kind of carer they want to be.

Effects over time

Many carers move in and out of different caring roles over the years. This can have a negative effect on other aspects of life and these can build up over time. For example, some carers may have moved in and out of jobs because of different caring roles. This can have a negative impact on contributions to superannuation savings and retirement income.

Examples of possible indicators include:

- Number and length of caring roles over time.
- Age at which care responsibilities commenced.
- Percentage of carers who gave up work to care.
- Percentage of carers who worked part-time to care.
- Percentage of carers who own their own home.
- Level of superannuation savings for carers.

3.6 Summary

Carers' substantial economic and social contribution to their families and the broader society was clearly evident in the focus groups. Carers provided vital support to their children, siblings, spouses, parents and/or grandparents that allow them to remain at home and connected to their communities. Although carers found providing support to their loved ones a rewarding experience, which gave them a broader perspective on life, they wanted recognition that their caring role saved governments money, often at the expense of their participation in other aspects of life, such as education and training, employment, leisure and social life. Disengagement from employment, education and social activities, together with the unpredictable and often constant demands of caring, meant carers could not plan ahead and experienced time pressure, poor health and financial insecurity over the short and long-term.

Young adult carers' pathways into their caring role varied; however, to them it was an integral part of family life. Despite the challenges faced by many YACs completing school, studying at university or TAFE, or finding work that accommodated their caring responsibilities, all were willing to sacrifice their own social inclusion in order to support the social inclusion of their relatives. YACs' future choices and transition to adulthood often were constrained by their caring responsibilities and potentially set them on a pathway to disadvantage and social exclusion. However, access to information, individualised and flexible support services, and carer-friendly educational structures and employment conditions ameliorated YACs' disadvantage and enhanced their social inclusion.

Similar to YACs, mid-age carers' entry into caring varied and resulted from a dramatic event or a slow deterioration of their relatives' health over time. Many mid-age carers supported other family members, without disabilities as well. Mid-age carers tended to prioritise the needs of their relatives over their own needs and organised their lives accordingly. Participation in paid work and social activities were often forfeited in order to sustain their caring responsibilities. Many mid-age carers experienced structural barriers to accessing appropriate services to support their relatives and themselves in their caring role. Years struggling with the service system often left them exhausted, both mentally and physically and concerned about the future. Carers living in areas where the NDIS had been implemented noted that, although support to their relatives had, for the most part, improved, access to respite services had been minimised and carers could now only access a form of respite indirectly through services for the care recipient. Access to information and appropriate, high-quality support for their relatives and respite services for themselves,

as well as flexible working conditions, were essential to sustain their social and economic participation.

Older carers, often, had spent many years in their caring role. Some had moved in and out of different caring roles over time, whereas others had simultaneous caring roles for a number of years. Some had provided care to their relatives for extensive periods of time without help, unaware that support services were available or that they were eligible for services, as they did not identify as carers. For some older carers the implementation of the NDIS had improved access to support services for their relatives. Providing care over time had a cumulative impact on older carers' health, social life and their financial security. Many expressed concerns about the future when they could no longer provide support to their relatives. Access to a support network, flexible and high quality respite services and accessible public spaces facilitated older carers' social inclusion.

Key stakeholders reiterated many of the issues raised by carers in the focus groups. They also noted barriers to carers' social inclusion, such as a lack of awareness about available services and the eligibility criteria for services and income support, especially when carers did not recognise themselves as carers. Key stakeholders also discussed the impact of carers' guilt in relation to asking for help, due to family or cultural expectations about caring for their relatives, and the ramifications this had on their mental and physical health. Service providers and policy makers drew attention to the issue that policies that redirect support away from carers in their own right may pose a risk to carer's social inclusion, especially if services for carers are reduced.

Currently, informal care for people with disability, illnesses, or frailty due to ageing, has a contradictory status within concepts and policies of social inclusion, as care can be a risk factor for exclusion and sometimes, conceptually, an indicator of inclusion. Some empirical measures of social inclusion only recognise a limited range of socially and culturally valuable activities. Current concepts of social inclusion do not adequately recognise and value the economic contributions and the social connectedness provided by informal care relationships in the private or community spheres. They also neglect the potential contradictions of being socially included in multiple spheres. The proposed framework and indicators endeavour to extend the theoretical understanding of social inclusion by exploring the place of care within existing social inclusion frameworks, and disentangling the relationships and contradictions between activities that can be simultaneously both indicators of inclusion and risk factors for exclusion. The proposed alternative framework of inclusion acknowledges the relational aspects of social bonds and takes account of the competing demands of multiple roles. The framework proposes indicators that recognise and assess the balance/imbalance of participation in multiple life domains, such as market activity, non-market relationships, obligations and social and political activities. Enhancing the robustness of the concept of social inclusion and the concomitant indicators will augment the development of policies and institutional change to facilitate the social inclusion of carers in their own right.

4 Carers and Social Inclusion in Australia
Melissa Wong and Trish Hill

The analysis of social inclusion and social exclusion indicators in this section explores the ABS *Census of Population and Housing* (Census) data for 2006 and 2011. The Census data was used as it provides population estimates and can identify the circumstances of carers from smaller population subgroups. Importantly, this encompasses carers from Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse communities. It also enables analysis of social inclusion and social exclusion outcomes by age and gender for these communities. In addition, the Census can provide data on carers in smaller geographical areas to identify spatial differences in carers' social inclusion and exclusion.

Comparisons have been made for carers and their non-carer peers by age (15–24, 25–44, 45–64 and 65 and over) and gender, for 2006 and 2011. This summary report contains key findings from the Census analysis. The full list of indicators and their respective graphs can be found in the *Technical Appendix: Evidence from the 2006 and 2011 Census*.

The indicators of social inclusion and exclusion for carers have been defined in terms of participation (all individual-based indicators, apart from living in a jobless household) and resources (all household-based, except for levels of spoke English). The indicators are listed below:

Participation

- Education: Young carers aged 20–24 years who have Year 12 (or equivalent) attainment.
- Engagement: Young carers aged 15–24 years who are not in employment, education or training (NEET).
- Education: Carers aged 25–64 years who have post-school qualifications.
- Employment: Working- age carers (15–64 years) who were engaged in paid employment.
- Relationship between employment and education: Carers aged 25–64 who were employed and have a post-school qualification.
- Employment: Working-age carers (15–64 years) who live in jobless households.
- Social participation: Carers who were involved in volunteering.

Resources

- Economic resources: Carers who live in households with low income.
- Material resources: Carers who are homeowners or purchasing a home.
- Material resources: Carers who live in a household with access to a motor vehicle.
- Social resources: Carers who live in a household with access to the internet.

- Skill resources: Carers with poor spoken English (only for carers from a Culturally and Linguistically Diverse (CALD) background in summary report).

4.1 Overall comparison of social exclusion of carers and non-carers

4.1.1 Participation

Overall, carers were less likely to participate in employment and had lower secondary school education achievement, yet carers were more likely to participate in volunteering than their non-carer peers.

Education: Young carers aged 20–24 years who have Year 12 (or equivalent) attainment

Young carers were less likely to complete Year 12 than their peers in 2006 and 2011 (Figure 4.1). Young female carers were most disadvantaged in terms of education outcomes vis-à-vis their female peers (Figure 4.2).

Figure 4.1 Proportion of carers and non-carers aged 20–24 who have completed Year 12, 2006 and 2011 (%)
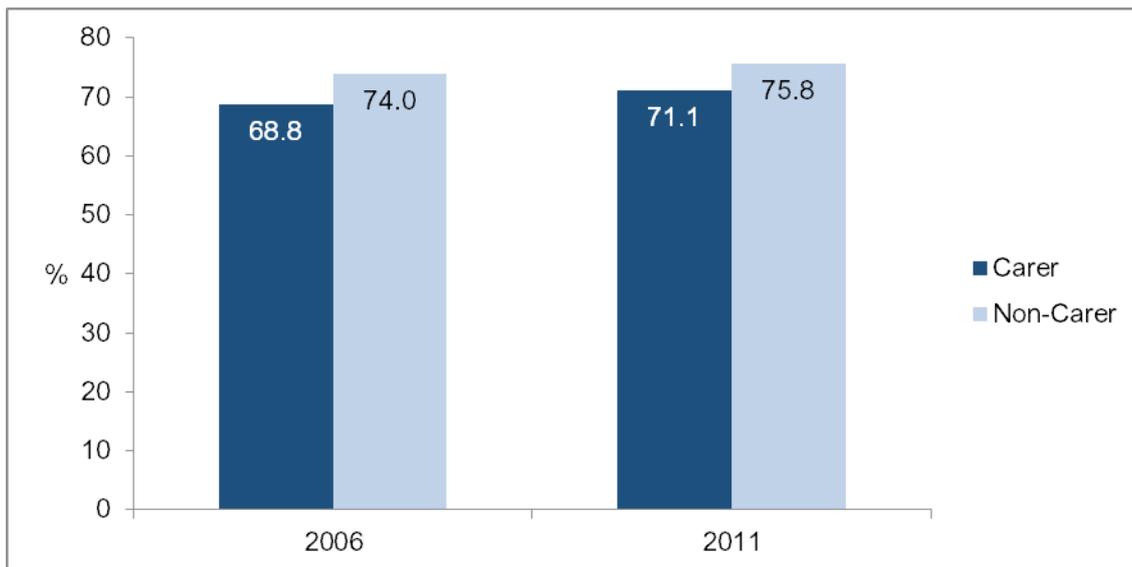
Figure 4.2 Gap between carers and non-carers aged 20–24 who have completed Year 12, by gender, 2006 and 2011 (% point difference)
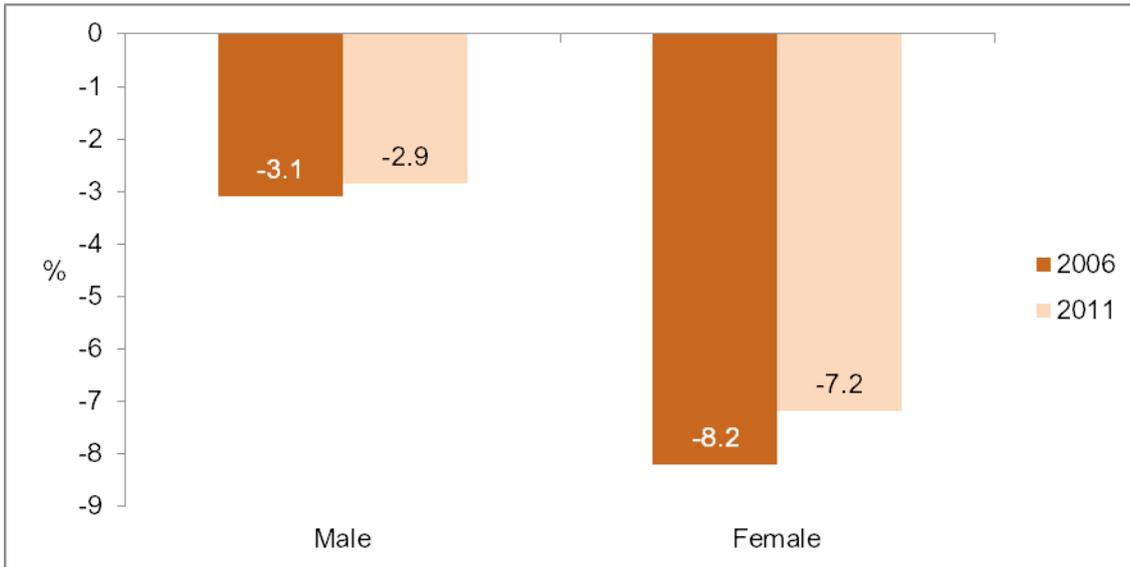
Engagement: Young carers aged 15–24 years who are not in employment, education or training (NEET)

Young carers aged 15–24 years were nearly twice as likely to be not in employment, education or training (NEET) compared to their non-carer counterparts in 2006 and 2011 (Figure 4.3). Young female carers had the highest rates of NEET (Figure 4.4).

Figure 4.3 Proportion of carers and non-carers aged 15–24 who are NEET, 2006 and 2011 (%)
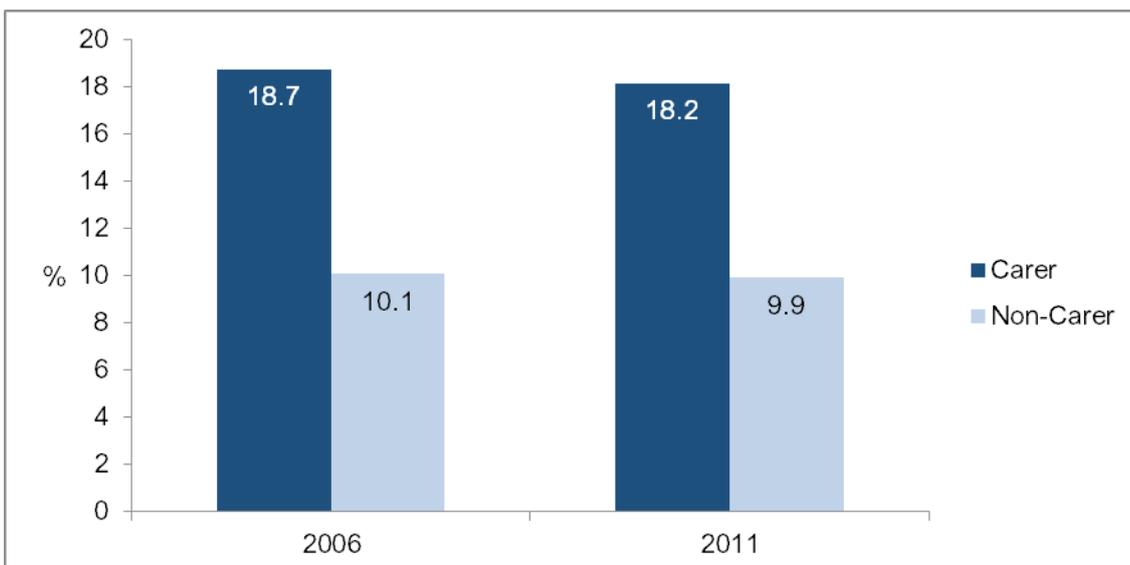
Figure 4.4 Gap between carers and non-carers aged 15–24 who are NEET, by gender, 2006 and 2011 (%)
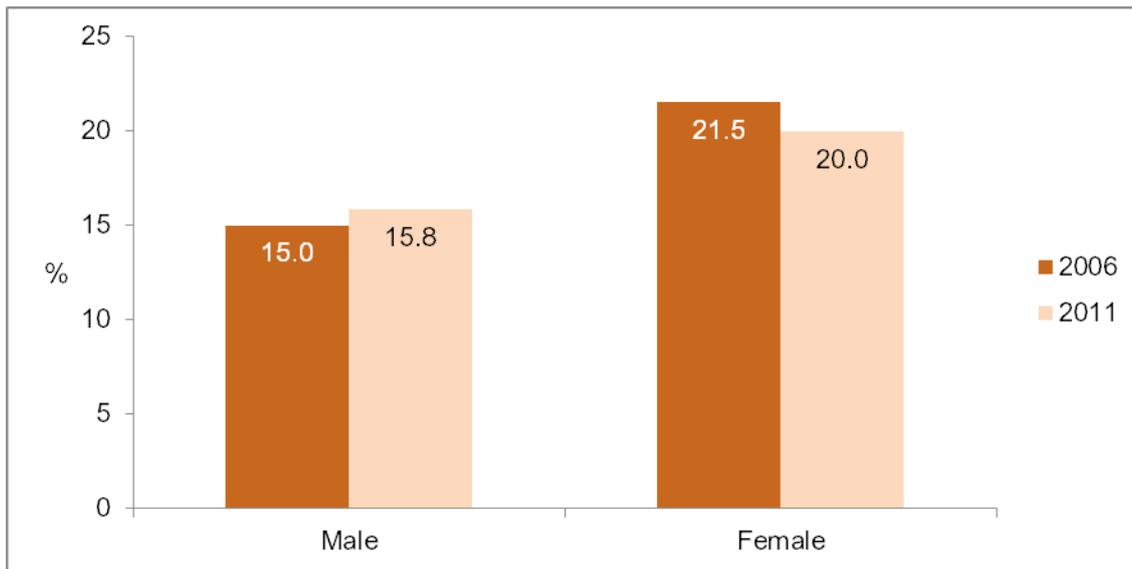
Education: Carers aged 25–64 years who have post-school qualifications

Overall, carers have been increasing their rates of obtaining post-school qualifications (Figure 4.5). Rates of non-school qualification varied according to age, which may be driven by types of caring roles, as older carers may be more likely to be caring for a spouse or parent (Figure 4.6).

Figure 4.5 Proportion of carers and non-carers who have a post-school qualification, 2006 and 2011 (%)
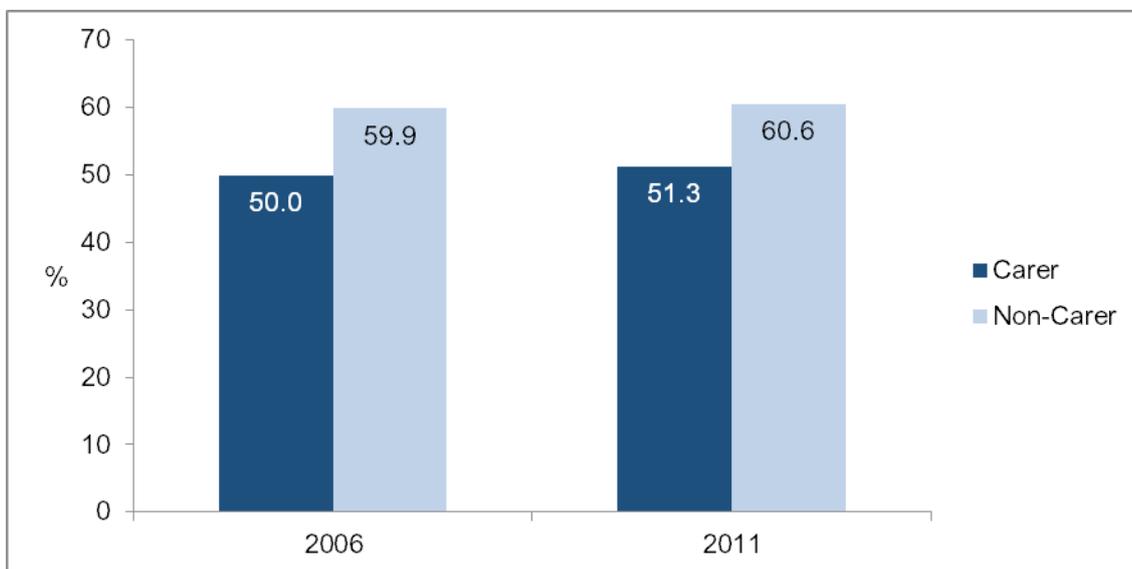
Figure 4.6 Gap between carers and non-carers who have a post-school qualification, by gender, 2006 and 2011 (% point difference)
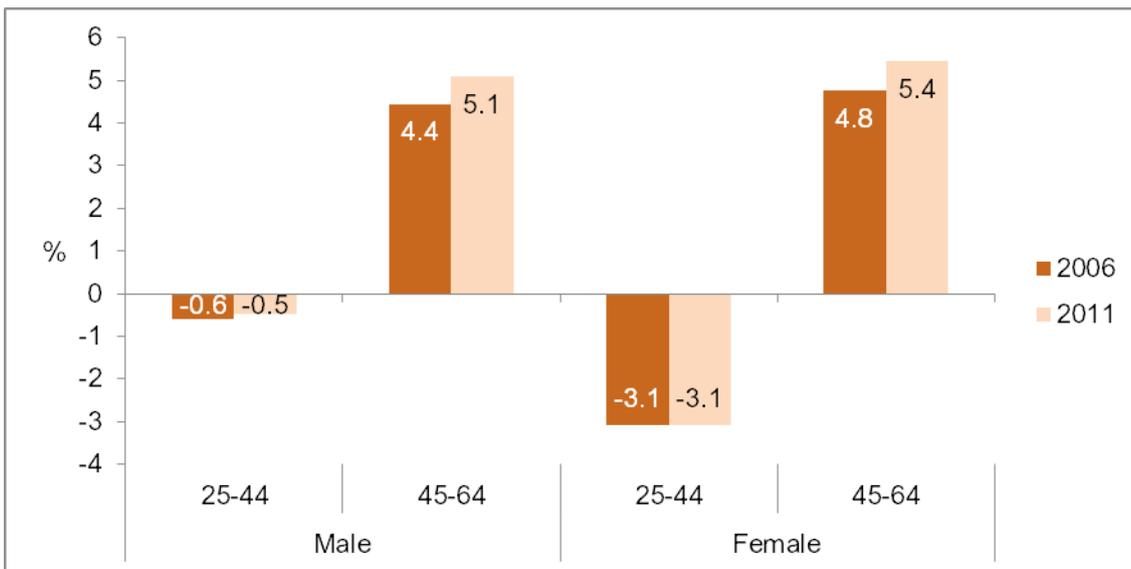
Employment: Working-age carers (15–64 years) who were engaged in paid employment

Women aged 25–44 years were the most disadvantaged group in terms of employment rates. Overall, employment rates were lowest for women carers in both 2006 and 2011 (Figure 4.7). The gap between carers and non-carers who were employed was largest for women in the 25–44 years age group (Figure 4.8).

Figure 4.7 Proportion of carers and non-carers who were employed, by gender, 2006 and 2011 (%)
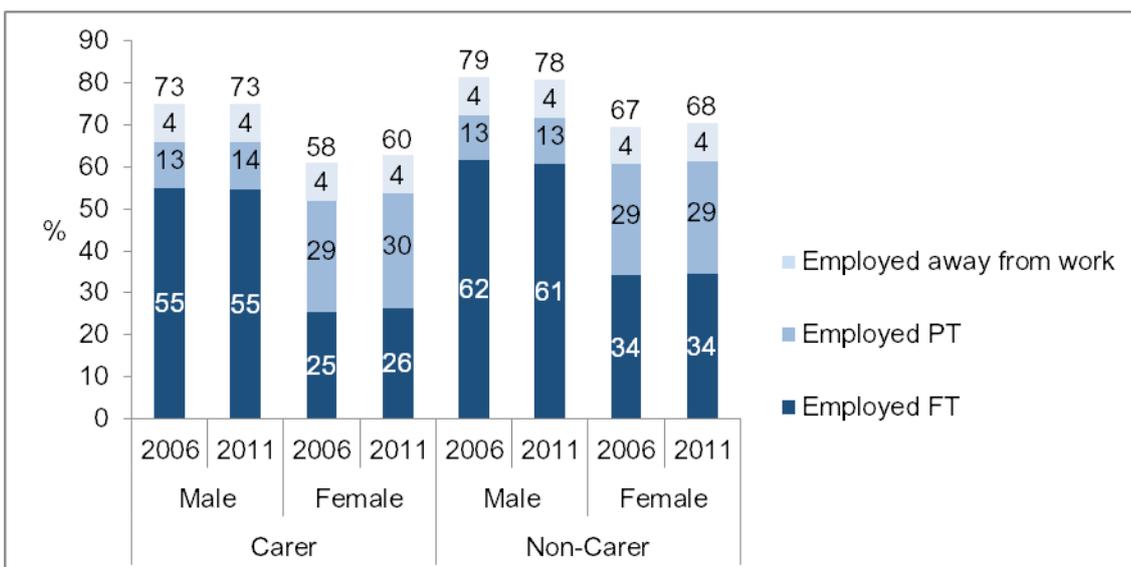
Figure 4.8 Gap between carers and non-carers who were employed, by age and gender, 2011 (% point differences)
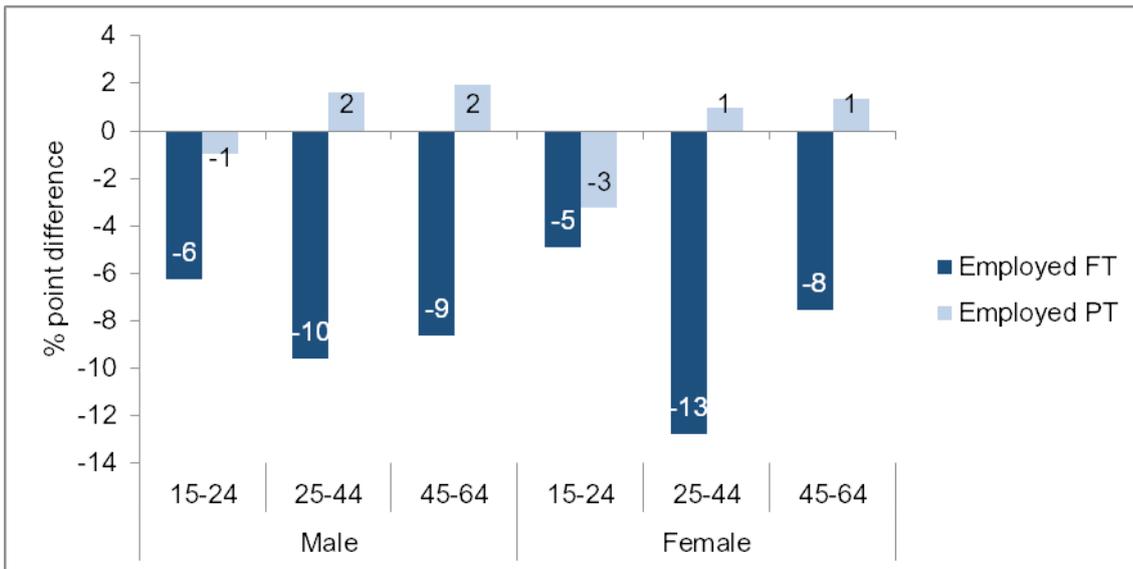
Relationship between employment and education: Carers aged 25–64 who were employed and have a post-school qualification

Employment disadvantage increased with education disadvantage (Figure 4.9), especially for female carers aged 25–44 years, where the gap was 15 percentage points (Figure 4.10).

Figure 4.9 Proportion of carers who were employed with and without a post-school qualification (NSQ), 2011 (%)
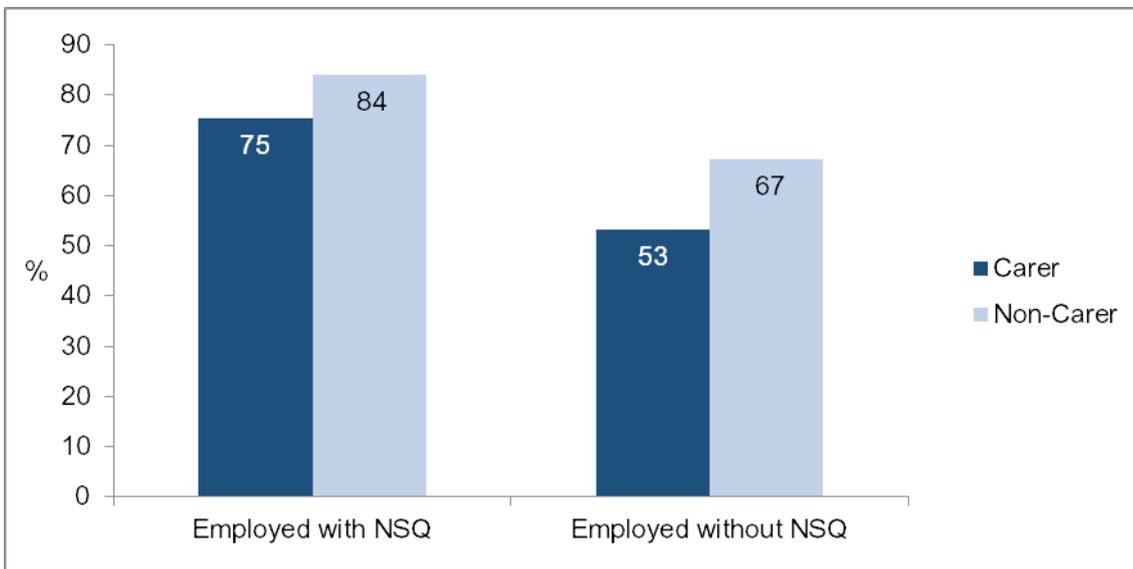
Figure 4.10 Gap between carers and non-carers who were employed with and without a post-school qualification, by age and gender, 2011 (% point differences)
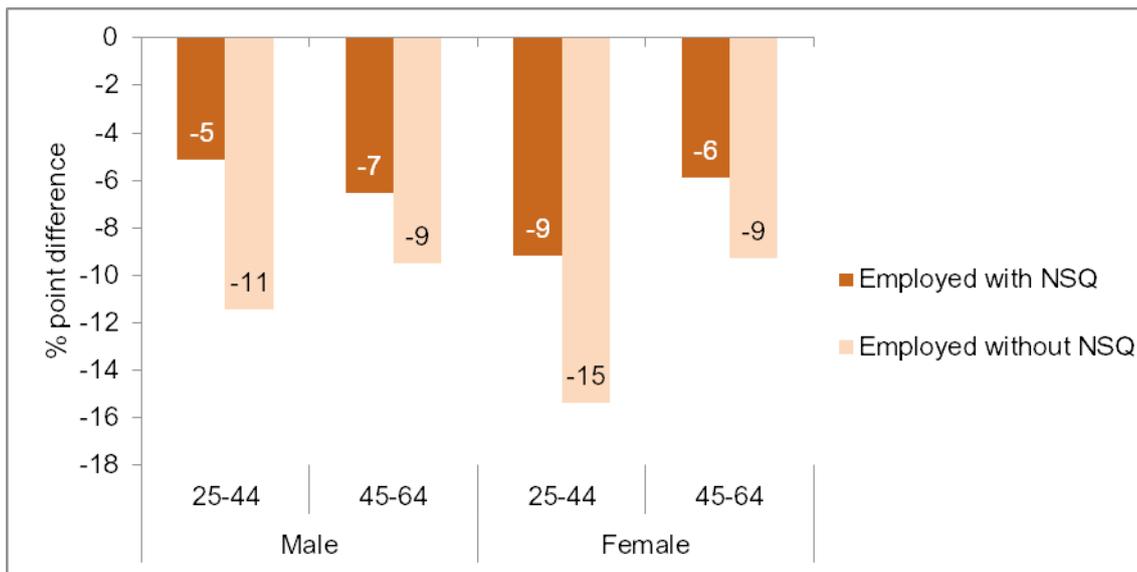
Employment: Working-age carers (15–64 years) who live in jobless households

Carers were more likely to live in jobless households than non-carers, although the rates had declined slightly between 2006 and 2011 (Figure 4.11). Female carers were more likely to live in jobless households than male carers (Figure 4.12).

Figure 4.11 Proportion of carers and non-carers in jobless households, 2006 and 2011 (%)
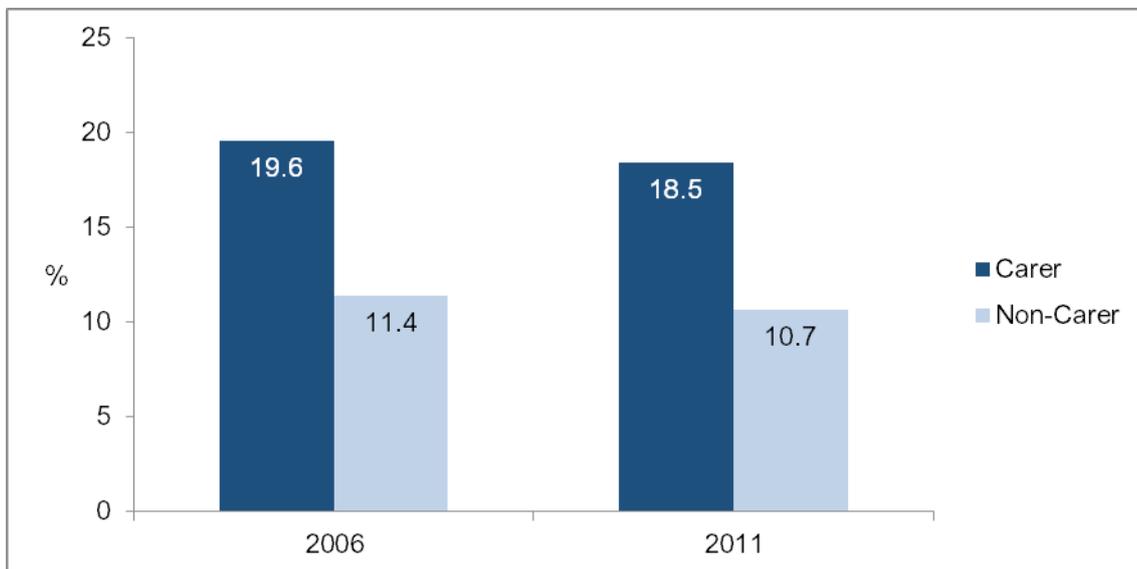
Figure 4.12 Proportion of carers in jobless households, by gender, 2006 and 2011 (%)
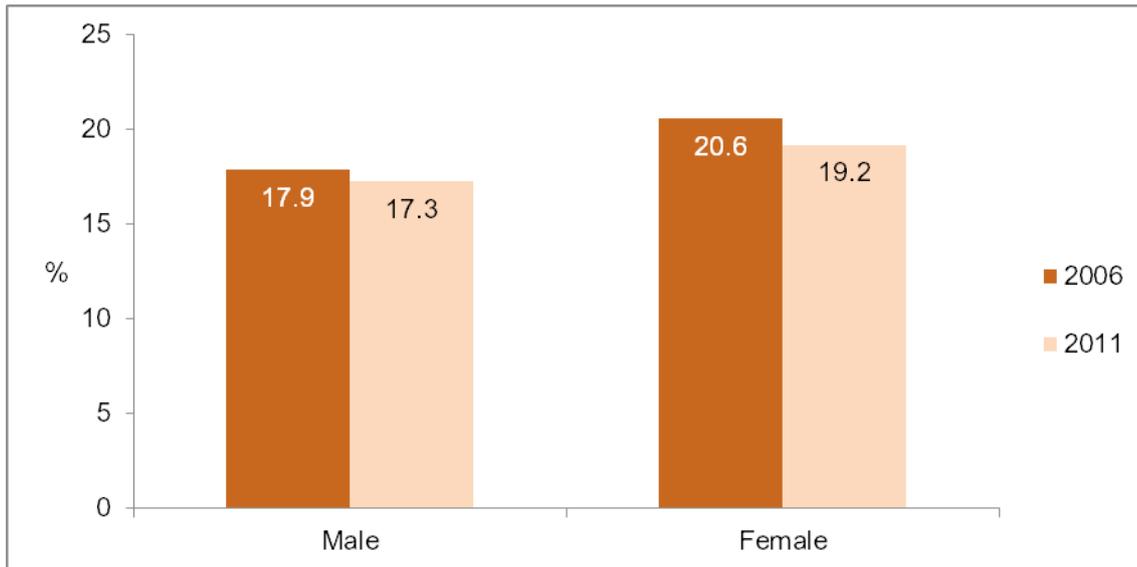
Social participation: Carers who were involved in volunteering

Carers were almost twice as likely as non-carers to report that they had volunteered in the last 12 months, with female carer more likely to volunteer than males (Figure 4.13). The gap between carers and non-carers in volunteering rates was highest for young males (Figure 4.14).

Figure 4.13 Proportion of carers and non-carers who volunteered, 2006 and 2011 (%)
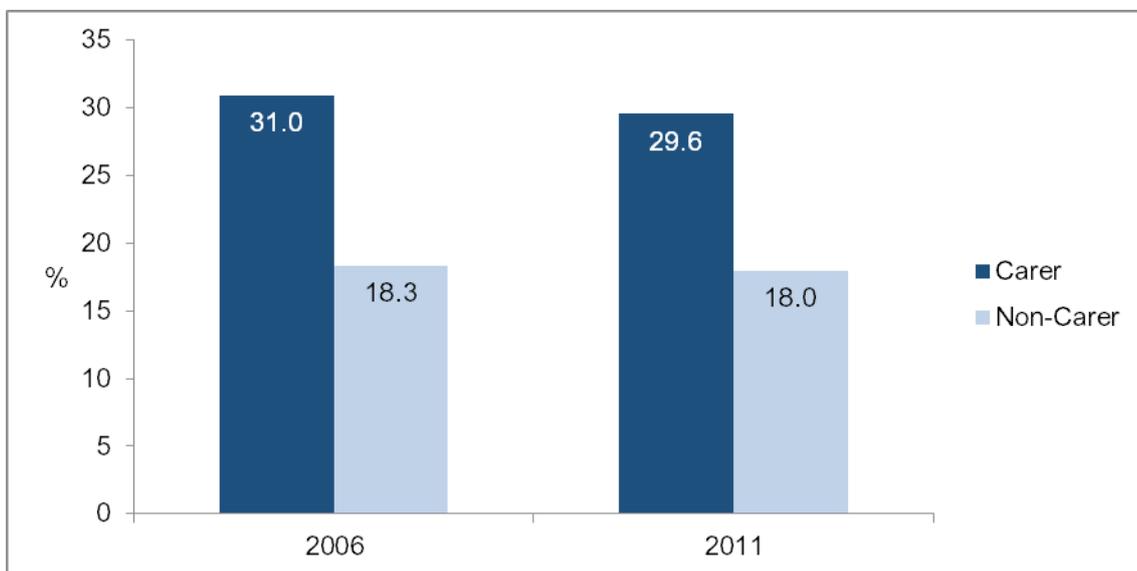
Figure 4.14 Gap between carers and non-carers who volunteered, by age and gender, 2006 and 2011 (% point difference)
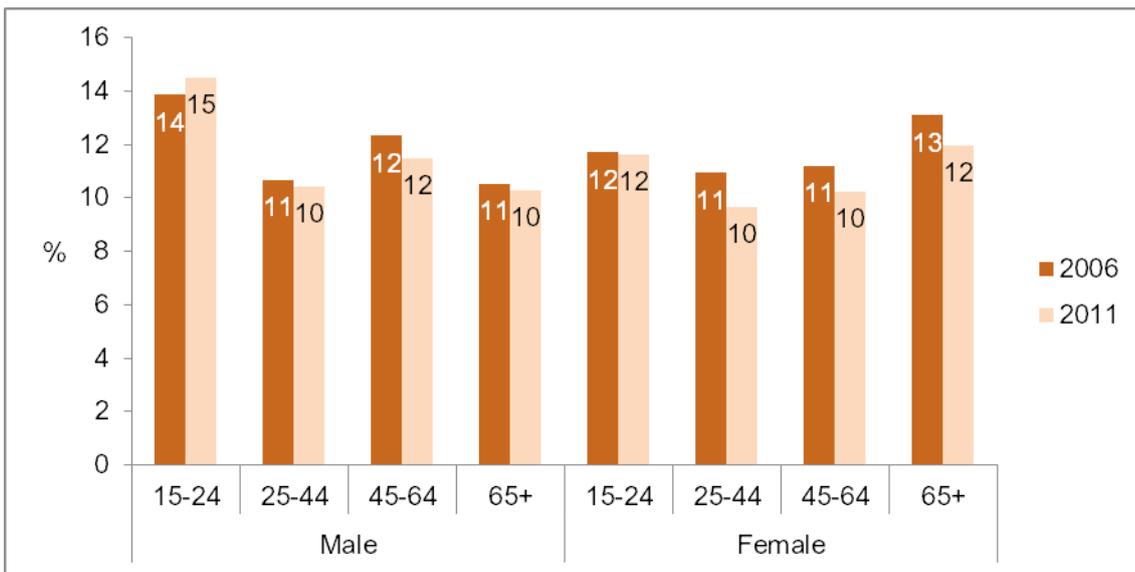
4.1.2 Resources

Overall, young carers were most disadvantaged with respect to access to economic and material resources, while older carers had higher rates of access to resources than their non-carer peers.

Economic resources: Carers who have low income (below the poverty line)

Carers were more likely to experience income poverty than non-carers (based on total household equivalised weekly income). Poverty rates for carers have increased between 2006 and 2011 (Figure 4.15), with younger carers being most disadvantaged vis-a-vis their peers (Figure 4.16). Older female carers had lower income poverty rates than their non-carer peers (Figure 4.16).

Figure 4.15 Proportion of carers and non-carers who live in households that are below the poverty line, 2006 and 2011 (%)
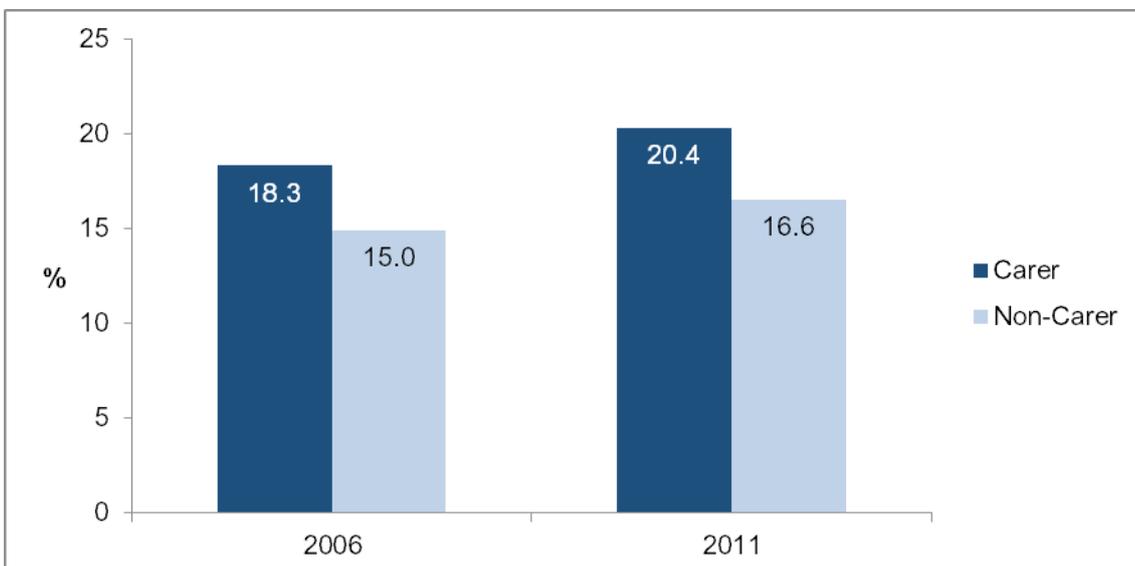
Figure 4.16 Gap between carers and non-carers who live in households that are below the poverty line, by age and gender, 2006 and 2011 (% point difference)
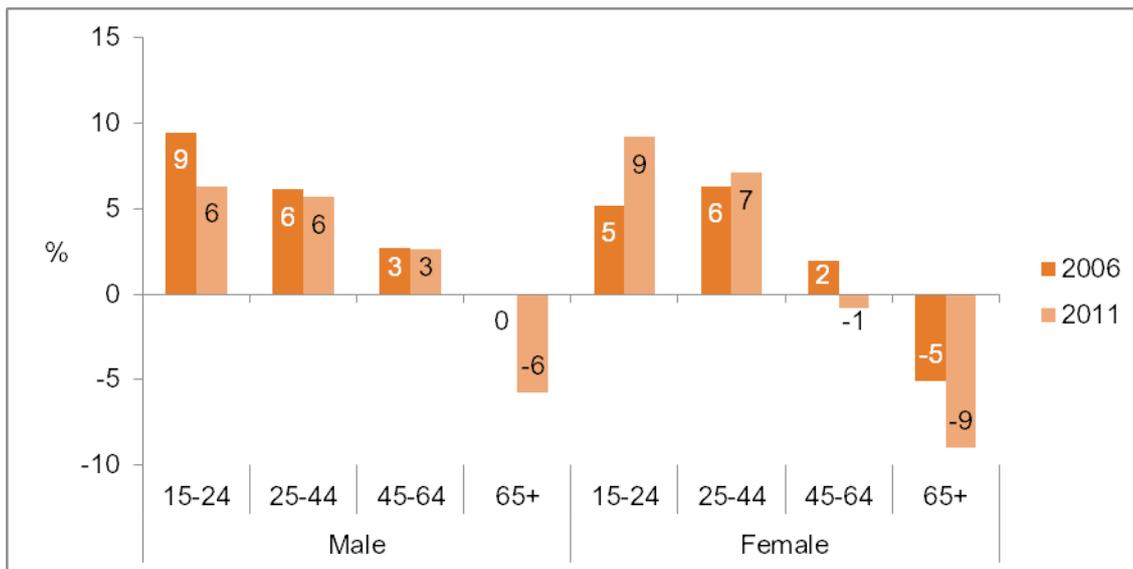
Material resources: Carers who are homeowners

The rate of homeownership (own outright or with a mortgage) was higher for carers than non-carers (Figure 4.17). However, young carers were more disadvantaged vis-a-vis their peers (Figure 4.18). This gap had increased between 2006 and 2011 for young carers, especially for young female carers.

Figure 4.17 Proportion of carers and non-carers who are homeowners, 2006 and 2011 (%)
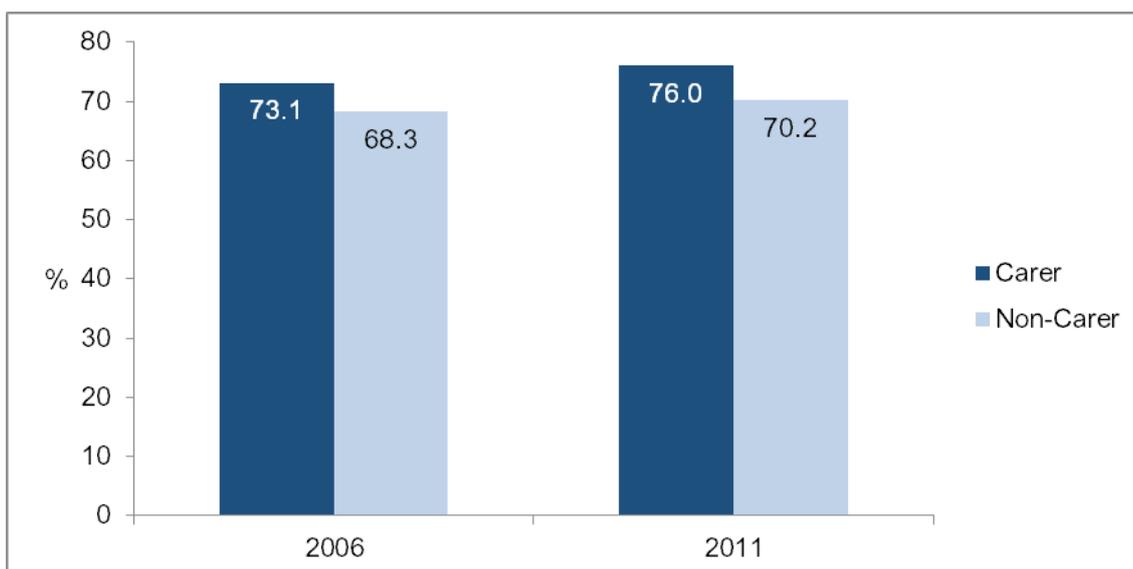
Figure 4.18 Gap between carers and non-carers who are homeowners, by age and gender, 2006 and 2011 (% point difference)
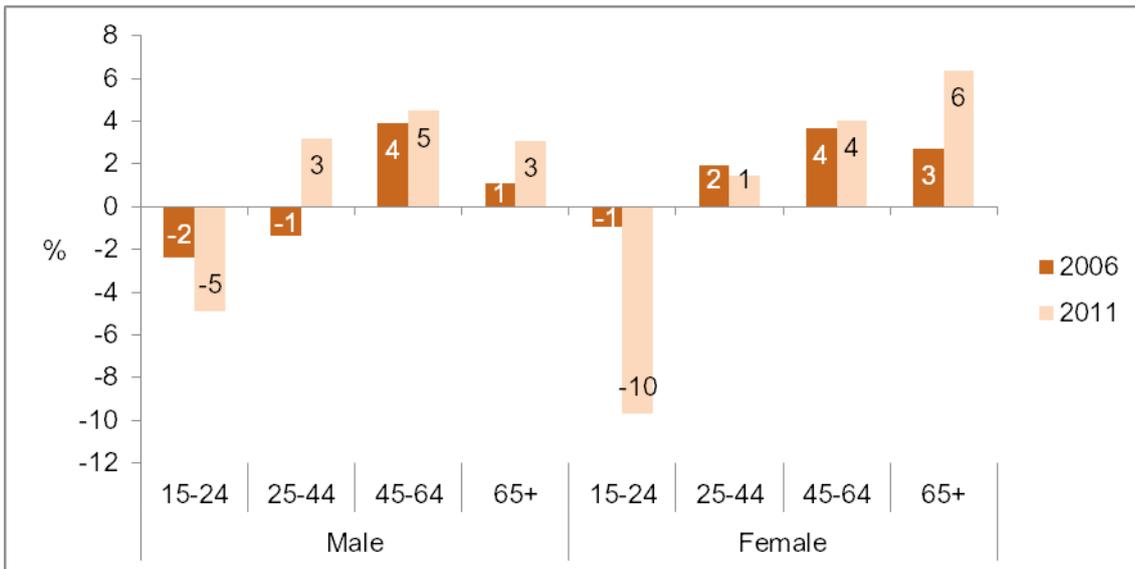
Material resources: Carers who have access to a motor vehicle

Young carers were less likely living in a house with a motor vehicle compared to their peers (Figure 4.20). Older carers, especially female older carers were more advantaged than their non-carer peers in terms of having access to this resource (Figure 4.20).

Figure 4.19 Proportion of carers and non-carers who have at least one motor vehicle at home, 2006 and 2011 (%)
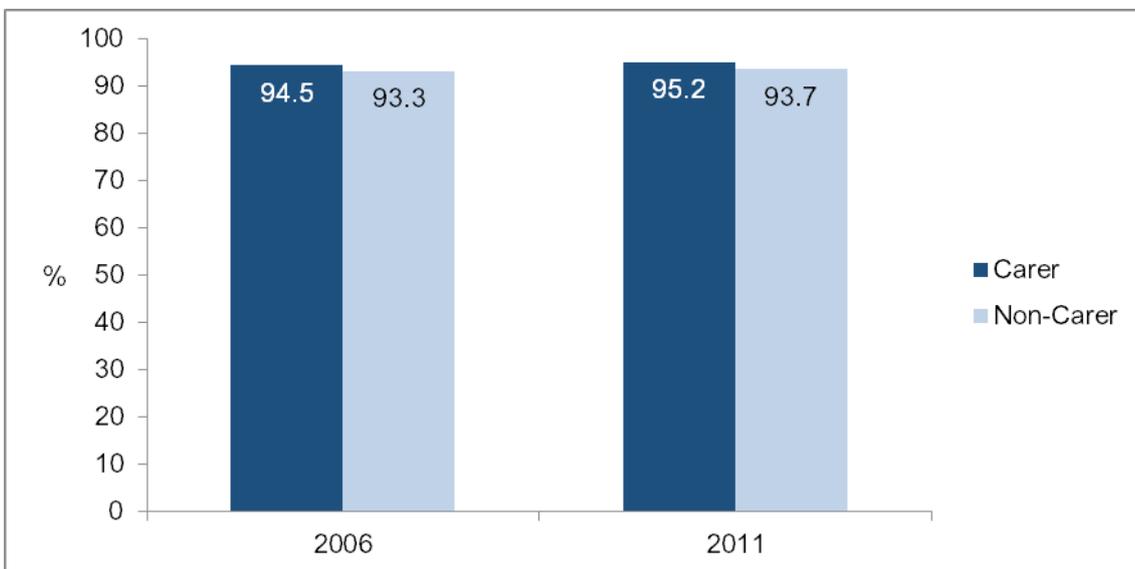
Figure 4.20 Gap between carers and non-carers who have at least one motor vehicle at home, by age, 2006 and 2011 (% point difference)
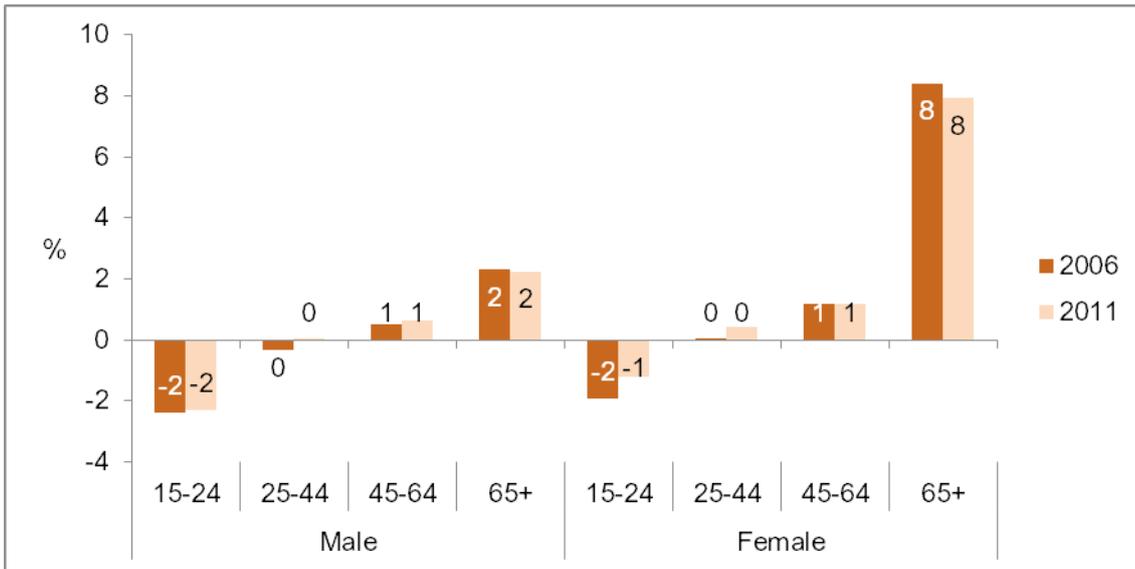
Social resources: Carers who have access to the internet

Carers under aged 45 years were disadvantaged compared to non-carer peers in terms of access to the internet (Figure 4.22). Female older carers (65+) had the highest level of advantage compared to their non-carer peers (Figure 4.22).

Figure 4.21 Proportion of carers and non-carers who have access to the internet at home, 2006 and 2011 (%)
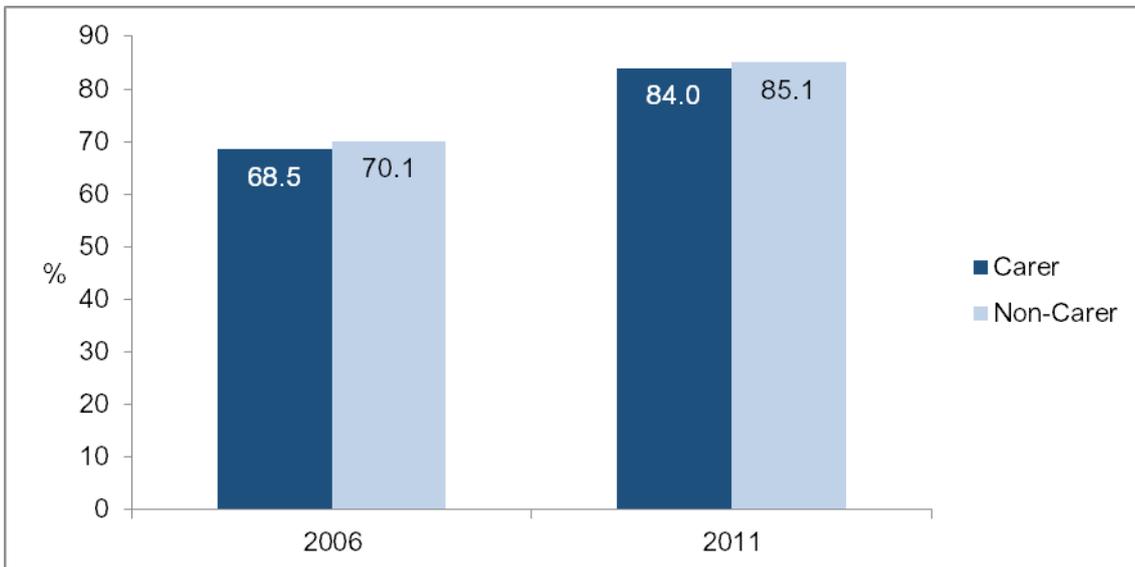
Figure 4.22 Gap between carers and non-carers who have access to the internet at home, by age and gender, 2006 and 2011 (% point difference)
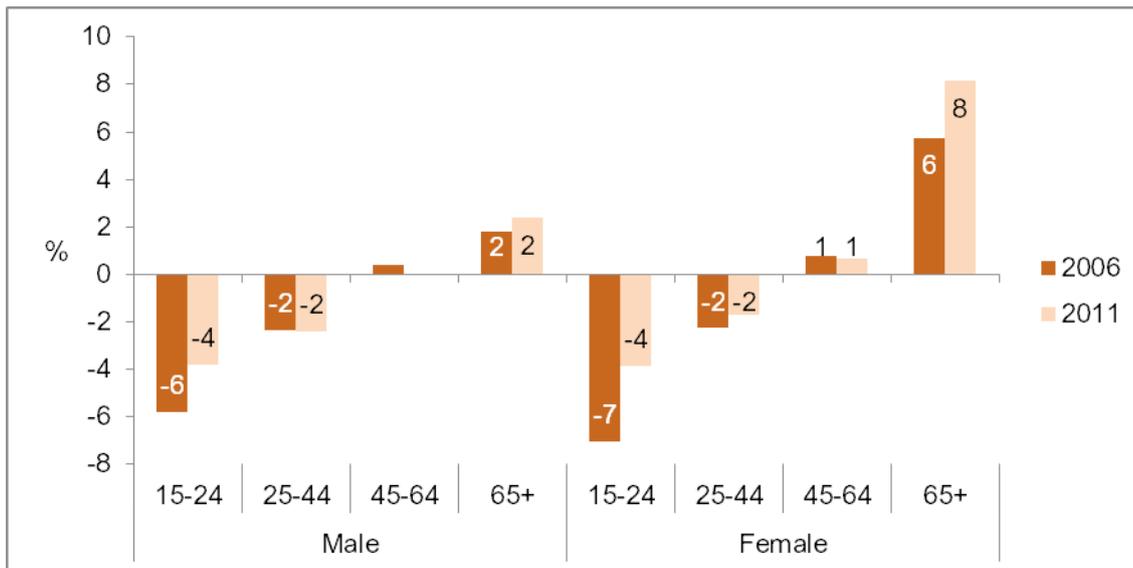
4.2 Indicators of social exclusion and inclusion for Indigenous carers

Indigenous carers in this analysis are persons aged 15 years and over who identified themselves as being of Australian Aboriginal and/or Torres Strait Islander origin, as well as providing unpaid assistance to a person with a disability in the two weeks prior to Census night. The total number of Indigenous carers identified in the Census in 2006 was 32,581 and in 2011, this number increased to 45,331. The average rate of care provision was around 15 per cent in 2011, with highest rate amongst women in the 45–64 years age group (22 per cent).

4.2.1 Participation

Education: Indigenous young carers aged 20–24 years who have Year 12 (or equivalent) attainment

Overall, young Indigenous carers were less likely to complete Year 12 compared to young Indigenous non-carers (Figure 4.23). Female young carers were around 7 percentage points less likely to complete Year 12 compared to their non-carer peers in both 2006 and 2011 (Figure 4.24). The gap between young male carers with their non-carer peers increased from 5 per cent to 8 per cent over the two Census periods (Figure 4.24).

Figure 4.23 Proportion of Indigenous carers and non-carers aged 20–24 years who have completed Year 12, 2011 (%)
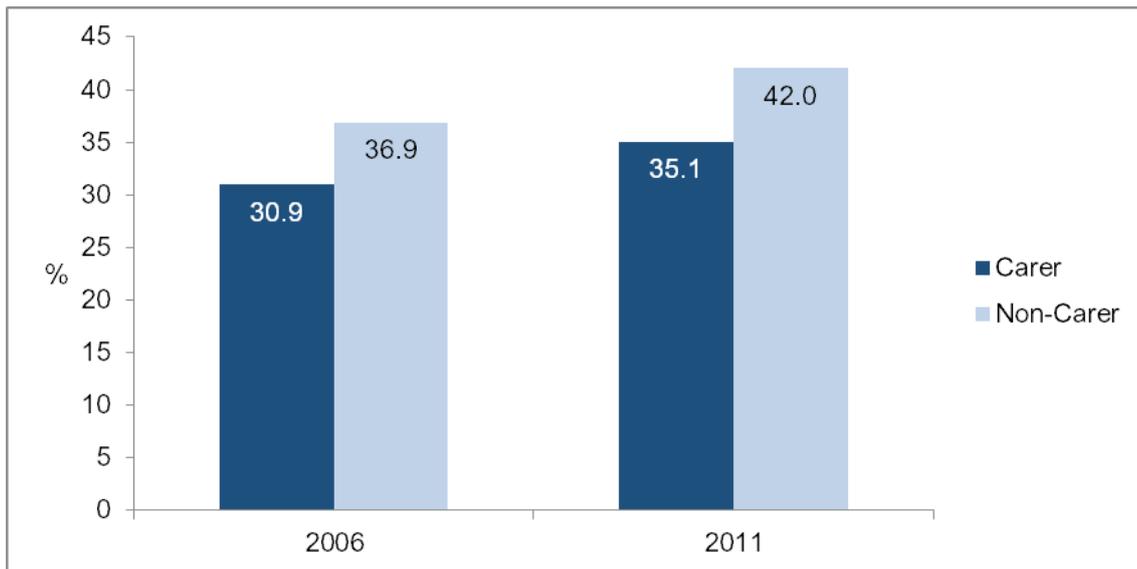
Figure 4.24 Gap between carers and non-carers who have completed Year 12, by gender, 2006 and 2011 (% point difference)
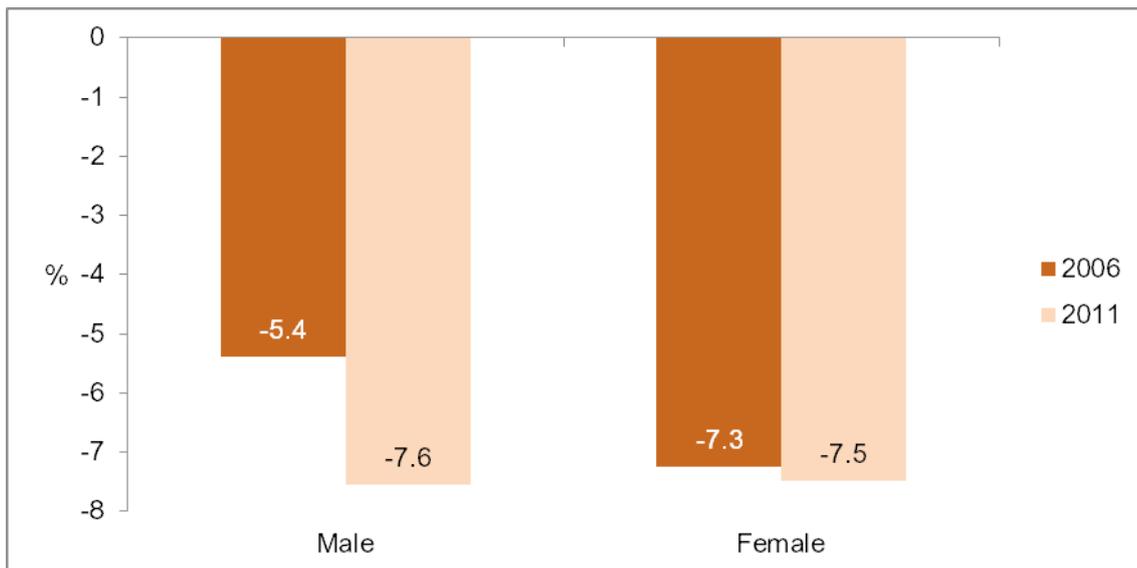
Engagement: Indigenous young carers aged 15–24 years who are not in employment education or training

The proportion of Indigenous young carers who are NEET increased at a higher rate compared to their non-carer peers between 2006 and 2011 (Figure 4.25). The gap between carers and non-carers was much higher for Indigenous young male carers, although the gap for Indigenous young female carers doubled between 2006 and 2011 (Figure 4.26).

Figure 4.25 Proportion of Indigenous carers and non-carers aged 15–24 years who are not in education, employment or training (NEET), 2006 and 2011 (%)
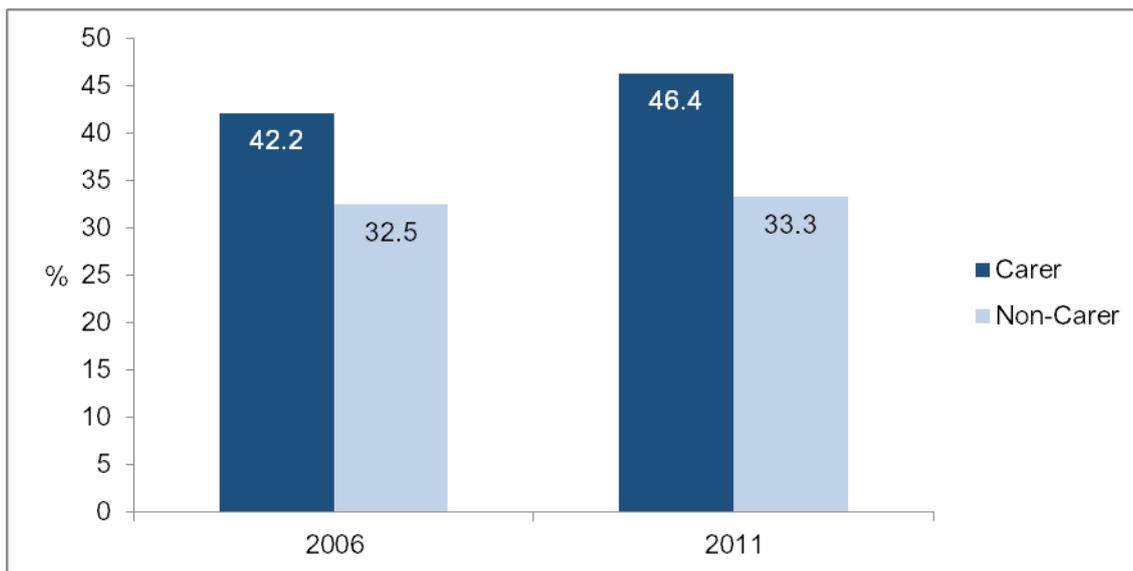
Figure 4.26 Gap between Indigenous carers and non-carers aged 15–24 years who are not in education, employment or training (NEET), by gender, 2006 and 2011 (% point difference)
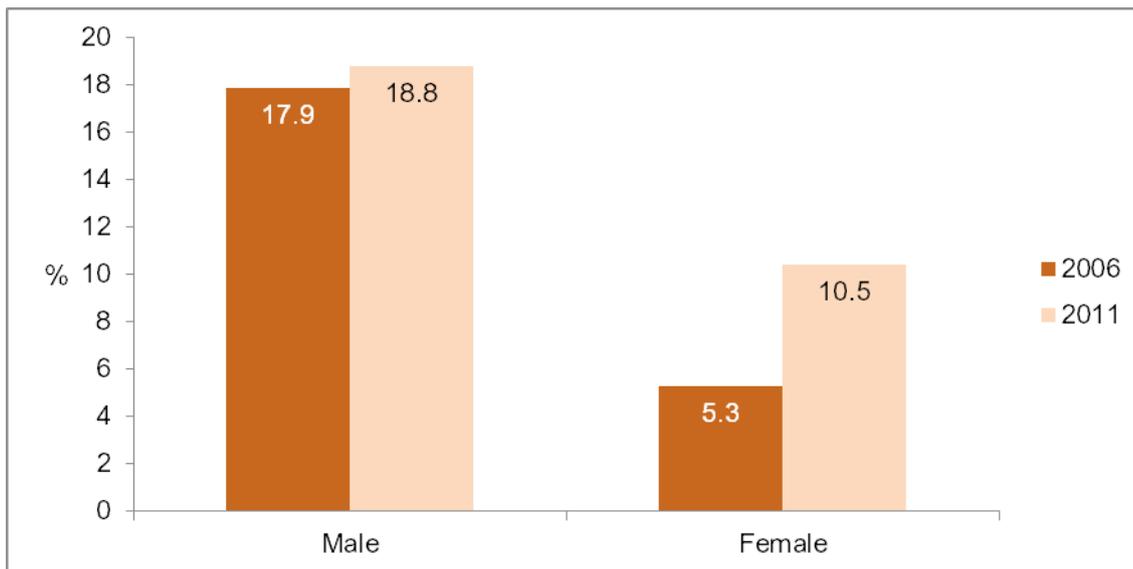
Education: Indigenous carers aged 25–64 years who have post-school qualifications

Overall, Indigenous carers have a higher rate of having a post-school qualification compared to their Indigenous non-carer peers (Figure 4.27). The gap between Indigenous carers and non-carers was larger for older carers (aged 45–64 years) and higher for male carers. This gap decreased over the two Census periods for all groups except female older carers (Figure 4.28).

Figure 4.27 Proportion of Indigenous carers and non-carers who have a post-school qualification, 2006 and 2011 (%)
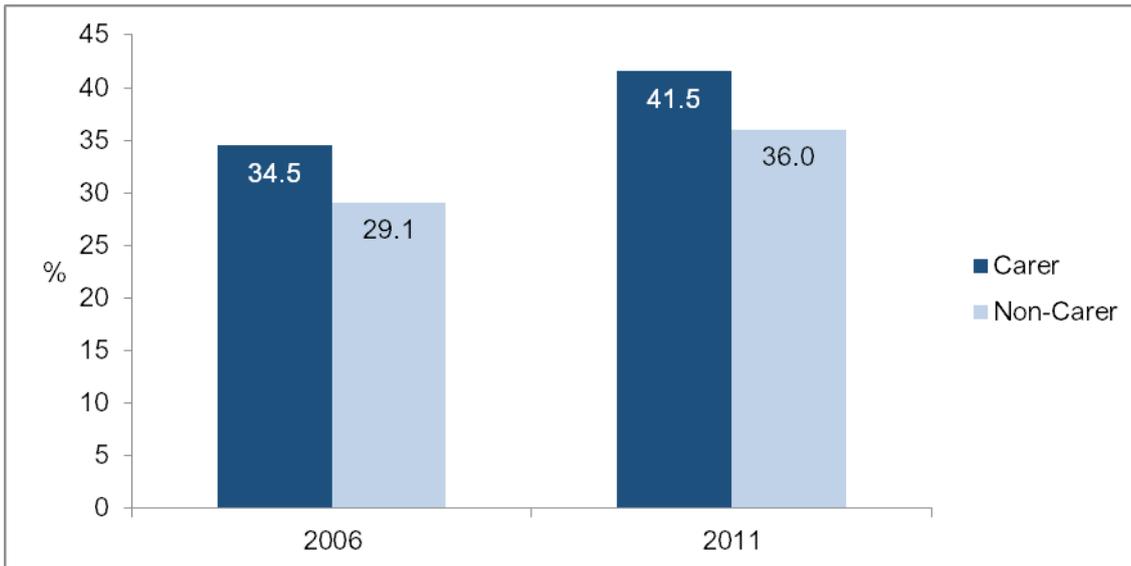
Figure 4.28 Proportion of Indigenous carers who have a post-school qualification, by gender, 2006 and 2011 (%)
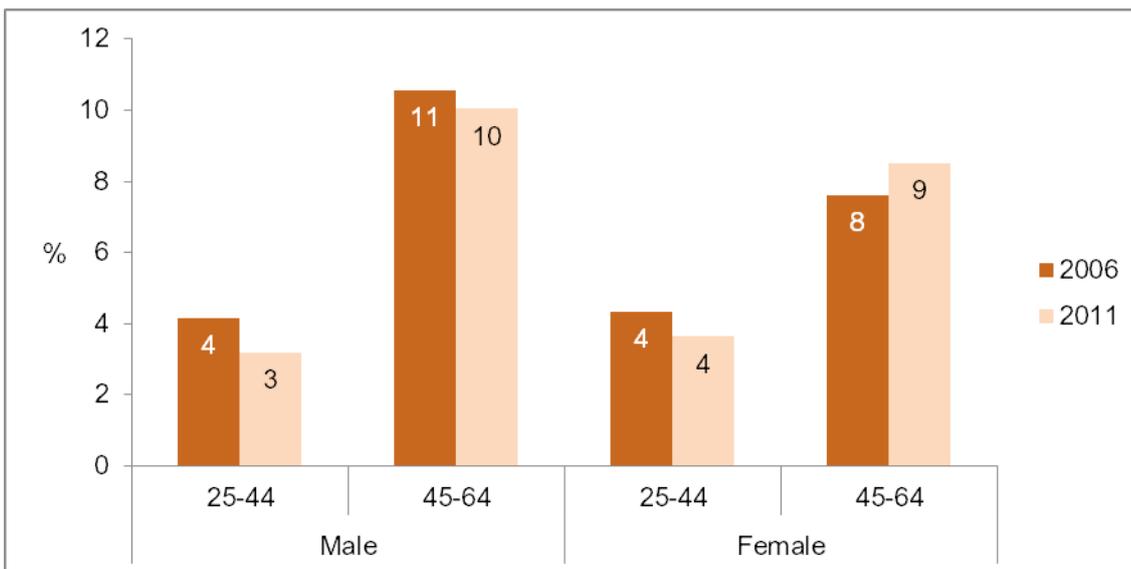
Employment: Indigenous working- age carers (15–64 years) who were engaged in paid employment

Indigenous carers aged 15–64 years were less likely to be employed compared to Indigenous non-carers (Figure 4.29). The gaps between carers and non-carers increased for all groups over the two Census periods, but increased substantially more for both male and female carers under the aged of 45 (Figure 4.30). Male carers aged 24–45 years had the highest level of disadvantage.

Figure 4.29 Proportion of Indigenous carers and non-carers who were employed, 2006 and 2011 (%)
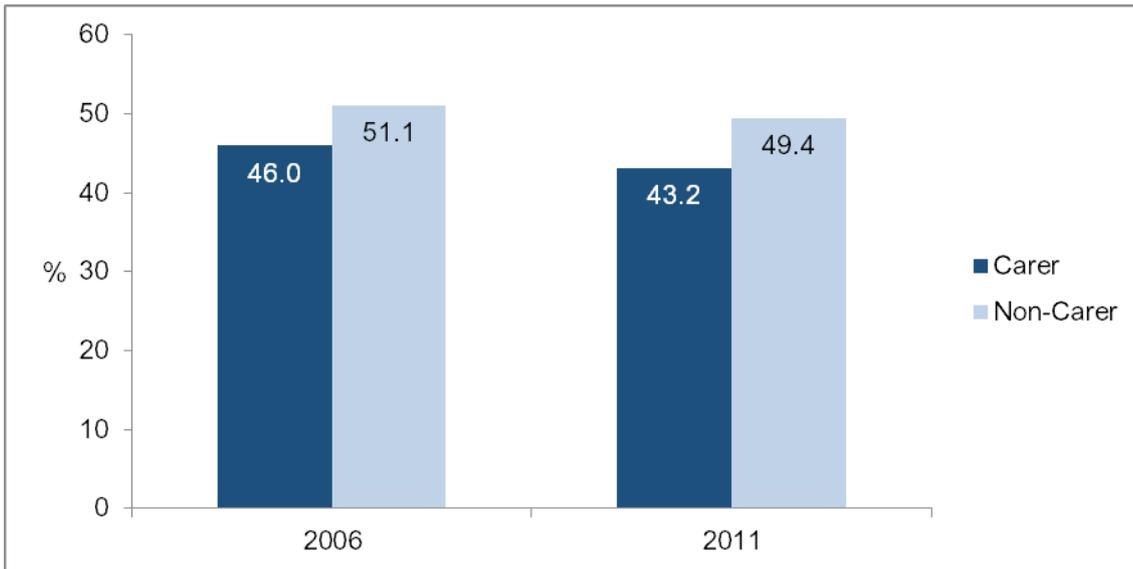
Figure 4.30 Gap between Indigenous carers and non-carers who were employed, by gender, 2006 and 2011 (% point difference)
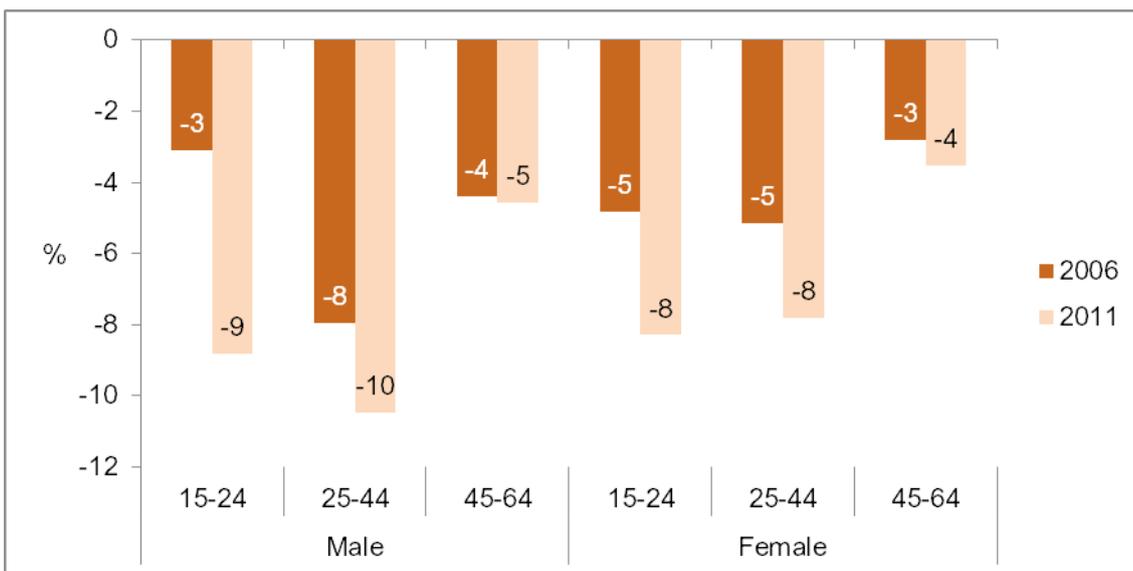
Social participation: Indigenous carers who were involved in volunteering

Indigenous carers were twice as likely to be volunteers compared to Indigenous non-carers in 2011 (Figure 4.31). The rate of volunteering was very similar for Indigenous male and female carers (Figure 4.32).

Figure 4.31 Proportion of Indigenous carers and non-carers who volunteered, 2011 (%)
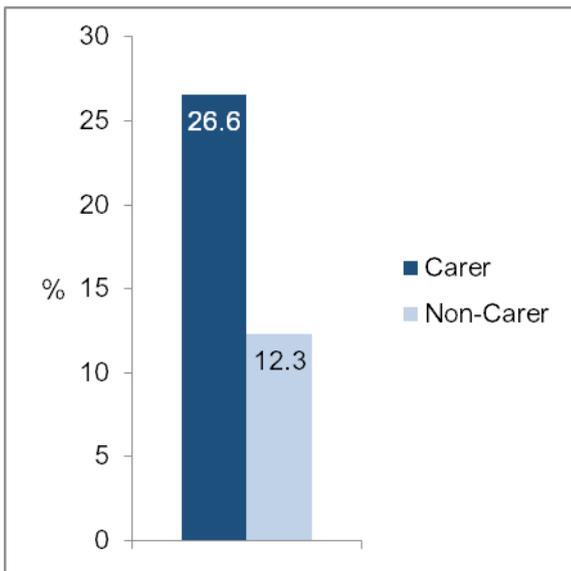
Figure 4.32 Proportion of Indigenous carers who volunteered, by gender, 2011 (%)
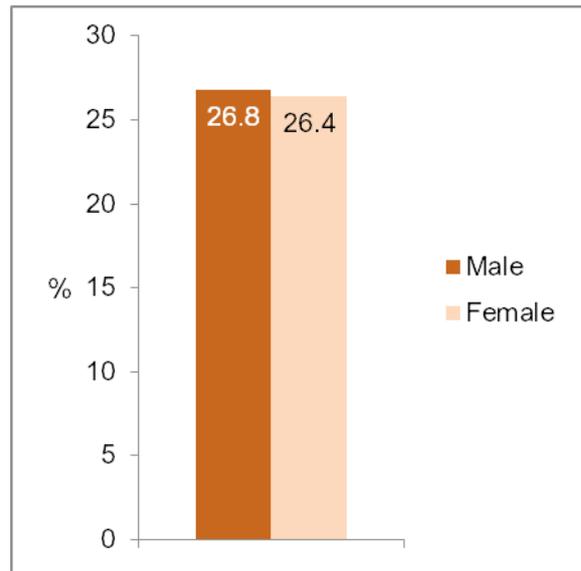
4.2.2 Resources

Material resources: Indigenous carers who have access to a motor vehicle

The proportion of Indigenous carers and non-carers who had access to a motor vehicle was relatively similar in 2011, with carers having a slightly higher rate compared to non-carers (Figure 4.33). Male carers had more access to a motor vehicle compared to their non-carer peers, whereas females had slightly less access compared to their non-carer peers (Figure 4.34).

Figure 4.33 Proportion of Indigenous carers and non-carers who have at least one motor vehicle at home, 2011 (%)
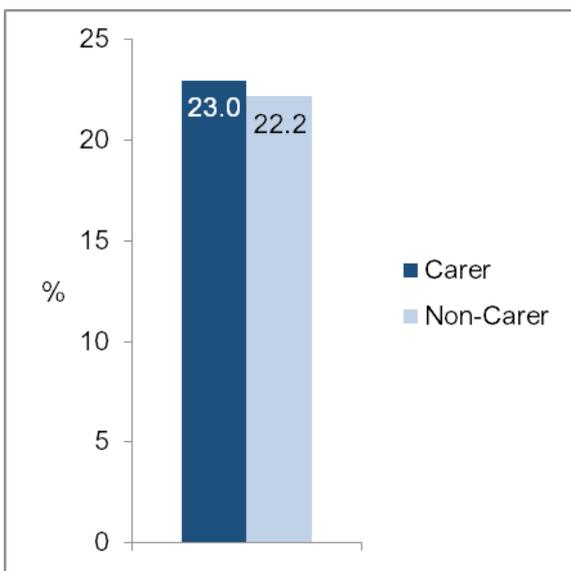
Figure 4.34 Gap between Indigenous carers and non-carers who have at least one motor vehicle at home, by age, 2011 (% point difference)
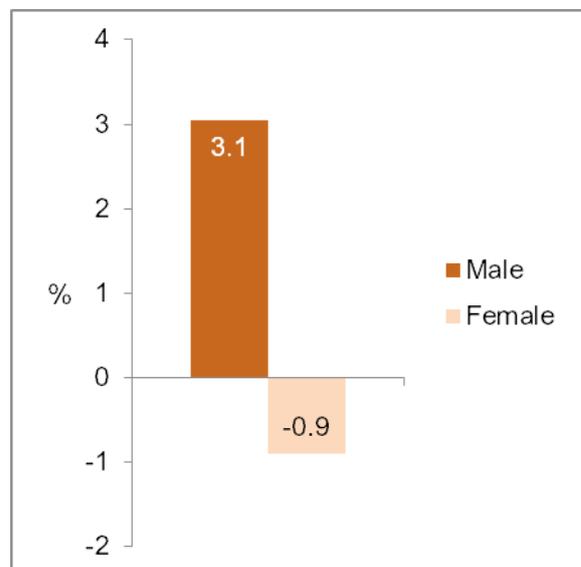
Social resources: Indigenous carers who have access to the internet

The proportion of Indigenous carers and non-carers who had access to the internet is relatively similar in 2011, with carers having slightly less access compared to non-carers (Figure 4.35). Male carers had less access to the internet compared to their non-carer peers (Figure 4.36).

Figure 4.35 Proportion of Indigenous carers and non-carers who have access to the internet at home, 2011 (%)
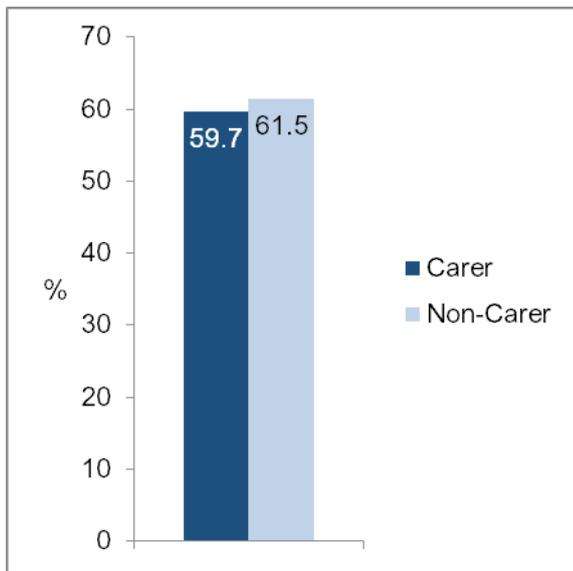
Figure 4.36 Gap between Indigenous carers and non-carers who have access to the internet at home, by gender, 2011 (% point difference)
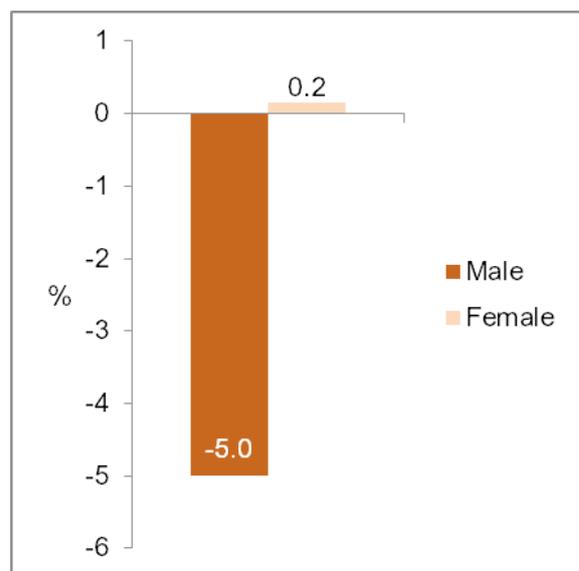
Economic resources: Indigenous carers who have low income (total personal gross weekly income)

Overall, the proportion of Indigenous carers whose total personal gross weekly income was less than $400 was slightly higher than Indigenous non-carers (Figure 4.37). The differences between Indigenous carers and non-carers for this indicator were greater for carers under the age of 65 and in particular, younger male carers under the age of 45 (Figure 4.38). This finding is most likely due to the high rate of male carers in this age group who were not employed (see Figure 4.30).

Figure 4.37 Proportion of Indigenous carers and non-carers whose income is less than $400 a week, 2011 (%)
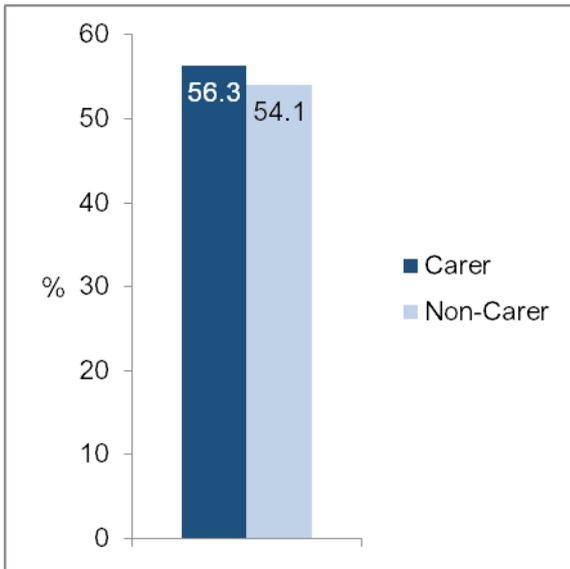
Figure 4.38 Gap between Indigenous carers and non-carers carers whose income is less than $400 a week, by age and gender, 2011 (% point difference)
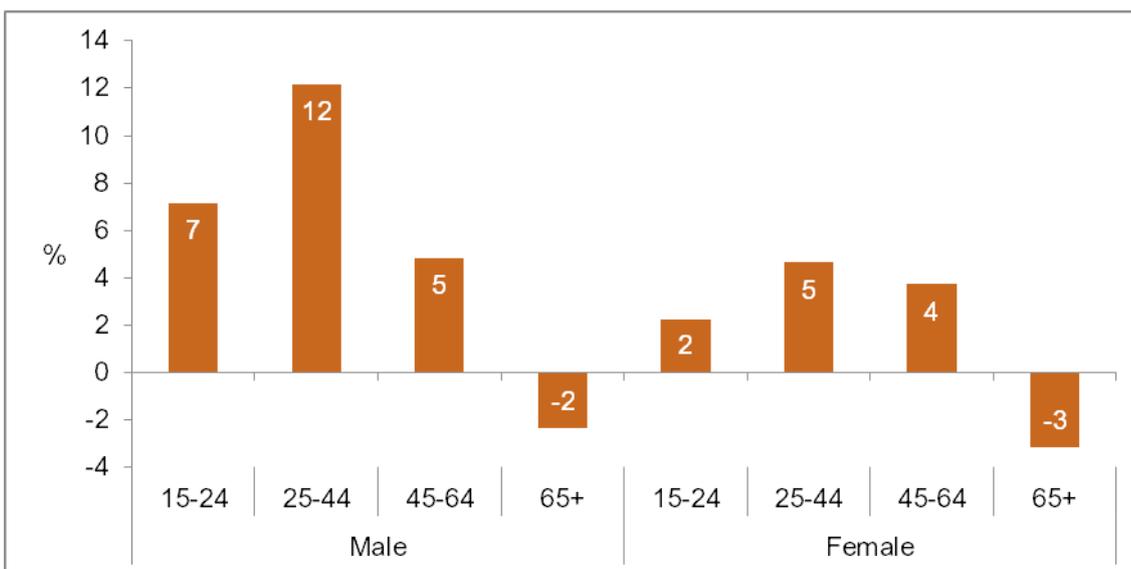
4.3 Culturally and linguistically diverse (CALD) carers

Carers who come from a culturally and linguistically diverse (CALD) background are defined in this analysis as: persons aged 15 years and over who provided unpaid assistance to a person with a disability two weeks prior to Census night, are not of Indigenous background, were born in a non-English speaking country or born in an English speaking country and speak another language at home (ABS, 2011b).

The total number of CALD carers in 2006 was 319,086 and in 2011, this number increased to 421,643. The average rate of care provision was around 11% in 2011, with the highest rate amongst women in the 45–64 years age group (19%).

4.3.1 Participation

Education: CALD carers aged 20–24 years with Year 12 (or equivalent) attainment

The rate of completing Year 12 was relatively high for CALD carers (Figure 4.39). However, there was still a gap between carers and non-carers, especially for females, which remains relatively consistent over the two Census periods (Figure 4.40).

**Figure 4.39 Proportion of CALD carers and non-carers aged 20–24 who have completed Year 12, 2006 and 2011 (%)**
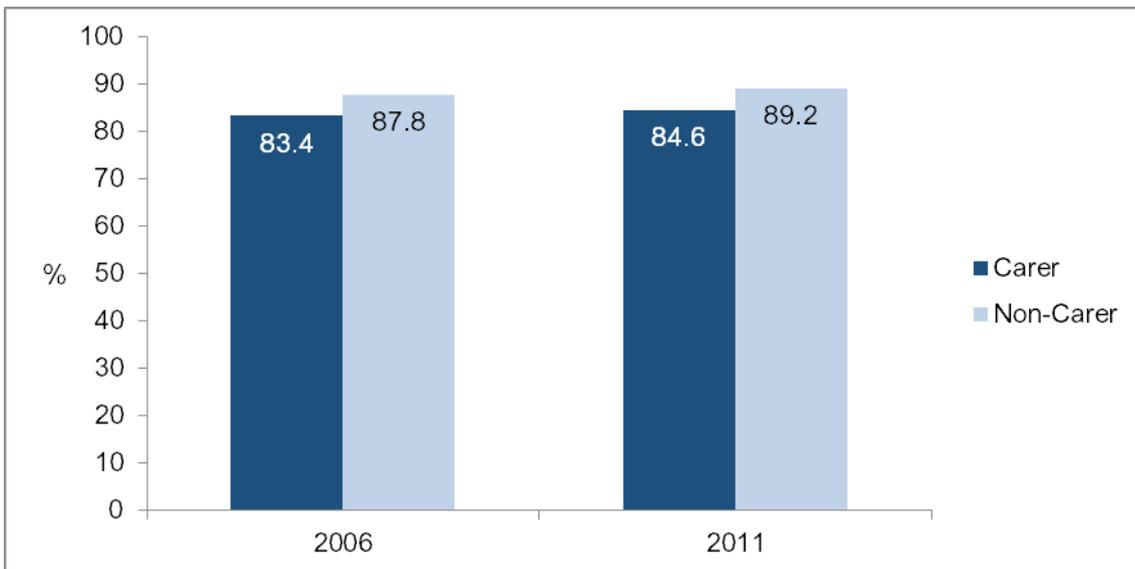
Figure 4.40 Gap between carers and non-carers who have completed Year 12, by gender, 2006 and 2011 (% point difference)
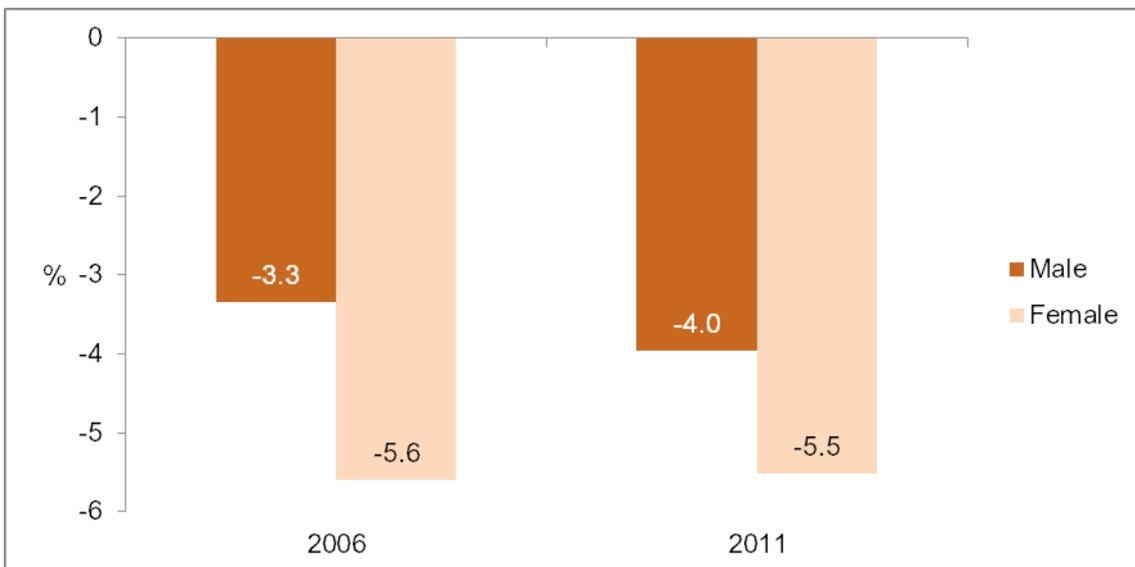
Employment: CALD Working- age carers (15–64 years) who were engaged in paid employment

The proportion of CALD carers of working age who were employed is lower than their non-carer counterparts in both years (Figure 4.41). The gap between carers and their non-carer peers was greatest for females aged 25–44 years and males aged 45–64 years (Figure 4.42).

Figure 4.41 Proportion of CALD carers and non-carers who were employed, 2006 and 2011 (%)
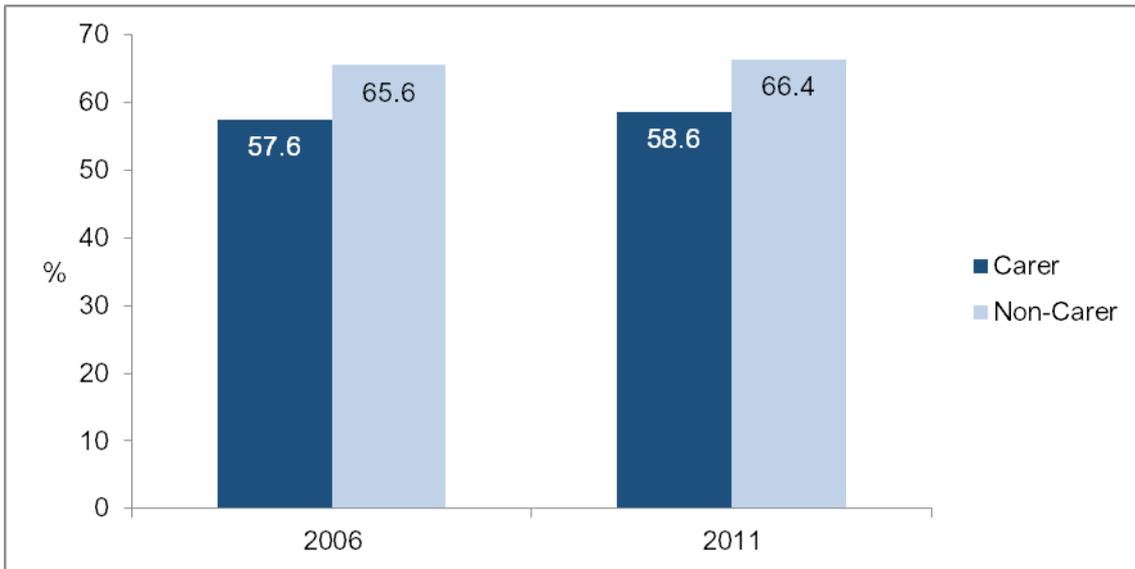
Figure 4.42 Gap between CALD carers and non-carers who were employed, by gender, 2006 and 2011 (% point difference)
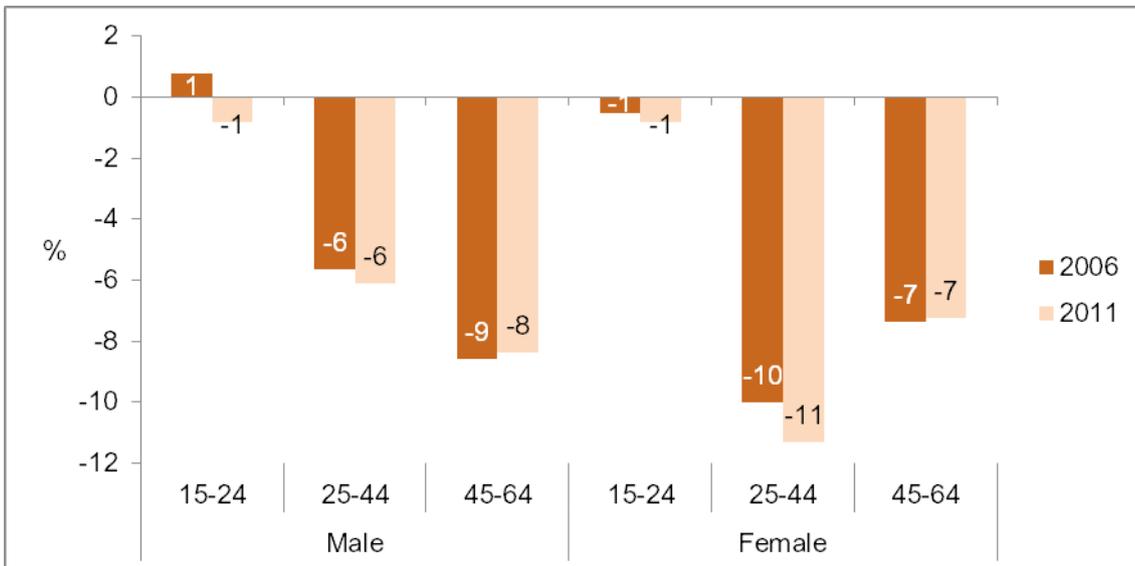
4.3.2 Resources

Skill resources: CALD carers with low levels of spoken English

The proportion of CALD carers who reported low levels of spoken English is very similar to their non-carer peers in both 2006 and 2011: around one in six or seven carers (Figure 4.43). Interestingly, older CALD carers (especially females) were less likely to report low levels of spoken English compared to their non-carer peers (Figure 4.44). There are few differences in spoken English levels between carers and non-carers in the younger age groups.

Figure 4.43 Proportion of CALD carers and non-carers who do not speak English well or at all, 2006 and 2011 (%)
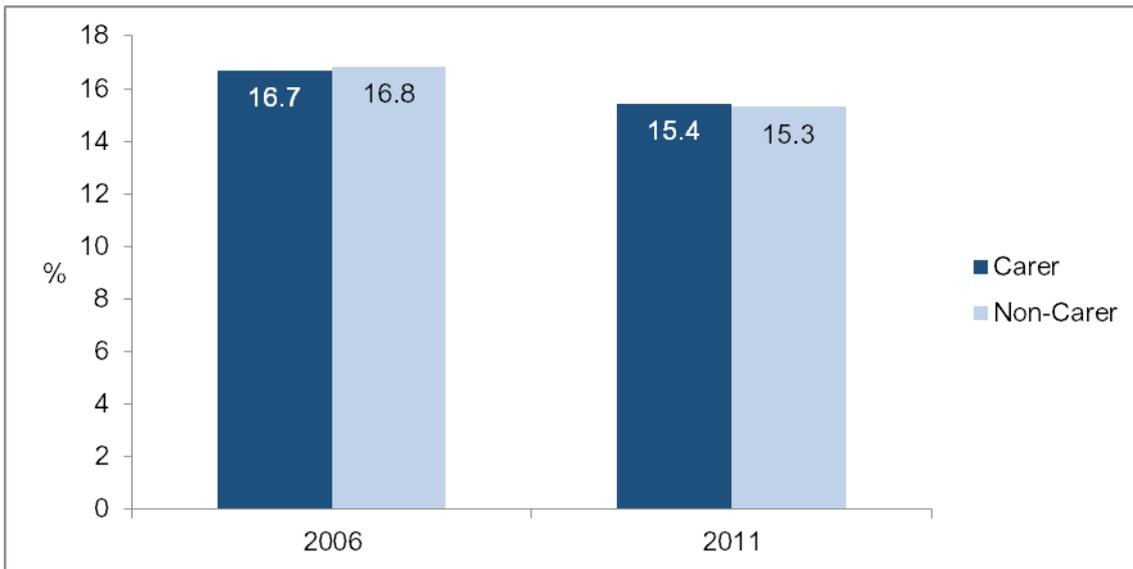
Figure 4.44 Gap between CALD carers and non-carers who do not speak English well or at all, by age and gender, 2006 and 2011 (% point difference)
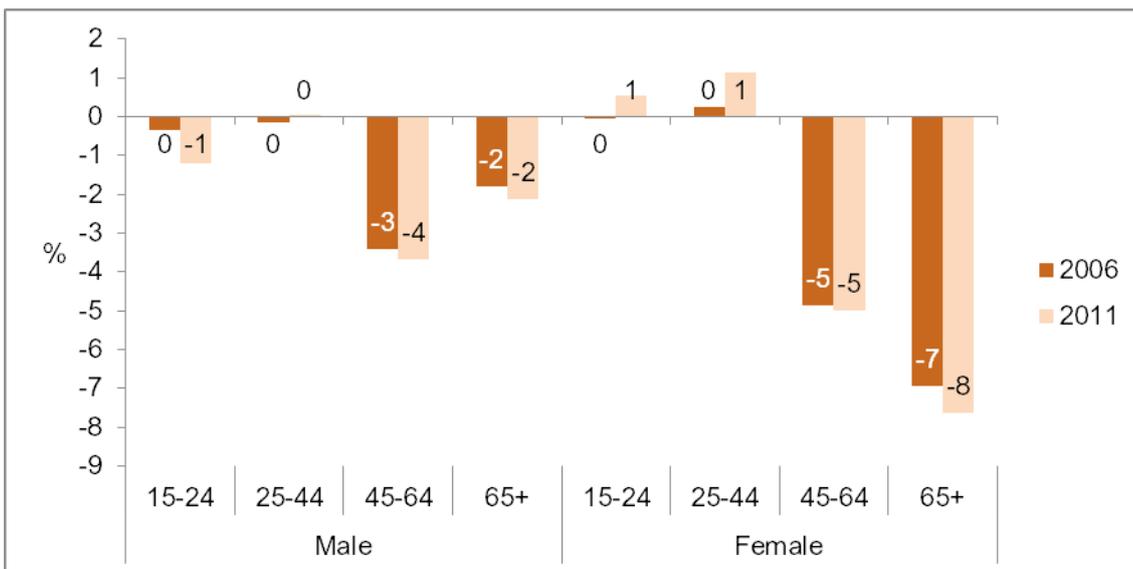
4.4 Age-based indices of social exclusion

This section focuses on the analysis of separate indices of social exclusion for carers in each age group (Table 4.1). Comparisons are made between male and female carers vis-a-vis their non-carer peers using the gaps of average rates of social exclusion, as well as multiple incidence rates of social exclusion. Note that because these are measures of social exclusion, a positive gap indicates disadvantage.

There was a clear pattern in terms of social exclusion over the life course; young carers (especially females) were most disadvantaged, but the gap reduced as carers got older. In fact, the gap actually reversed for older carers, that is, they were better off than their non-carer peers (Figure 4.45). This pattern is likely to occur due to the different types of pathways into caring and caring situations over the life course.

Table 4.1 Indicators of social exclusion by age groups of carers

Young carers (15–24): 9 indicators	Working age carers (25–44) : 8 indicators	Working age carers (45–64): 8 indicators	Older carers (65+): 5 indicators
No Year 12 attainment	No post-school qualifications	No post-school qualifications	No motor vehicle
NEET	Not employed	Not employed	No internet access
Not employed	No motor vehicle	No motor vehicle	Below 50% poverty line
No motor vehicle	No internet access	No internet access	Not a homeowner
No internet access	Below 50% poverty line	Below 50% poverty line	Not a volunteer
Below 50% poverty line	Not a homeowner	Not a homeowner	
Not a homeowner	Not a volunteer	Not a volunteer	
Not a volunteer	In a jobless household	In a jobless household	
In a jobless household			

Figure 4.45 Gap between carers and non-carers, by average rate of social exclusion, by age group, 2011 (% point difference)
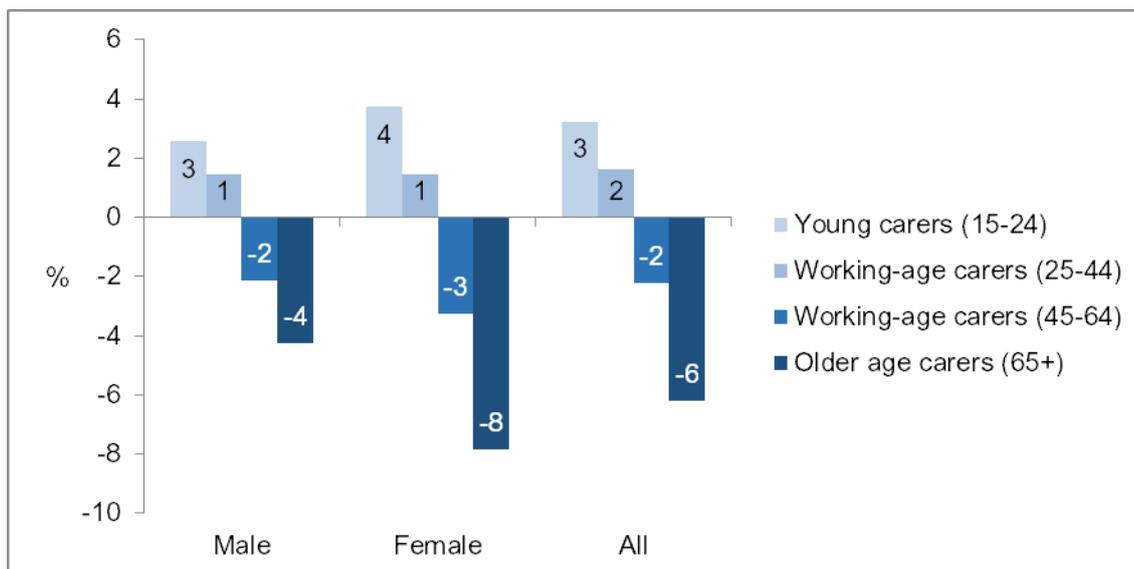
The multiple incidence rates of social exclusion were measured based on the number of indicators of social exclusion in each age group.

A threshold for disadvantage between carers and non-carers (where the rate of social exclusion was higher for carers) was identified as four or more indicators. This level was used as a measure of disadvantage. (See Figure 4.46 and Figure 4.47.)

Demographic characteristics of carers who experienced four or more indicators of social exclusion are described below.

- Young carers (15–24 years): Compared to their peers, carers in this age group were more likely to not be in school or were part-time students, and more likely to work in the public sector as managers, community and personal service workers, clerical and administrative workers, sales workers or labourers. Young carers also were more likely than their non-carer peers to be disadvantaged if they lived in couple families with children under 15 or one parent families with children under 15.

- Working-age carers (25–44 years): Compared to their peers, carers in this age group were more likely to work in the public sector; in occupation groups such as community and personal service workers; sales workers; or labourers. Family composition for this group most likely consisted of one parent families with and without dependent children under the age of 15.

Figure 4.46 Gap between young (15–24 years) carers and non-carers by multiple incidence of social exclusion, by gender, 2011 (% point difference)
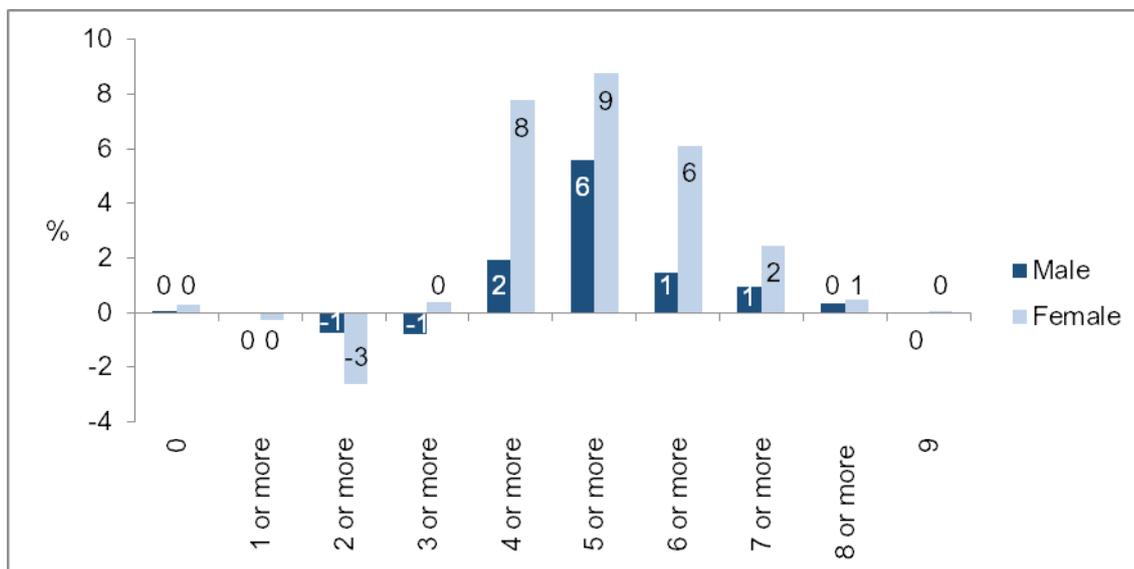
Figure 4.47 Gap between working-age (25–44 years) carers and non-carers by multiple incidence of social exclusion, by gender, 2011 (% point difference)
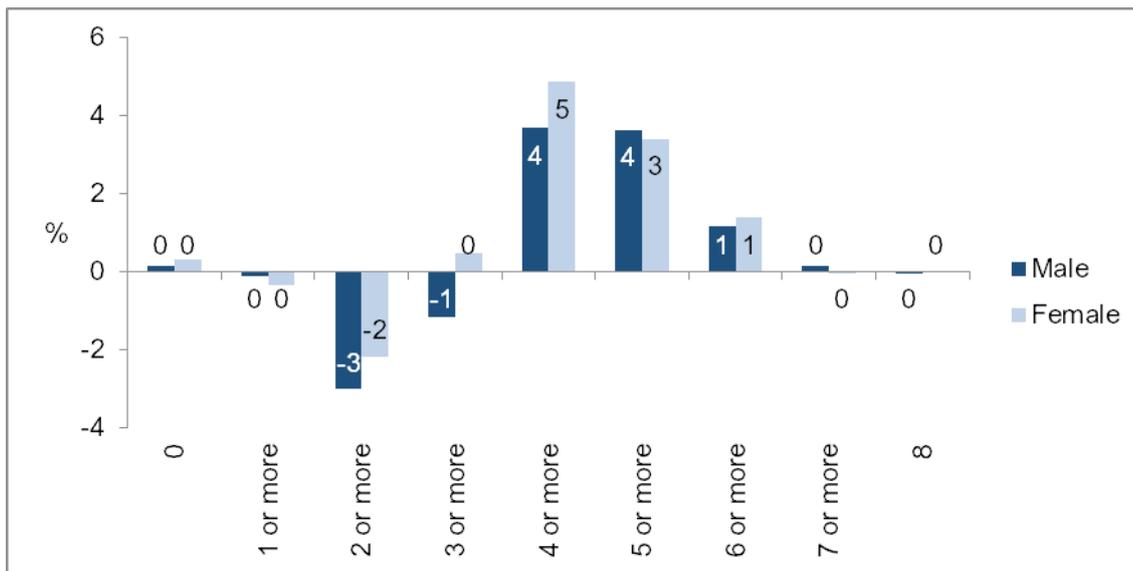
4.5 Summary

The analysis of the Census data considered participation and resource indicators of social inclusion. In terms of participation indicators of social inclusion, while, overall, carers were less likely to participate in employment and had lower secondary education achievement, there was clear evidence in the Australian Census that female carers experienced a greater impact on their capacity to participate in education and employment.

- Young women carers were most disadvantaged compared to their non-carer peers in education, and being not in employment, education or training (NEET).

- Female carers aged 25–44 were most disadvantaged vis-a-vis their peers in terms of education and employment. The employment disadvantage is increased for women without non-school qualifications.

- Overall, female carers of working age were more likely than male carers to live in jobless households.

For women, the impact of informal disability or elder care responsibilities may be compounded by child care responsibilities and gender norms within households and in social expectations around managing work and care.

The analysis of the Census data of resource indicators of social inclusion showed that, overall, younger carers were more disadvantaged with respect to household income, home ownership or purchasing, access to a motor vehicle, and access to the internet. These consistent findings of resource disadvantage highlight the impact of caring at different stages in the life course. Caring situations for young people earlier on in life, associated with caring for parents or siblings with illness or disability, impact on both the parent's capacity to be employed and also the costs associated with disability. Both these factors will affect the resources available to the household.

Rates of caring are higher in Indigenous communities than non-Indigenous communities

in Australia. On participation indicators, young Indigenous carers (aged 15–24 years) experienced education and employment disadvantages compared to their non-carer peers, and these disadvantages increased between 2006 and 2011. Younger male carers showed greater levels of disadvantage with respect to the being in the NEET group, and male carers aged under 45 years were more disadvantaged with respect to employment. On resource indicators, young male Indigenous carers were more disadvantaged with respect to access to the internet and income. The reasons for greater impacts on male Indigenous carers compared to their peers have yet to be explored in the literature.

Among carers from CALD backgrounds, young women were more disadvantaged with regard to Year 12 completion, while female carers aged 25–44 years and male carers aged over 45 years were more disadvantaged with respect to employment participation.

Age-based analyses of multiple indicators of social exclusion confirmed that younger carers were more disadvantaged than older carers. Characteristics of carers who had multiple disadvantages on the social inclusion indicators were carers living in one parent households, employed in the public sector and in specific occupations.

5 Care, Social Exclusion and Geography
Trish Hill

Further analysis of area-level aggregate data on carers' social inclusion was undertaken using the Census data for 2011. Data on carers' social exclusion was analysis by Local Government Areas (LGAs) for NSW and SA. This analysis has two components – one which outlines the rates of participation or resources and identifies areas where carers have relatively low rates on the indicators. The second component of the analysis considers carers' relative disadvantage on the indicators compared to non-carers in the same area and identifies areas with the largest gap in social exclusion outcomes between carers and non-carers. LGAs with fewer than 20 carers identified in the Census are excluded from the analysis due to lack of reliability of the data and appear as white areas on the maps. The dark blue areas on the maps indicate the areas with the highest level of disadvantage.

5.1 Participation

5.1.1 Education

Year 12 completion for 20–24 year olds

In NSW, the rate of completion of Year 12 for young carers aged 20-24 years ranged from 25.5 per cent in Moree Plains to 97.3 per cent in Woollahra. Lower rates of completion were identified in regional LGAs. Young carers had lower rates of completion than non-carers in 79 LGAs (blue and orange areas), and higher rates in 33 LGAs (yellow areas). Forty-one LGAs had too few carers in this age group (less than 20) to have reliable data and some data must be interpreted with caution due to relatively low numbers (Figure 5.1). The LGA with the highest disadvantage for young carers was Tenterfield (gap of 27.2 percentage points) (Figure 5.2).

Figure 5.1 NSW LGAs: Year 12 completion rates for carers aged 20–24 years, 2011
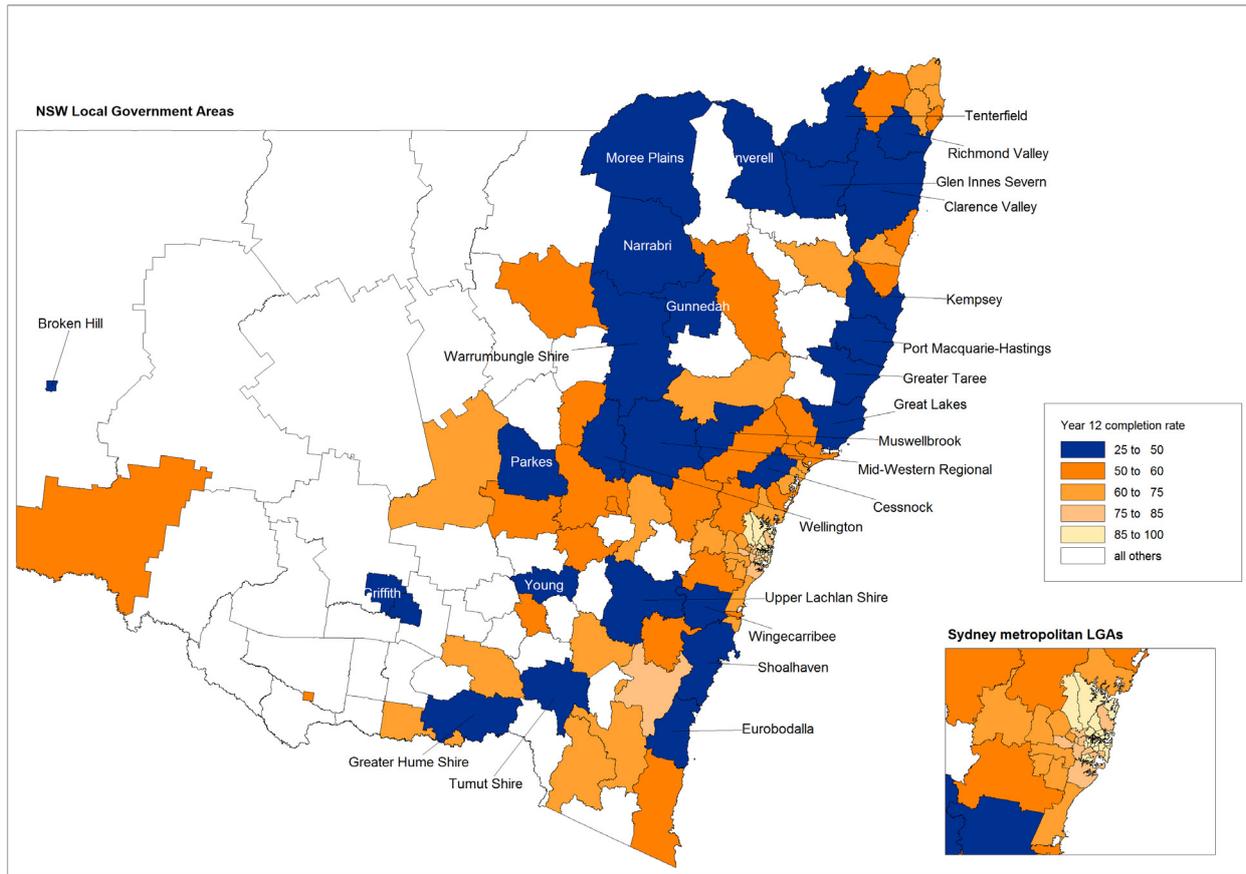
Figure 5.2 NSW LGAs: Gap in Year 12 completion rates between carers and non-carers aged 20–24 years, 2011
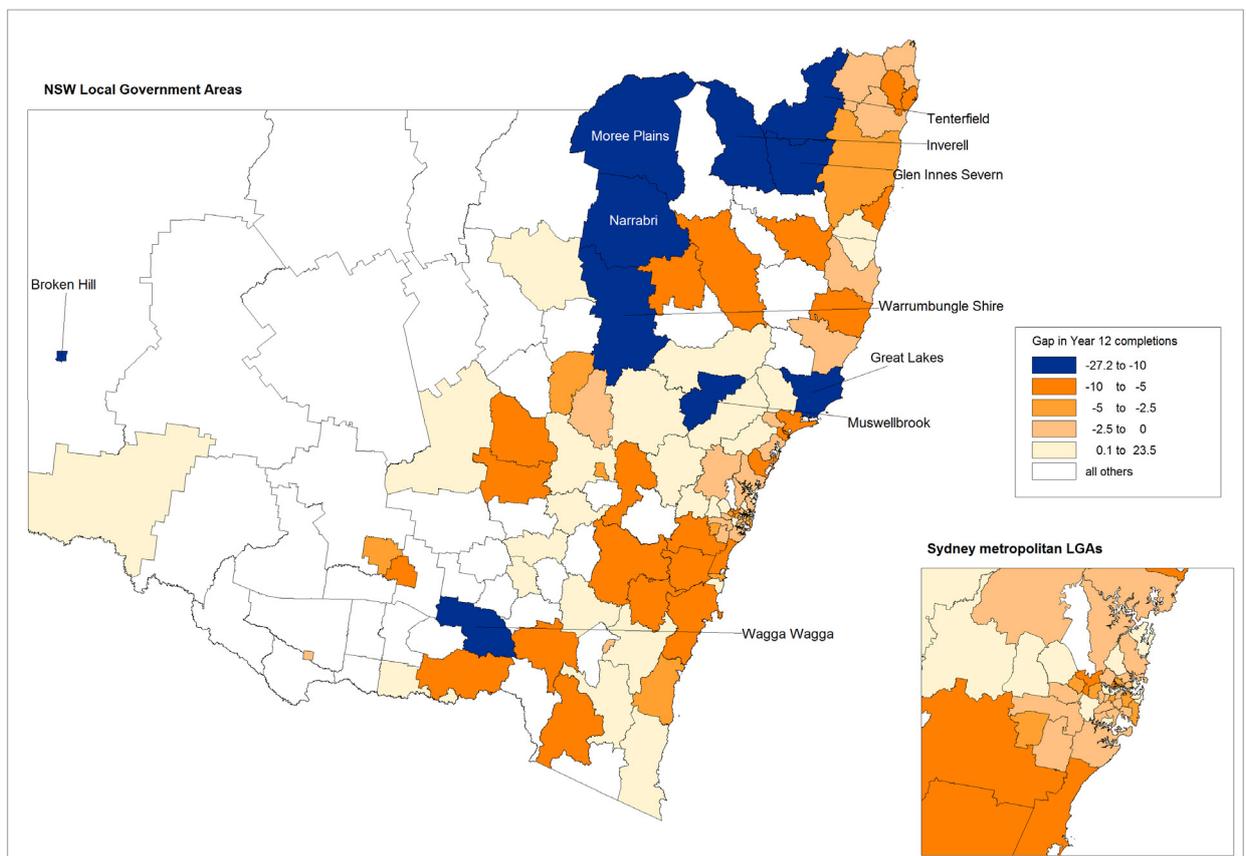
In SA, the rate of completion of Year 12 for young carers ranged from 12 per cent in Anangu Pitjantjatjara to 92.2 per cent in Unley. Young carers had lower rates of Year 12 completion in 27 LGAs and higher rates in 14 LGAs. (Thirty LGAs were excluded from the analysis due to small numbers of carers in this age group in those areas.) (Figure 5.3). The area with highest young-carer disadvantage was Berri and Barmera (gap of 19.4 percentage points).

Figure 5.3 SA LGAs: Year 12 completion rates and gap in Year 12 completion rates between carers and non-carers, aged 20–24 years, 2011
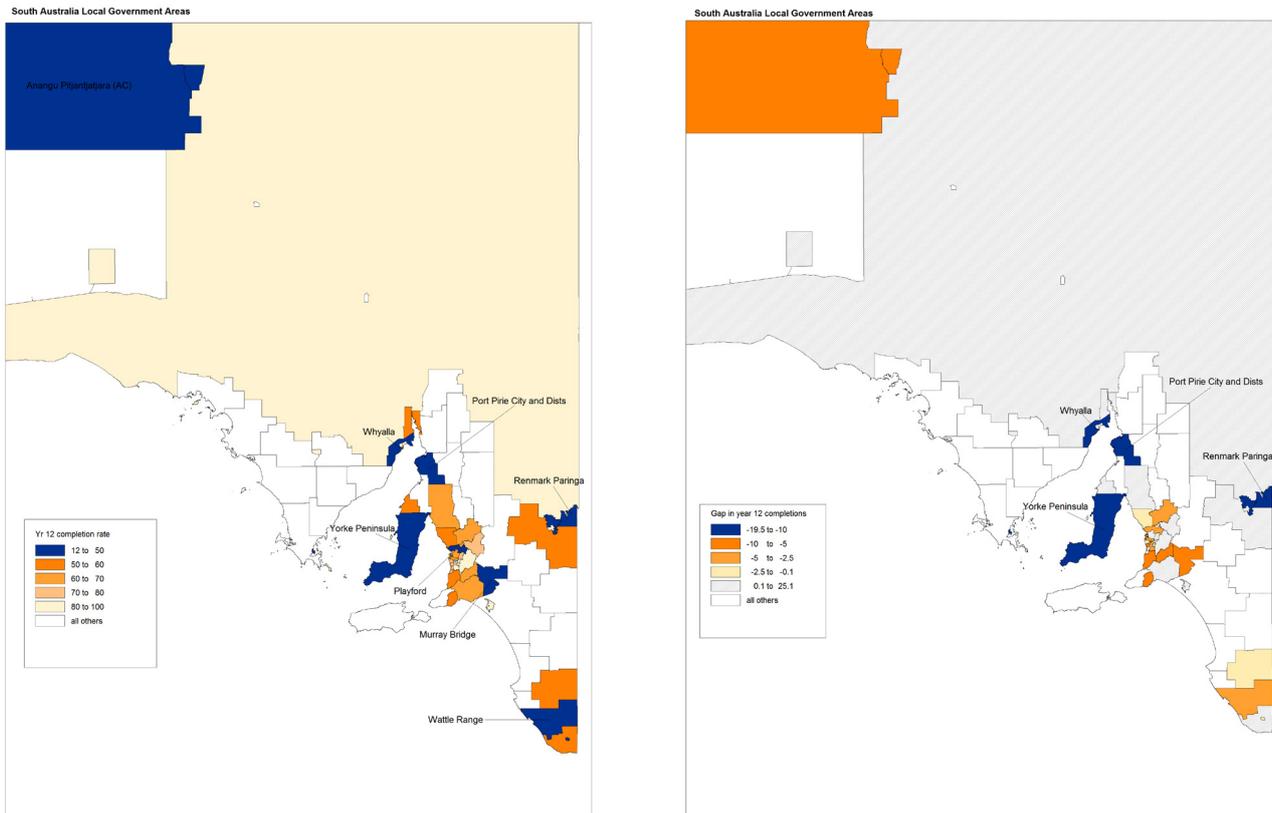
Employment

In NSW, the employment to population ratios for carers ranged from 77 per cent in Queanbeyan to 45 per cent in Fairfield. Overall, carers had lower employment to population ratios in 151 of 153 LGAs. The two LGAs where carers were more advantaged were Armidale Dumeresq and Brewarrina (Figure 5.4). The gap in employment to population ratios between carers and non-carers ranged from 18.3 percentage points disadvantage to 4.2 percentage point advantage (Figure 5.5).

Figure 5.4 NSW LGAs: Employment to population ratios: carers aged 15–64 years, 2011
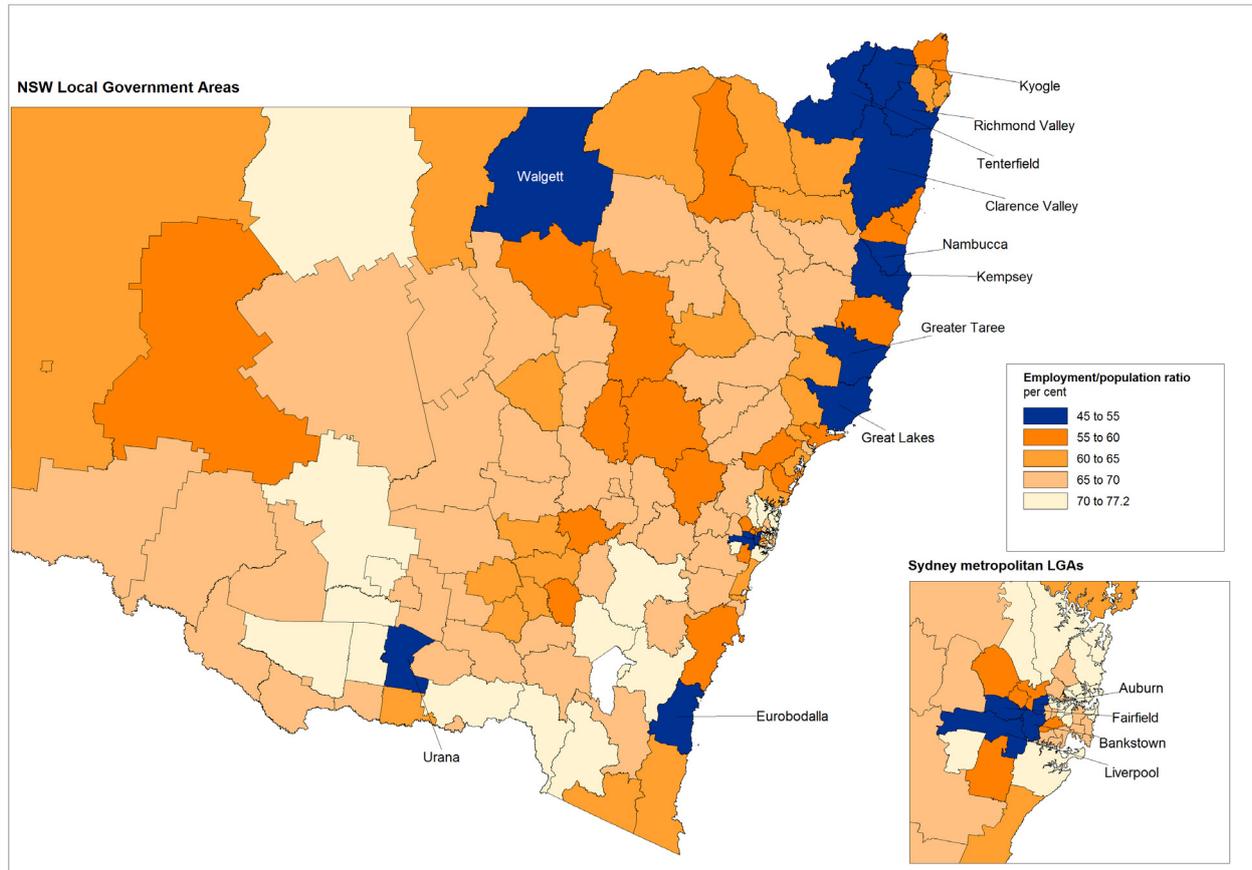
Figure 5.5 NSW LGAs: Employment to population ratio gaps: carers compared to non-carers aged 15–64 years, 2011
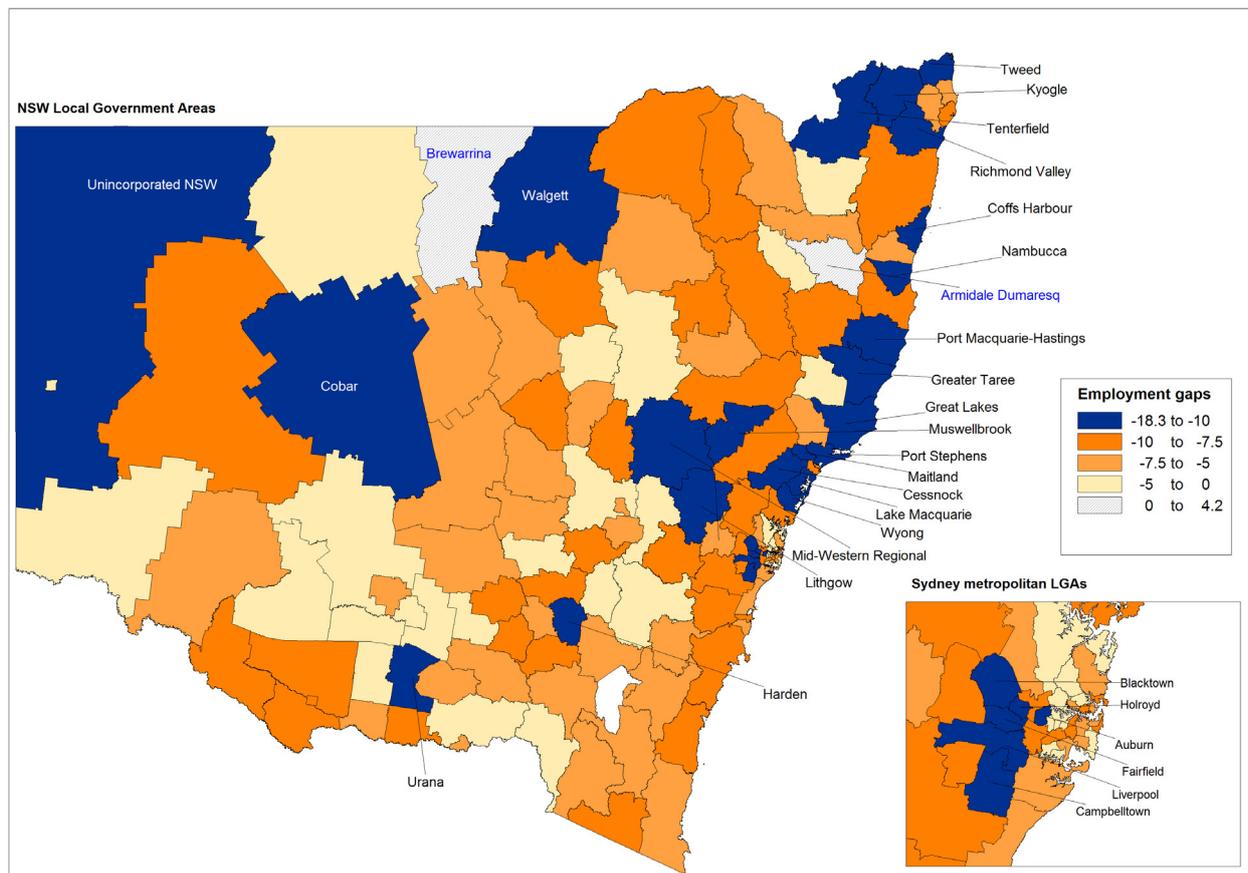
In SA, employment to population ratios for carers ranged from 85.4 per cent in Wudinna to 48.2 per cent in Peterborough. Overall, carers were less likely to be employed than non-carers in 66 out of the 70 LGAs for which there were reliable data. The gaps in employment to population ratios between carers and non-carers ranged from minus 12.9 percentage points in Wakefield (carers more disadvantaged) to a carer advantage in 6.4 percentage points in Anangu Pitjantjatjara (Figure 5.6).

Figure 5.6 Employment to population ratios and gaps : SA LGAs carers aged 15–64 years, 2011
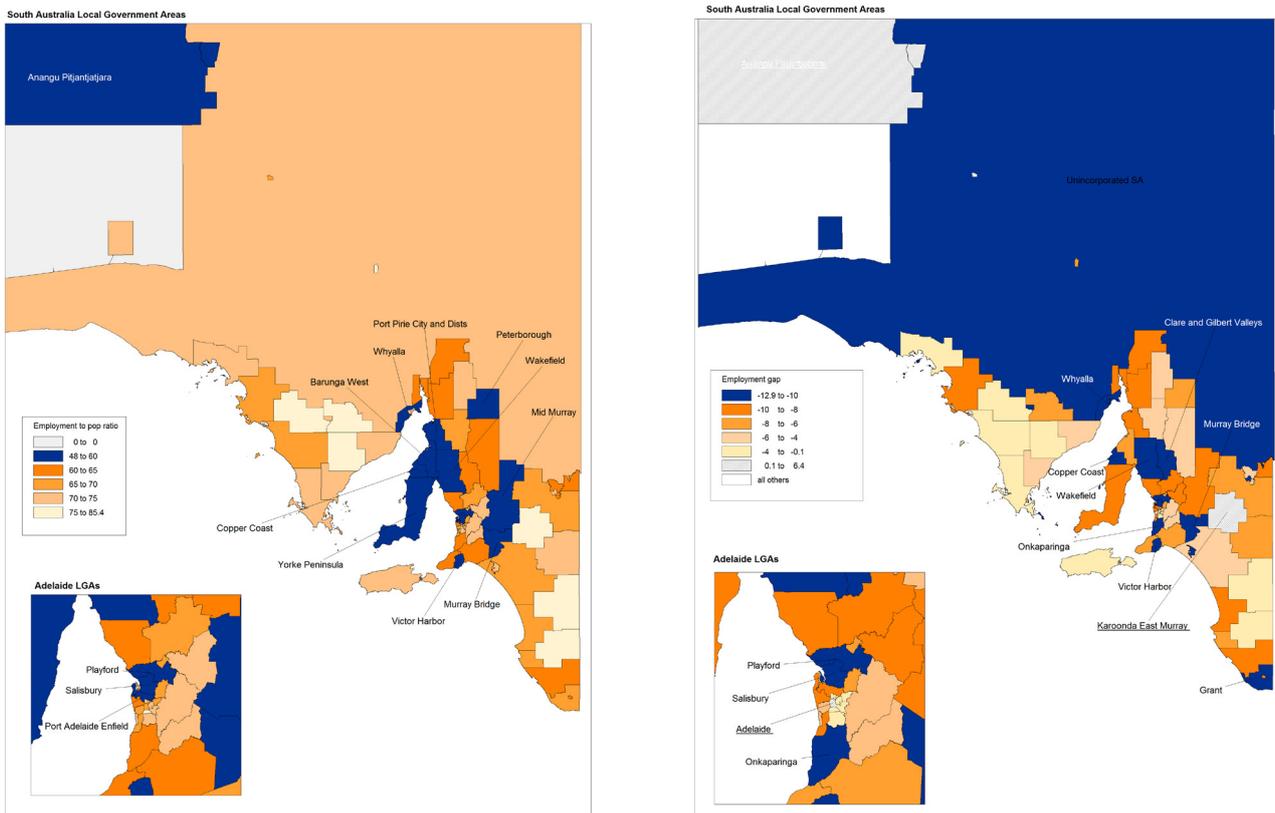
Employment by educational qualifications

Employment ratios and gaps were also analysed by educational qualifications comparing outcomes for carers with and without a non-school qualification (NSQ).

In NSW, the employment to population ratio for carers with an NSQ ranged from 58 per cent in Nambucca to 87.4 per cent in Bourke. Nambucca also had the lowest rate for employment for carers without a NSQ at 35 per cent, while the highest rate was found in Murrumbidgee at 72.8 per cent. Carers with NSQs were disadvantaged compared to their peers in all but three NSW LGAs – Urana, Brewarrina and Boorowa. The gap between carers and non-carers for those with a NSQ ranged from –14.2 in Lithgow to 0.6 percentage points advantage for carers in Boorowa (Figure 5.7). Carers without NSQs were disadvantaged compared to their non-carer peers in all NSW LGAs. The gap between carers and non-carers ranged from –27.2 percentage points in Urana to –2.1 percentage points in Hay. Carers without an NSQ were more disadvantaged compared to non-carers than those with an NSQ, as shown by the greater number of dark blue LGAs (gap of over 10 per cent) in Figure 5.8 below.

Figure 5.7 NSW LGAs: Employment to population ratio gaps: carers and non-carers with NSQ, aged 15–64 years, 2011
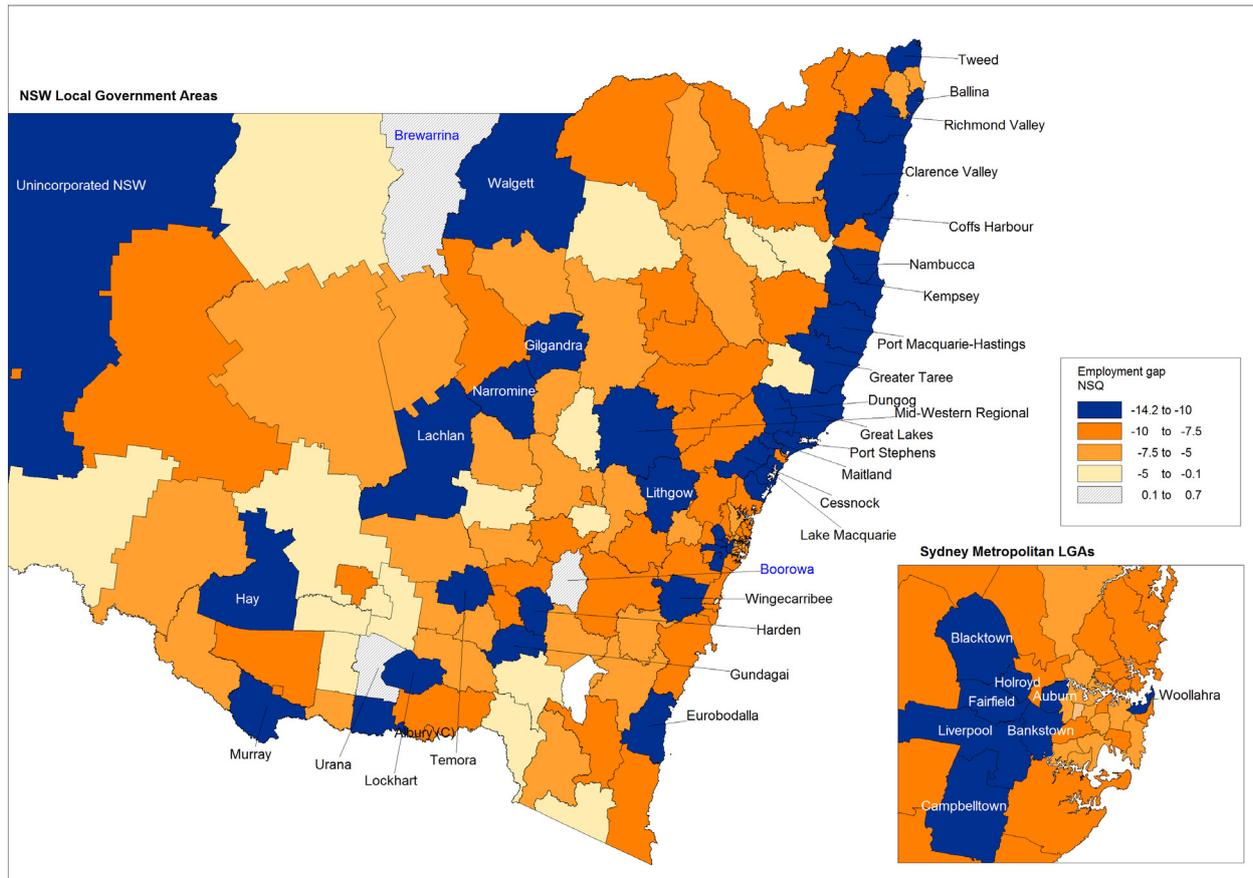
Figure 5.8 NSW LGAs: Employment to population ratio gaps: carers and non-carers without a NSQ, aged 15–64 years, 2011
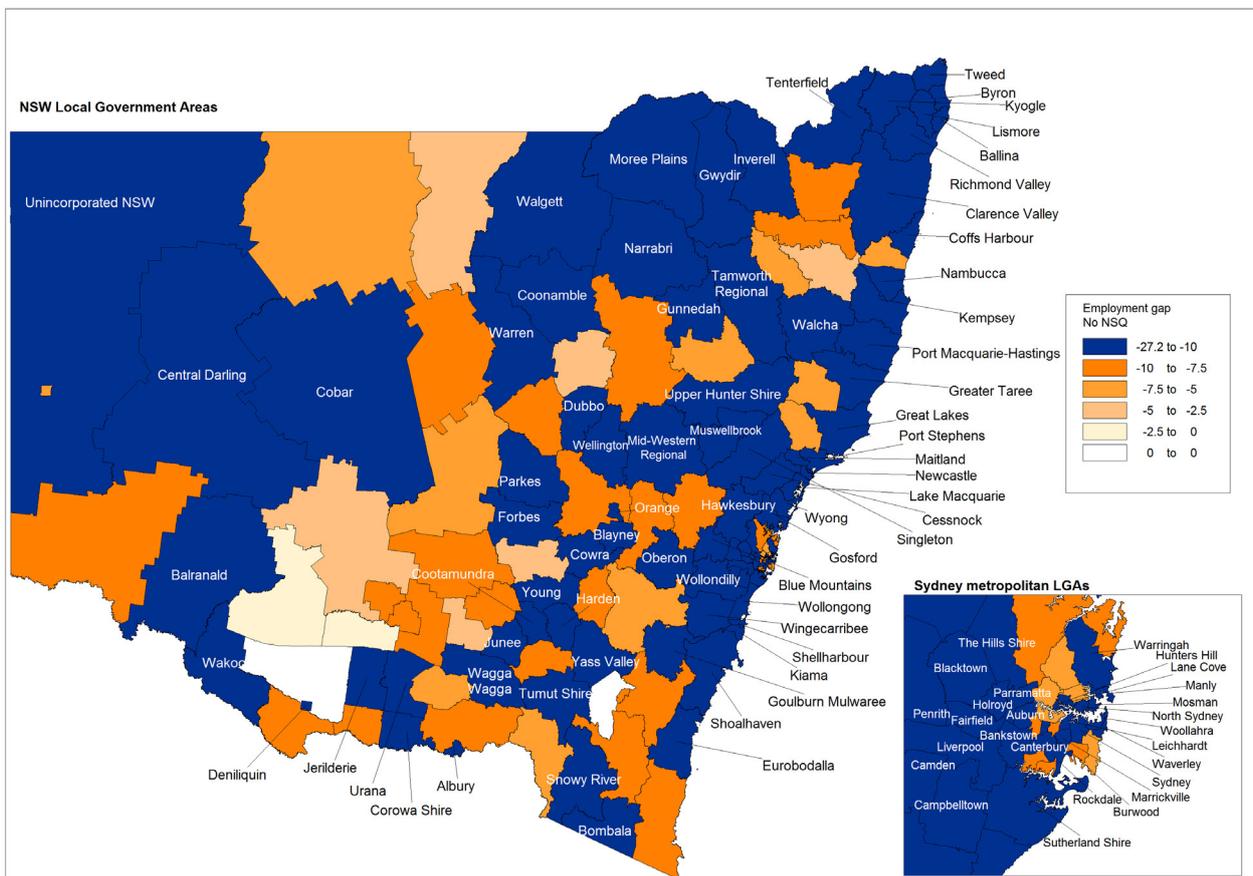
In SA, the employment to population ratio for carers with an NSQ ranged from 56.7 per cent in Peterborough to 89.5 per cent in Wudinna. Anangu Pitjantjara had the lowest rate for employment for carers without an NSQ at 37.1 per cent, while the highest rate was found in Wudinna at 82.4 per cent. Carers with NSQs were disadvantaged compared to their peers in all but four SA LGAs – Wudinna, Tumby Bay, Karoonda East Murray, and Cleve. The gap between carers and non-carers for those with an NSQ ranged from –15.9 in Kimba to 2.4 percentage points advantage for carers in Cleve. Carers without NSQs were disadvantaged compared to their non-carer peers in all but three SA LGAs. The gap between carers and non-carers ranged from –18.1 percentage points in Wakefield to 5.2 percentage point advantage for carers in Franklin Harbour. As with NSW, carers without an NSQ were more disadvantaged compared to non-carers as indicated by the number of dark blue areas (gap of over 10 per cent in the second map) (Figure 5.9).

Figure 5.9 SA LGAs: Employment to population ratio gaps: carers and non-carers with and without an NSQ, aged 15–64 years, 2011
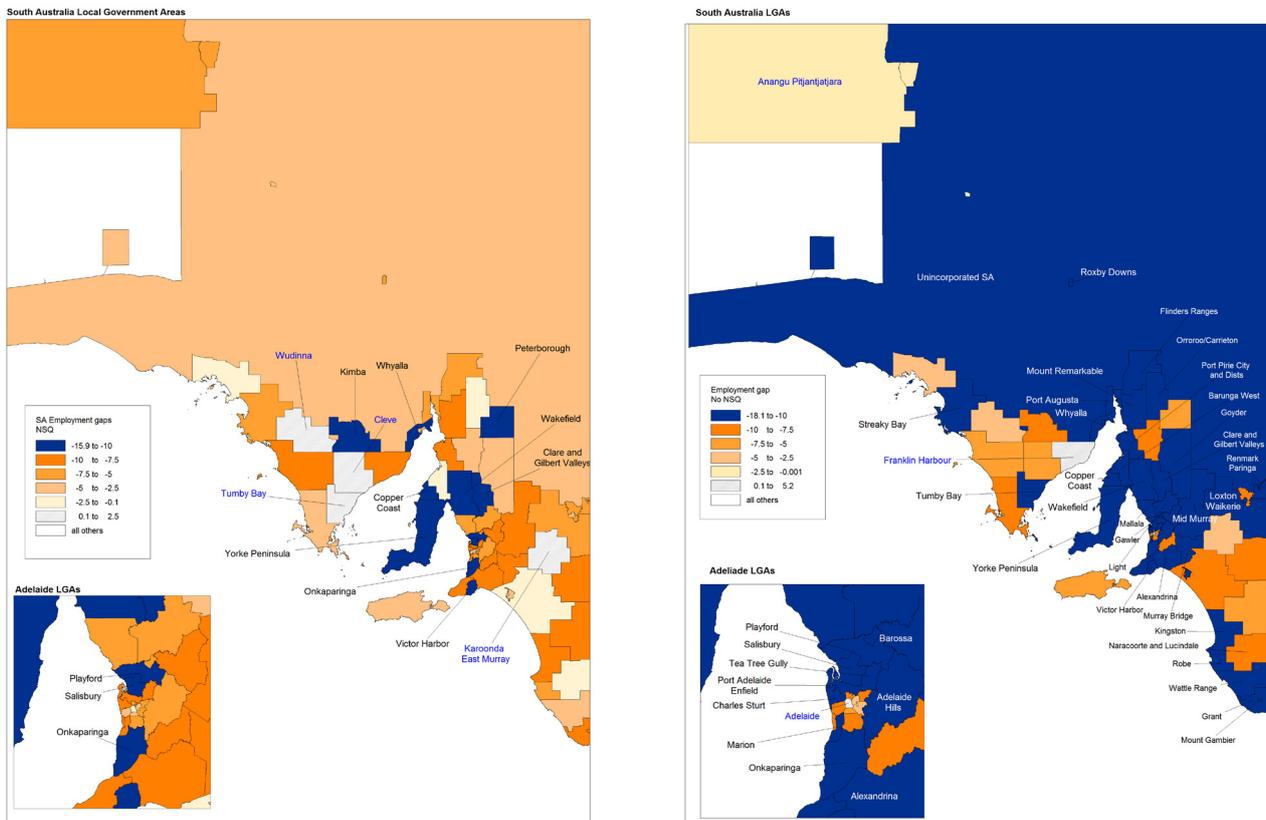
5.2 Resources

Low income

In NSW, the proportion of carers who had less than $400 gross personal income per week ranged from 22.5 per cent in North Sydney to 61.2 per cent in Urana. In 27 LGAs in NSW, 50 per cent or more of carers had low incomes. All but three of these LGAs (Auburn, Bankstown and Fairfield) were in regional NSW (Figure 5.10).

Figure 5.10 NSW LGAs: Low income rates, carers aged 15–64 years, 2011
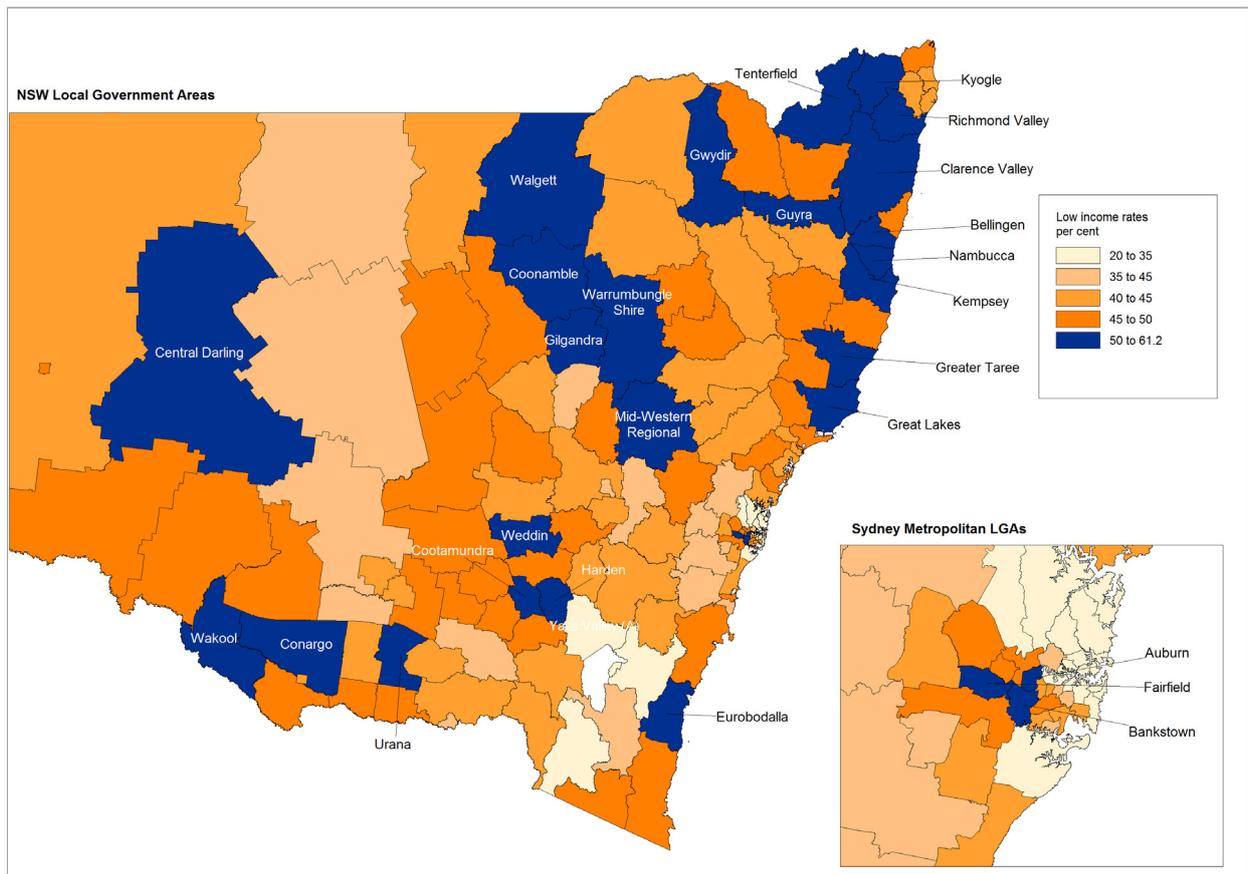
In 126 LGAs, carers were more likely than non-carers to have low income (although only two LGAs had a gap of more than 10 per cent – Conargo and Urana), in three LGAs the rates of low income were equal, and in 24 LGAs the rates for carers were lower than non-carers (blue labels in map). The gap between carers and non-carers ranged from a 14 percentage point disadvantage for carers in Conargo to a nine percentage point advantage for carers in Brewarrina (Figure 5.11).

Figure 5.11 NSW LGAs: Low income gaps, carers and non-carers aged 15–64 years, 2011
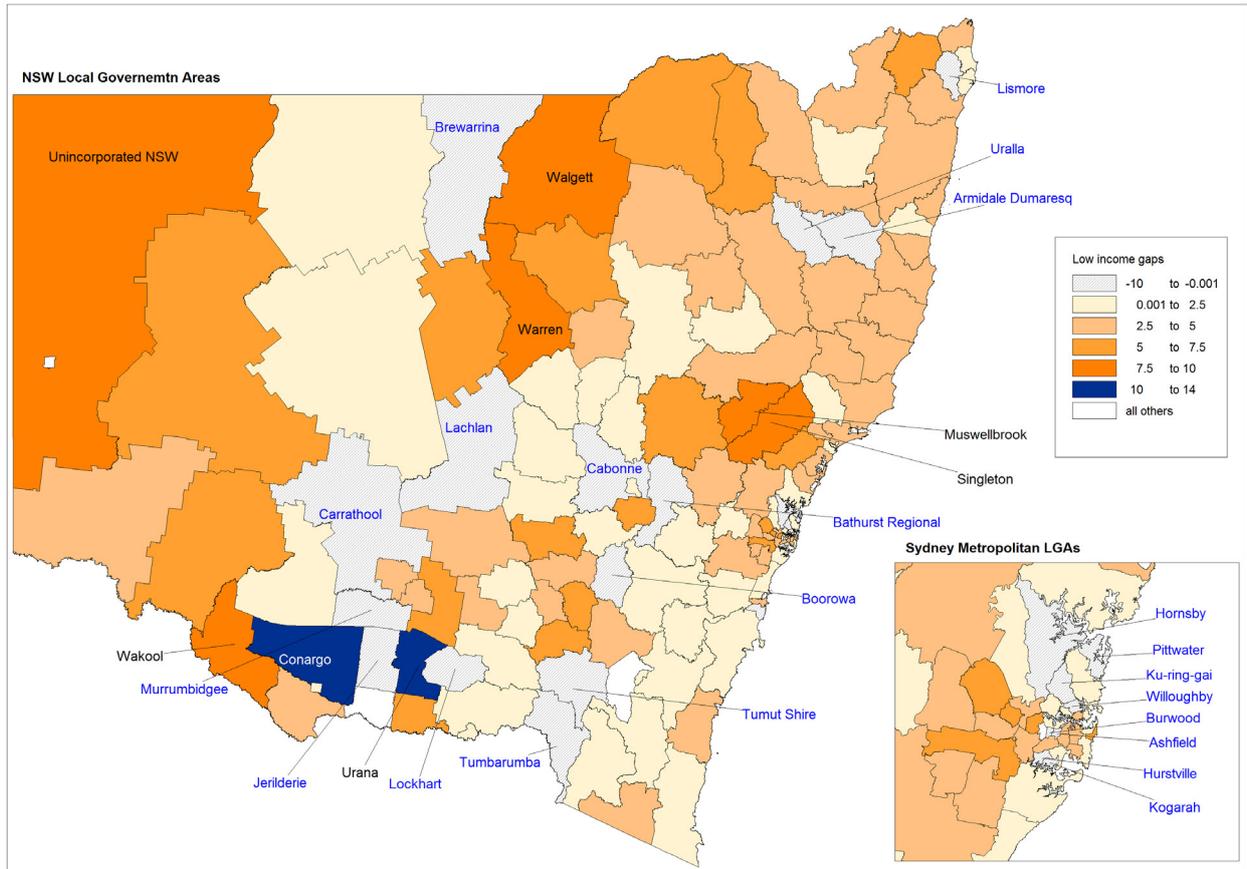
In SA, the proportion of carers who had less than $400 gross individual income per week ranged from 20.7 per cent in Roxby Downs to 72.4 per cent in Anangu Pitjantjatjara. In 15 LGAs, 50 per cent or more of carers had low income (dark blue areas on left box in Figure 5.12). Carers were more likely to have low income in 56 LGAs, had equal rates of disadvantage in one LGA and had lower rates of low income in 13 LGAs. The gap in rates of low income for carers and non-carers ranged from a 10 per cent disadvantage for carers in Southern Mallee to a 10.1 per cent advantage in Walkerville (right box, Figure 5.12).

Figure 5.12 SA LGAs: Low income rates for carers and gaps: carers and non-carers, aged 15–64 years, 2011
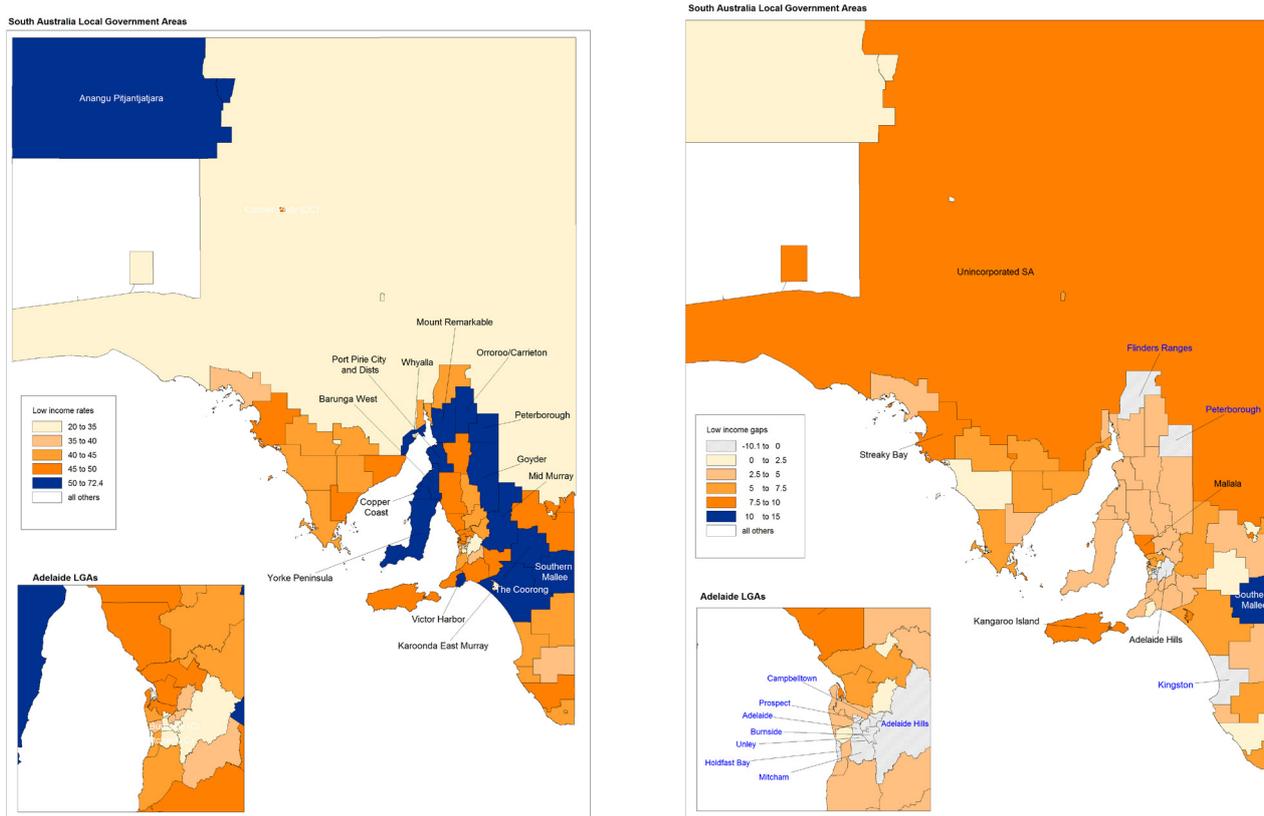
Housing tenure

The analysis explored the proportion of carers who were living in a home that was owned outright or being purchased. In NSW, the proportion of carers living in a home that was owned or being purchased ranged from 44.8 per cent in Brewarrina to 89.8 per cent in Palerang. Less than 70 per cent of carers were living in homes that were owned or being purchased in 14 LGAs in NSW (Figure 5.13). Carers were more likely to live in a home that was owned or being purchased than non-carers in all but 11 LGAs in NSW. The gap in home ownership/purchasing ranged from –2.2 percentage point disadvantage for carers in Urana, to a 20.5 percentage point advantage in Waverley (Figure 5.14). The results may be indicative of carers being, on average, older than the non-carer population in LGAs and therefore more likely to own or be purchasing a home.

Figure 5.13 Proportion of carers who live in a home that is owned or being purchased, 2011
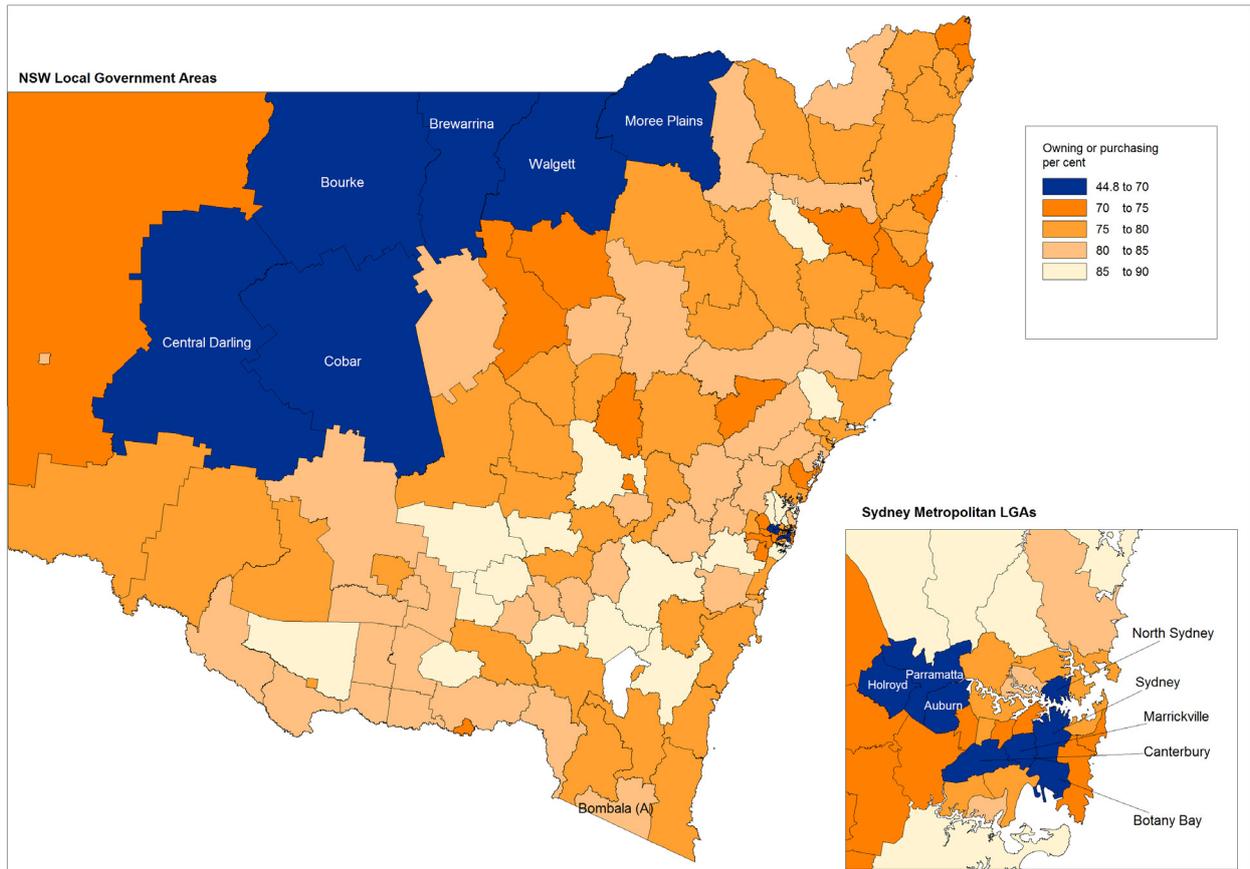
Figure 5.14 Gap between carers and non-carers in proportion of carers who live in a home that is owned or being purchased, 2011
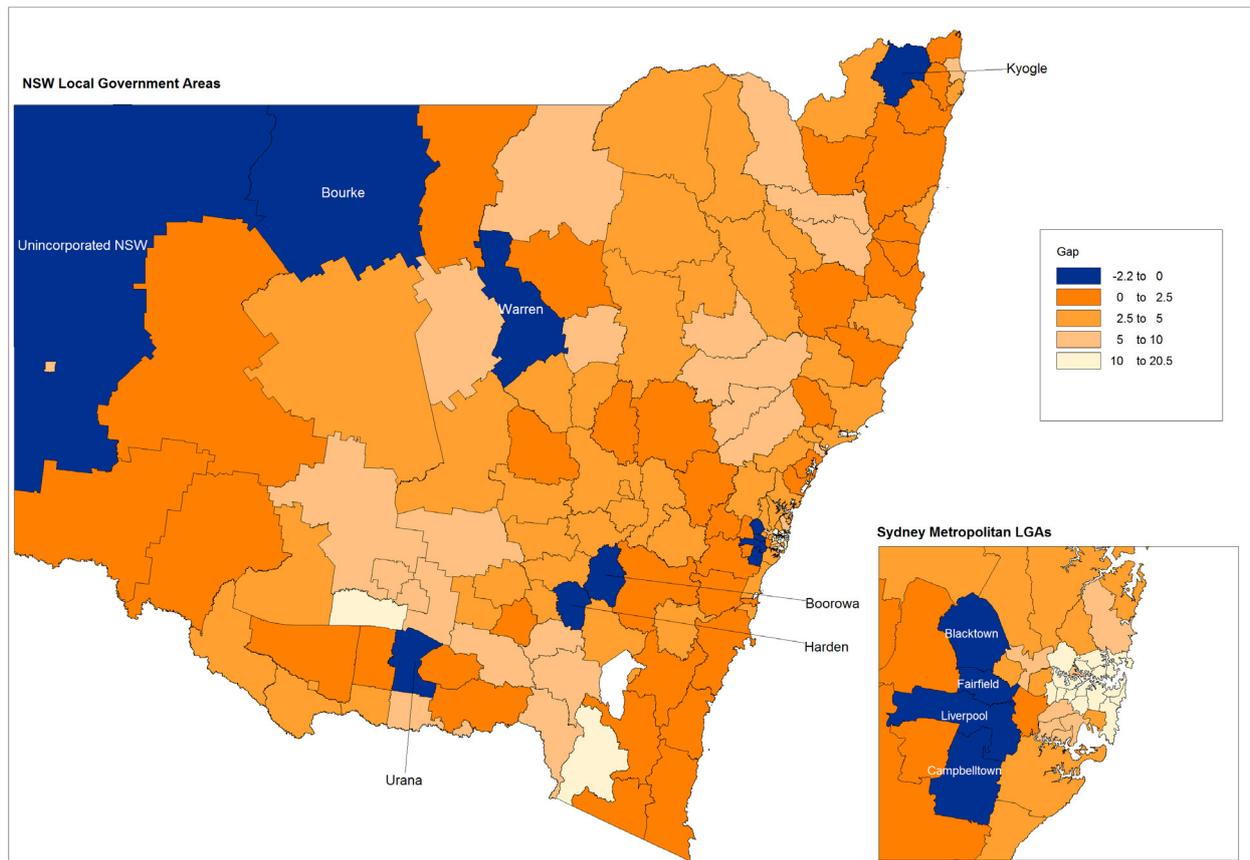
In SA, the rates of home owning or purchasing for carers ranged from 5.5 per cent in Anangu Pitjantjatjara to 93.1 per cent in Wudinna. In 11 LGAs the home ownership/ purchasing rates were below 70 per cent. Carers were more likely than non-carers to own or be purchasing their home in all but four LGAs (Burunga West, Tumby Bay, Anangu Pitjantjatjara, and Cooper Pedy), once again possibly reflecting carers being older than non-carers on average. The gap ranged from –2.6 percentage point disadvantage for carers in Burunga West to a 22.2 percentage point advantage for carers in Adelaide (Figure 5.15).

Figure 5.15 SA LGAs: Home owning/purchasing rates for carers and gaps: carers and non-carers, aged 15–64 years, 2011
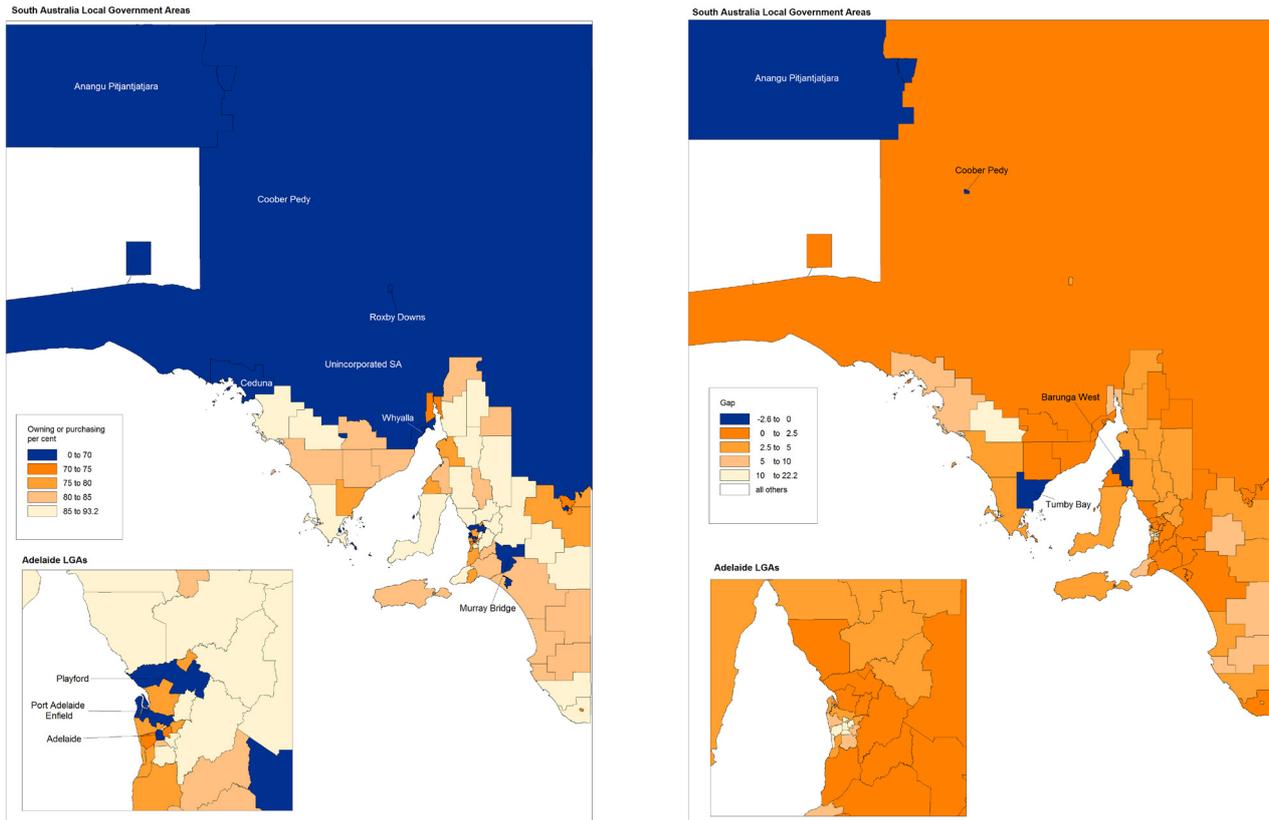
Motor vehicle access

Motor vehicle access is defined as living in a household with one or more motor vehicles.

In NSW, motor vehicle access for carers ranged from 71.9 per cent in Sydney to 100 per cent in Conargo, Urana and Walcha (Figure 5.16). Thirteen LGAs had rates of motor vehicle access less than 90 per cent. Carers were more likely than non-carers to have access to a motor vehicle in all but eight LGAs in NSW. The gap ranged from −3.6 percentage point disadvantage for carers in Bourke to an 8.5 per cent advantage for carers in Sydney.

Figure 5.16 Proportion of carers who live in a household with motor vehicle access, 2011
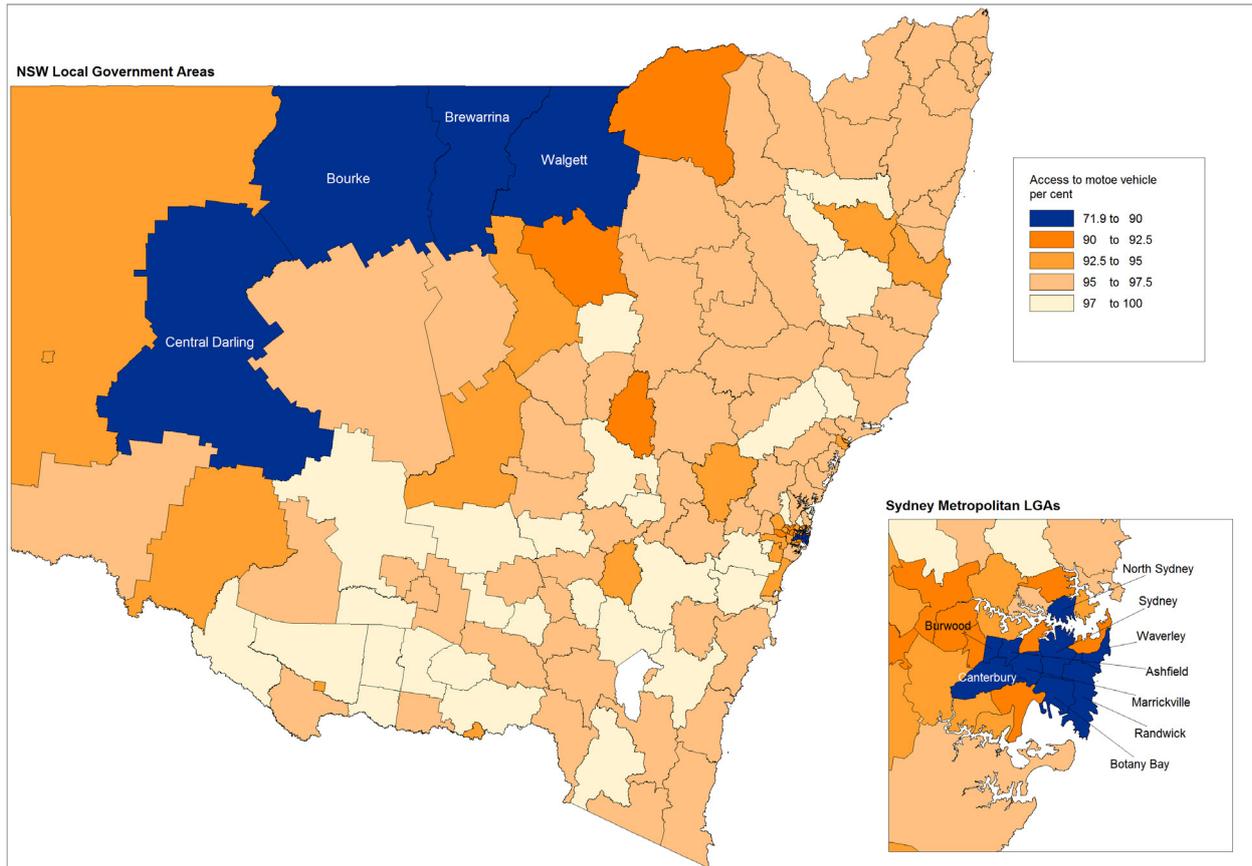
In SA, the rate of motor vehicle access ranged from 46.5 per cent in Anangu Pitjantjatjara to 100 per cent in seven LGAs: Elliston, Franklin Harbour, Karoonda East Murray, Kimba, Kingston, Orroroo Carrieton, and Wudinna (Figure 5.17). Carers were more likely than non-carers to have access to a motor vehicle in all but eight LGAs. The gap ranged from –2.5 percentage points in Anangu Pitjantjatjara to a carer advantage of 13.7 percentage points in Adelaide.

Figure 5.17 SA LGAs: Proportion of carers who live in a household with motor vehicle access, 2011
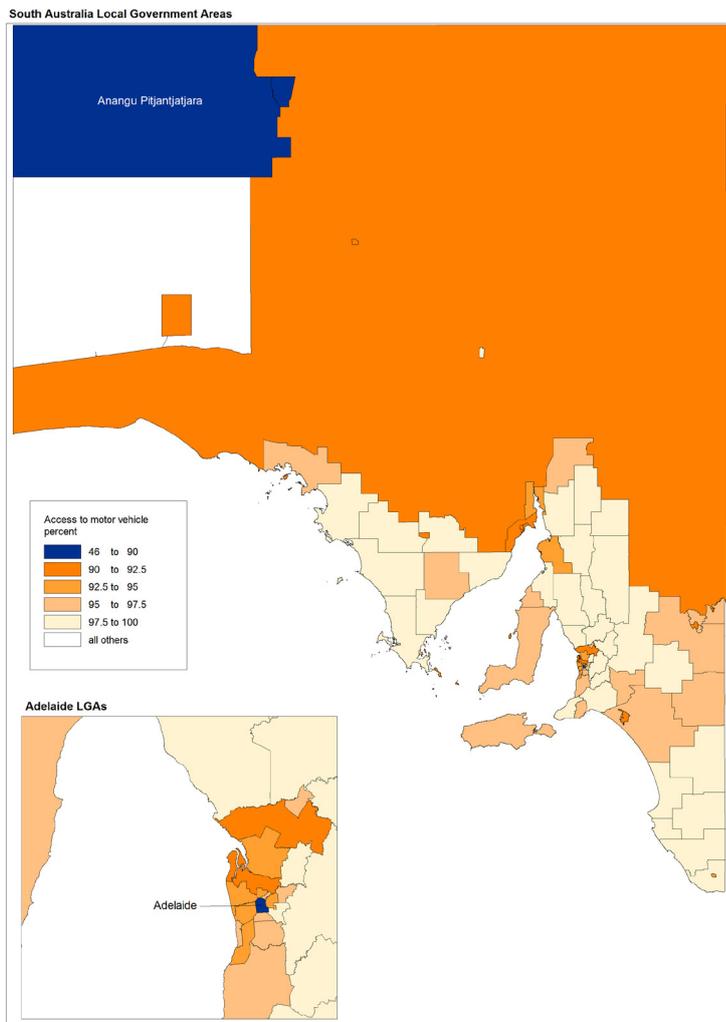
Internet access

In NSW, internet access ranged from 53.7 per cent in Central Darling to 94.4 per cent in Ku-ringai. Less than 70 per cent of carers had access to the internet in 12 LGAs and less than 80 per cent of carers had access to the internet in 76 LGAs (Figure 5.18). Carers were less likely to have access to the internet in 70 LGAs, although in many cases the gap was not large as only two LGAs (Unincorporated NSW and Urana) had a gap greater than 5 percentage points. The gap ranged from 9.6 in Unincorporated NSW to an 8.7 percentage point advantage for carers in Murrumbidgee.

Figure 5.18 Proportion of carers who live in a household with internet access, 2011
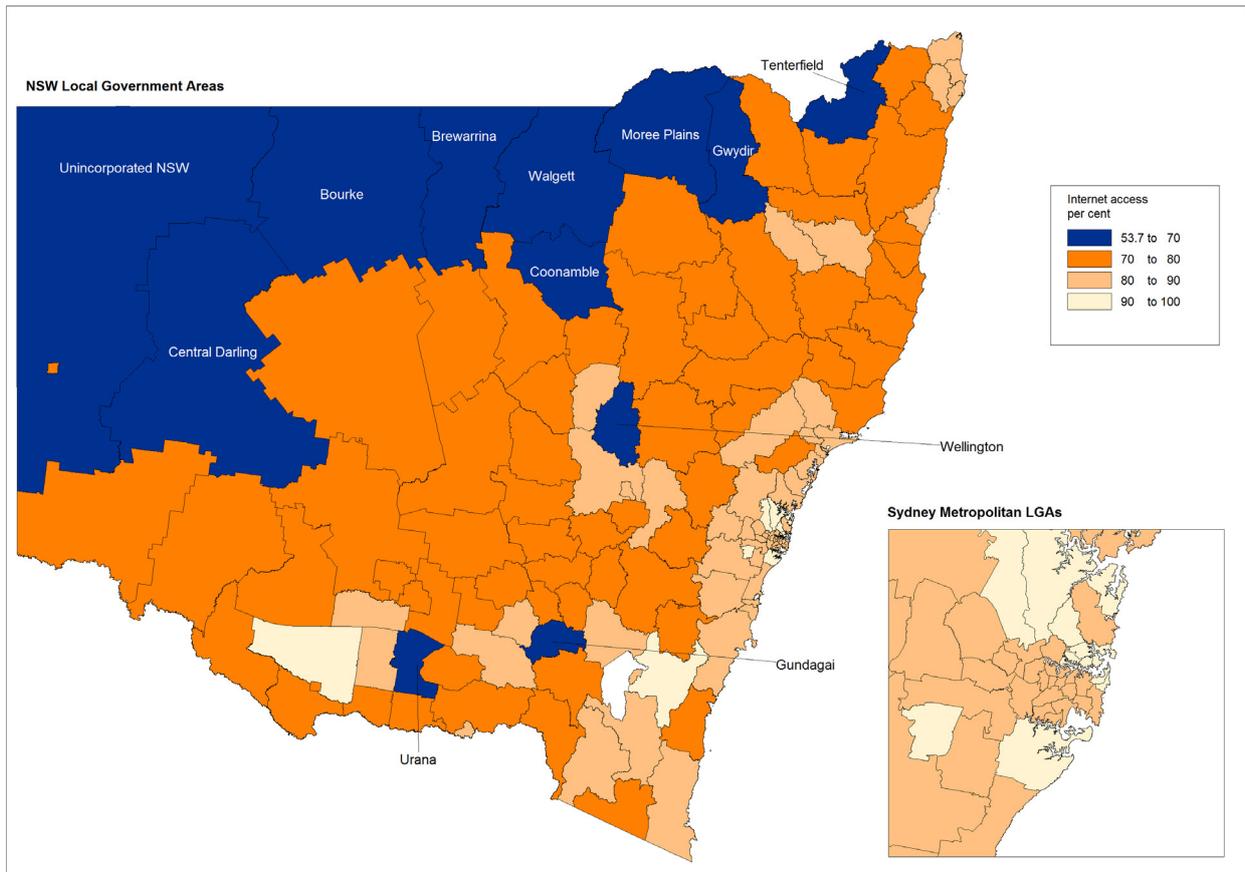
In SA, the rates of internet access for carers ranged from 16 per cent in Anangu Pitjantjatjara to 95.9 per cent in Roxby Downs Six LGAs had rates of access less than 70 per cent and 38 LGAs had rates of less than 80 per cent (Figure 5 19). Carers had lower rates of internet access in 36 LGAs, although only one LGA had more than a 5 percentage point difference (Streaky Bay). The gap ranged from a 9 percentage point disadvantage in Streaky Bay to a 13.3 percentage point carer advantage in Orroroo/Carrieton.

Figure 5.19 SA LGAs: Proportion of carers who live in a household with internet access, 2011
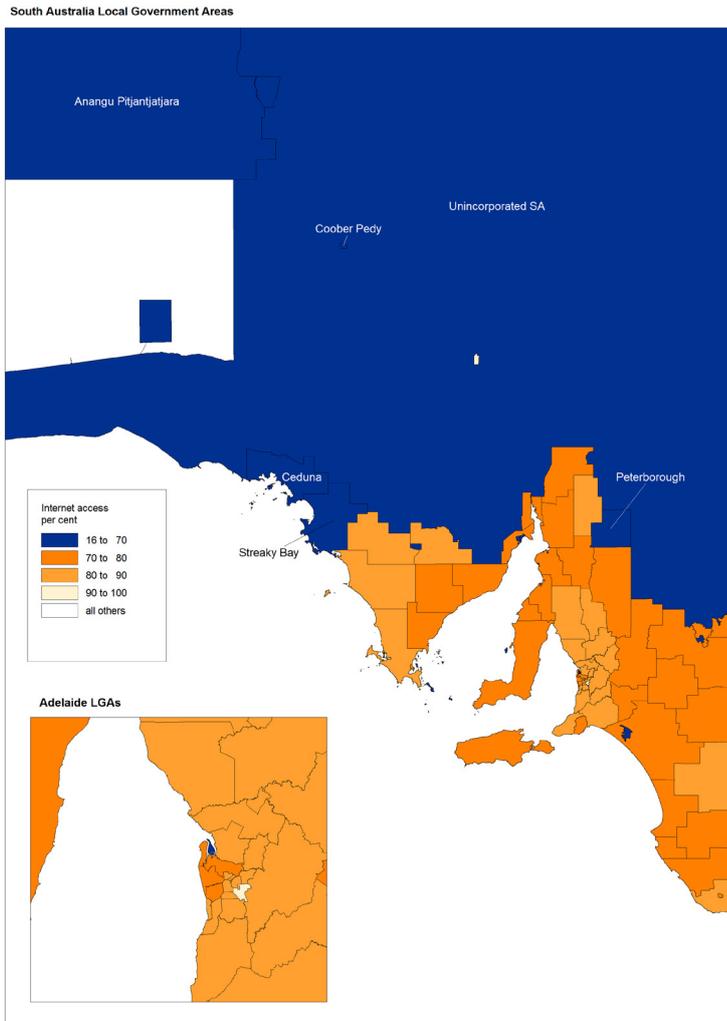
5.3 Summary

Participation

Young carers were less likely than non-carers to complete Year 12 education in over two-thirds of LGAs for which there was reliable data. Disadvantage for young carers was more pronounced in regional areas in NSW and SA. Rates of employment for working aged carers (15–64 years) varied across urban and regional areas in NSW and SA. Carers were disadvantaged in nearly all LGAs in NSW and SA with regard to employment. The employment participation disadvantage for carers increased in terms of the number of LGAs and size of the gap between carers and non–carers for carers without a non-school qualification.

Resources

LGAs where a higher proportion of carers had low incomes were mostly in regional NSW and SA. The disadvantage for carers was greatest in regional areas in both states. However, at the LGA level in both states, carers were more likely to own or be purchasing their home and have access to a motor vehicle than non-carers, which may be indicative of the age groups of the two populations. While carers in regional areas hade lower rates of internet access in 2011, there were few marked differences between carers and non-carers.

This analysis of Census data for Australia in 2011 suggests that location matters for carers social inclusion outcomes, particularly with regard to education, employment and as a likely a consequence, income. It highlights the key role of education in protecting carers' participation in employment and the need to explore the reasons for the greater level of carer disadvantage on these key participation indicators in regional areas in both NSW and SA.

6 Social Inclusion Indicators in the HILDA Survey

Melissa Wong and Trish Hill

This section explores analysis of other social inclusion indicators in the domains of participation, resources and quality of life undertaken using the Household, Income and Labour Dynamics in Australia (HILDA) Survey data. This data is from a panel survey which commenced in 2001 and has followed members of the households each year to date. In addition to considering a broader range of domains of social inclusion, this data enables an analysis of the ways in which carers' social inclusion may have changed over time. Specific questions identifying carers were introduced in 2005 and repeated in each subsequent wave and this analysis considers carers social inclusion in 2005, 2007, 2009, 2011 and 2013. The indicators analysed here draw on the framework established the Bristol Social Exclusion Matrix (B-SEM) (Levitas et al 2007). The B-SEM includes aspects of quality of participation, a wider definition of resources (social as well as economic) and quality of life (including physical and mental health, life satisfaction). The section below highlights key results.

6.1 Participation

The HILDA data offered the opportunity to explore a more nuanced set of social inclusion indicators that could encompass aspects of the quality of working life, including the terms of inclusion from both an objective and subjective perspective. In addition, this data set contained information on social participation. These indicators included those outlined in Table 6.1.

Table 6.1 Participation indicators in the HILDA Survey data

Domain	Indicators
Employment status	Proportion of carers marginally attached
	Proportion of carers underemployed (PT workers who prefer and is available to work more hours)
Nature of working life	Proportion of carers working in low level occupations
	Proportion of carers in casual or fixed term jobs
Quality of working life	Workplace conditions • Hours usually worked in all jobs (works more than 40 hours) • Preferred hours of work (prefer fewer hours) • Paid holiday leave • Paid sick leave • Work at home • Anti-social hours (works evenings , nights or weekends) • Fixed term/casual or/ contract basis • % on collective/individual agreement (versus those on award rate)

Quality of working life (cont.)	**Workplace entitlements (SCQ) - % yes**
	• Special leave for caring for family members
	• Permanent part-time work
	• Home-based work
	• Flexible start and finish time
	Job security - % chance
	• Likely to leave job voluntarily
	• Likely to lose your job in the next 12 months
	Job satisfaction (1-10) - mean score
	• Pay
	• Job security
	• Work itself
	• Hours you work
	• Flexibility to manage work and non-work commitments
	• Overall
	Job characteristics:
	Stress
	• My job is more stressful than I had ever imagined
	• I fear that the amount of stress in my job will make me physically ill
	Equity
	• I get paid fairly for the things I do in my job
	Security
	• I have a secure future in my job
	• The company I work for will still be in business 5 years from now
	• I worry about the future of my job
	Complexity
	• My job is complex and difficult
	• My job often requires me to learn new skills
	• I use many of my skills and abilities in my current job
	Autonomy
	• I have a lot of freedom to decide how I do my own work
	• I have a lot of say about what happens on my job
	Flexibility
	• I have a lot of freedom to decide when I do my work
	• I have a lot of choice in deciding what I do at work
	• My working times can be flexible
	• I can decide when to take a break
	Complexity
	• My job requires me to do the same things over and over again
	• My job provides me with a variety of interesting things to do
	• My job requires me to take initiative

Quality of working life (cont.)	Intensity
	• I have to work fast in my job
	• I have to work very intensely in my job
	• I don't have enough time to do everything in my job
Social Participation	• Get together socially with friends or relatives not living with you less than once a month

Employment status

Over the time period under consideration (2005–2013), carers were statistically significantly more likely than non-carers to be marginally attached to the labour force from 2009 onwards, with the gap between carers and non-carers increasing over this time period (Figure 6.1)[16]. In 2013, male carers were more likely to be marginally attached to the labour force (11%) than any other group. In 2013, carers were also less likely to report underemployment (part-time workers who prefer and are available to work more hours) than non-carers.

Figure 6.1 Proportion of carers and non-carers who were marginally attached to the labour force, 2005–2013 (%)
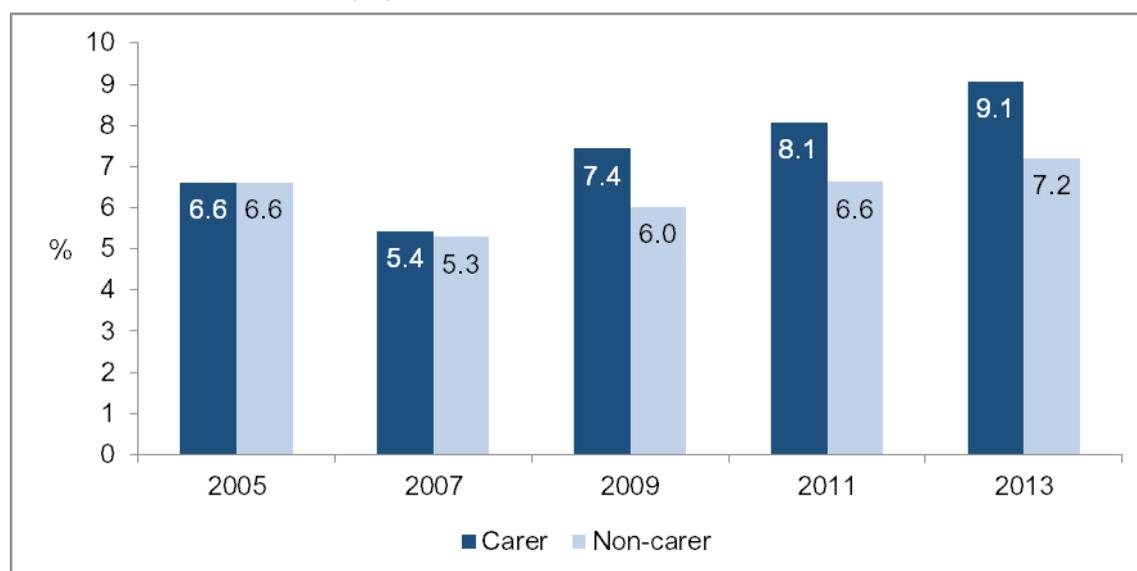
Nature of working life

Overall, there were few significant differences in terms of the broad occupational classification of carers and non-carers. In 2013, employed carers were less likely than employed non-carers to be in low-level occupations[17]. There were only a few significant differences over this time period between employed carers and non-carers in terms of rates of casual or fixed term jobs.

16   A person is marginally attached to the labour force if he or she: (i) is not available to start work in the reference week, but wants to work and is actively looking for work; or (ii) is not actively looking for work, but wants to work and is available to start work within four weeks.
17   Low-level occupations include Machinery Operators and Drivers, Machine and Stationary Plant Operators, Mobile Plant Operators, Road and Rail Drivers, Storepersons, Labourers, Cleaners and Laundry Workers, Construction and Mining Labourers, Factory Process Workers, Farm, Forestry and Garden Workers, Food Preparation Assistants and Other Labourers.

Quality of working life

Work conditions

Employed carers were more likely than employed non-carers to say they are working long hours (more than 40 hours a week) (Figure 6.2). In 2013, this finding holds for both men and women. While this is a surprising finding, only in 2013 were employed carers who worked more than 35 hours per week more likely than non-carers in this group to report that they would prefer to work fewer hours.

Figure 6.2 Proportion of carers and non-carers who report that they work long hours, 2005–2013 (%)
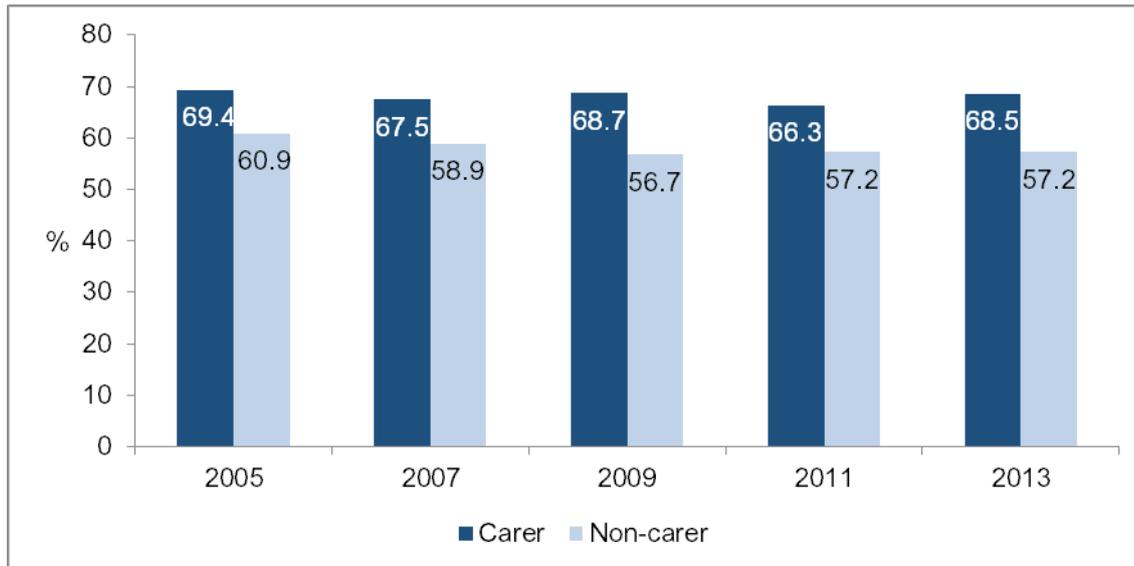
Following on from the lack of difference in casual employment rates, there is similar access to paid holiday leave between carers and non-carers. However, carers were less likely to have sick leave in 2009 and 2011. There are no significant differences in terms of access to working at home between carers and non-carers. Carers are also less likely to be working 'anti-social hours' hours in most years (evenings, nights or weekends).

Carers in 2013 were more likely to be paid according to award rates rather than based on individual or collective agreements[18]. In general, there are few consistent significant differences between employed carers and non-carers in terms of workplace entitlements.

Job security and satisfaction

Overall, there were few differences between carers and non-carers in terms of job security over the 2005–2013 period. Although there are no consistent differences in terms of satisfaction with aspects of work over this time, in 2013 employed carers reported significantly higher levels of satisfaction on a number of indicators (pay, the work itself, flexibility to manage work and life commitments and overall job satisfaction) than employed non-carers.

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18 The minimum wages and conditions an employee is entitled to are set out in awards and depends on the industry they work in or the job that they do. A registered agreement sets out the terms and conditions of employment between an employee or group of employees and one or more employers (Fair Work Ombudsman (2015), www.fairwork.gov.au)

Job characteristics

Generally, carers were more likely to report stress in their job than non-carers over the 2005–2013 period. In particular, both male and female carers reported higher agreement compared to non-carers when asked if they fear the amount of stress in their jobs will make them physically ill (Figure 6.3).

There were however, no differences in terms of perceptions of pay fairness and only few differences in terms of job security. Over the 2005–2013 period, male and female carers were also more likely to report that they don't have enough time in their jobs to do everything (Figure 6.4).

Figure 6.3 Carer and non-carer mean score responses to fearing the amount of stress from job will make them physically ill, 2005–2013 (mean score, scale 1–7)
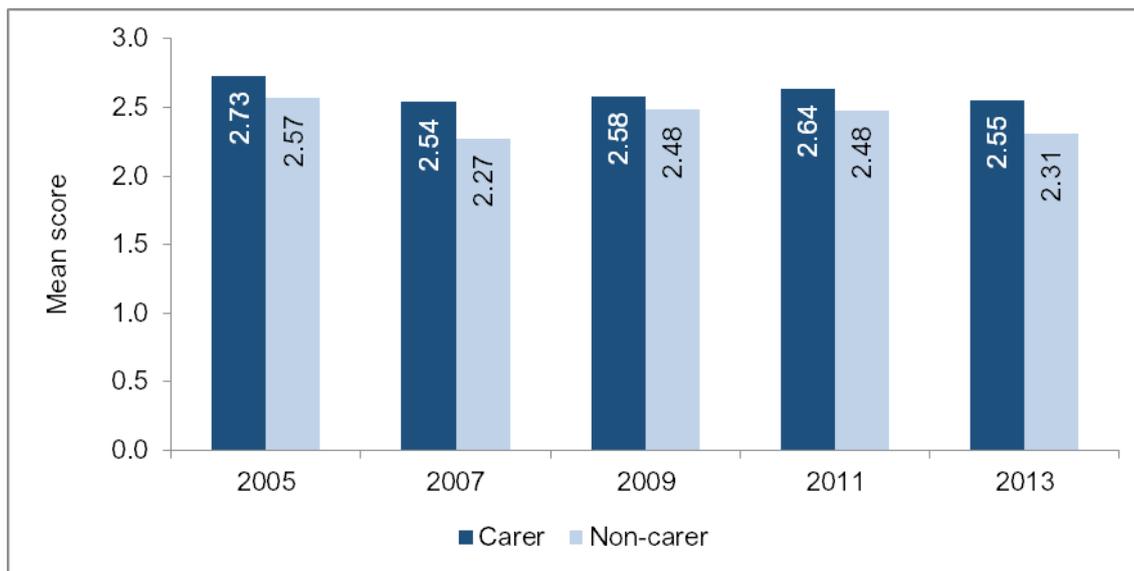
Figure 6.4 Carer and non-carer mean score responses to not having enough time to do everything in job, 2005–2013 (mean score, scale 1–7)
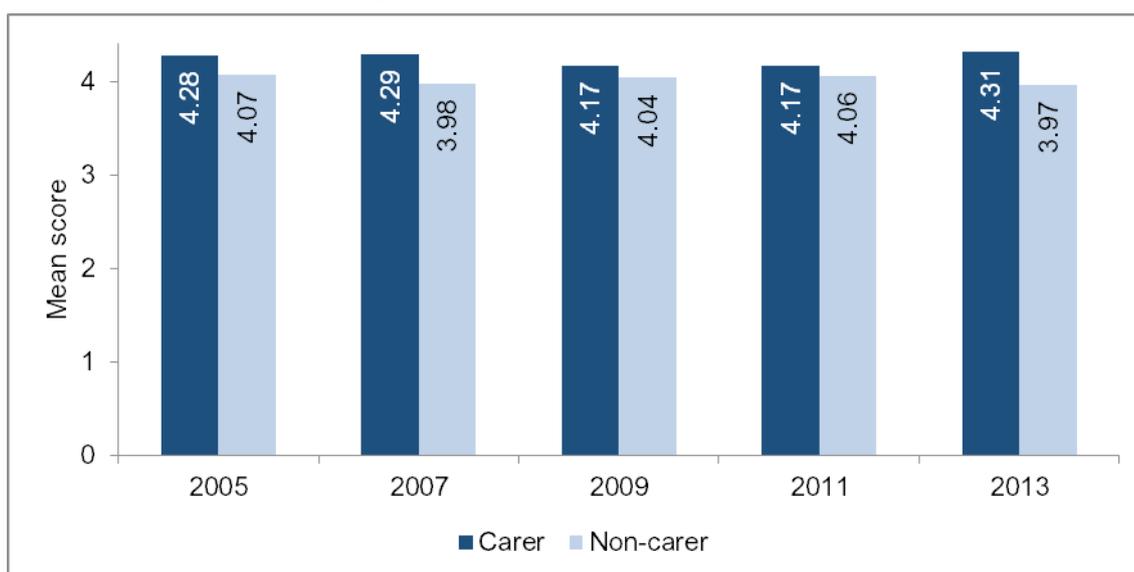
Social Participation

Carers were more disadvantaged on the social participation indicator across all years of data, with this data being statistically significant (Figure 6.5). Nearly half of all carers reported that their social participation was constrained in this way.

Figure 6.5 Proportion of carers and non-carers who get together socially with relatives and friend less once a month or less, 2005–2013
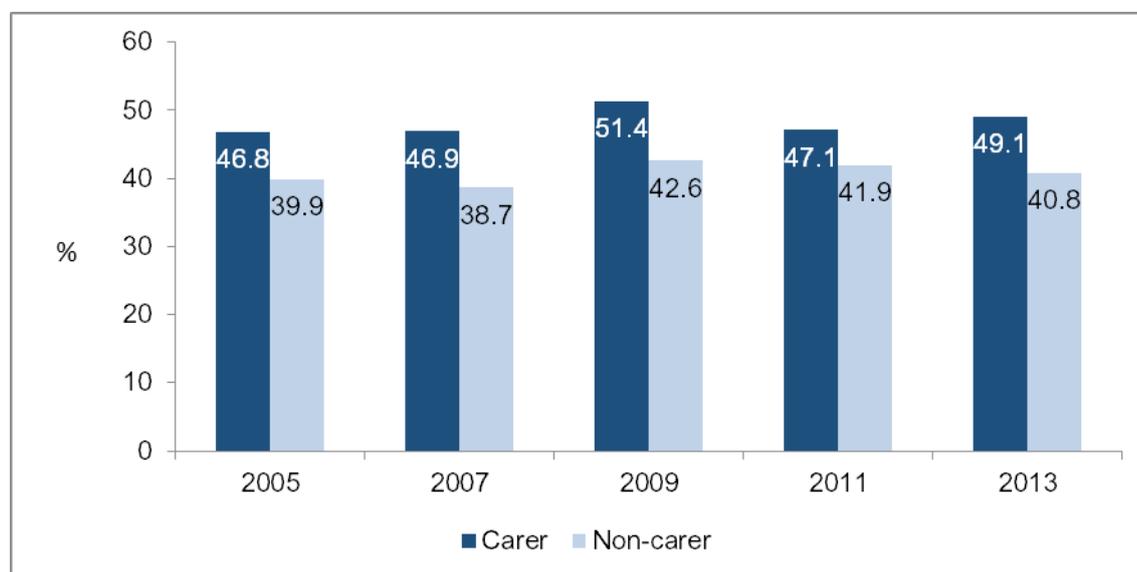
6.2 Resources

The following indicators of resources outlined in Table 6.2 were examined.

Table 6.2 Resource indicators in the HILDA Survey data

Domain	Indicators
Economic resources	• Household income and household wealth less than 60% of median • 2 or more indicators of financial stress • Feels like just getting along, poor or very poor
Social resources	Social support mean score based on following questions: • People don't come to visit me as often as I would like • I often need help from other people but can't get it • I seem to have a lot of friends • I don't have anyone that I can confide in • I have no one to lean on in times of trouble • There is someone who can always cheer me up when I'm down • I often feel very lonely • I enjoy the time I spend with the people who are important to me • When something's on my mind, just talking with the people I know can make me feel better • When I need someone to help me out, I can usually find someone

Economic resources

Carers were more likely to have low income (less than 60% of median total disposable equivalised household income) in all years compared to non-carers. Carers were also more likely to experience two or more indicators of financial stress in all years except for 2007 (Figure 6.6)[19].

Compared to their non-carer peers, female carers are more likely to say that they were poor and also unable to save. Carers, were however, less likely to have high levels of debt compared to non-carers which may be due to the older age of carers.

Figure 6.6 Proportion of carers and non-carers who experienced two or more indicators of financial stress, 2005–2013 (%)
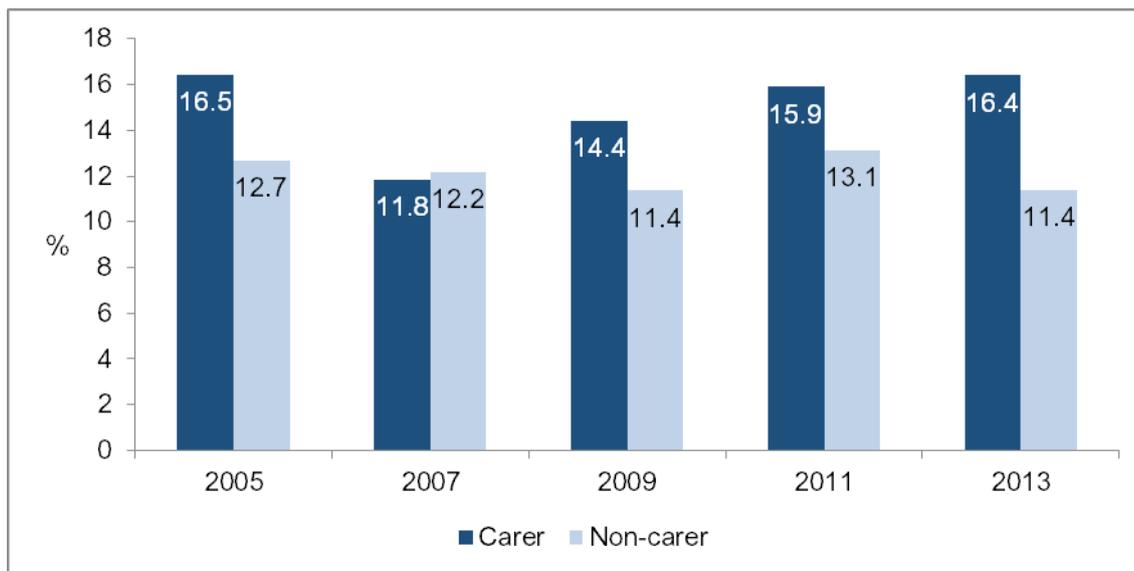
Social Support

Overall, carers reported lower levels of social support and were more likely to have low scores on the social support questions compared to their non-carer peers for all years (Figure 6.7). In 2013, carers aged 25–44 years are the most disadvantaged in terms of social support compared to their peers (Figure 6.8).

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19 Indicators of financial stress include could not pay utility bills on time, could not pay mortgage or rent on time, pawned or sold something, went without meals, was unable to heat home, asked for financial help from friends or family, and asked for help from welfare/community organisations.

Figure 6.7 Carers and non-carer mean score response to level of social support, 2005–2013 (mean score)
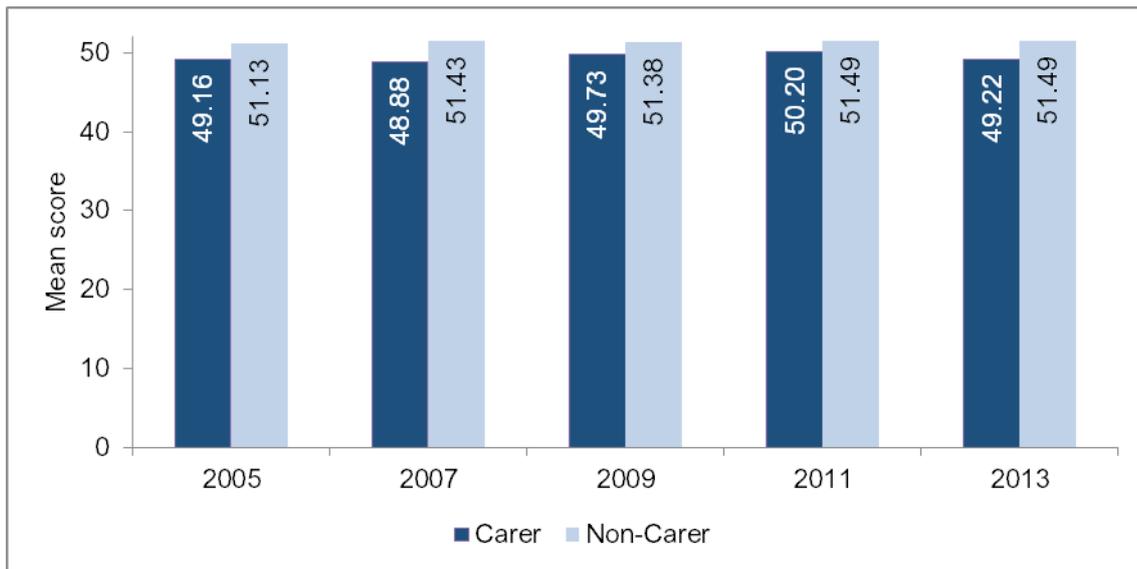
Figure 6.8 Gap between carers and non-carer, social support, by age and gender, 2013 (mean score differences)
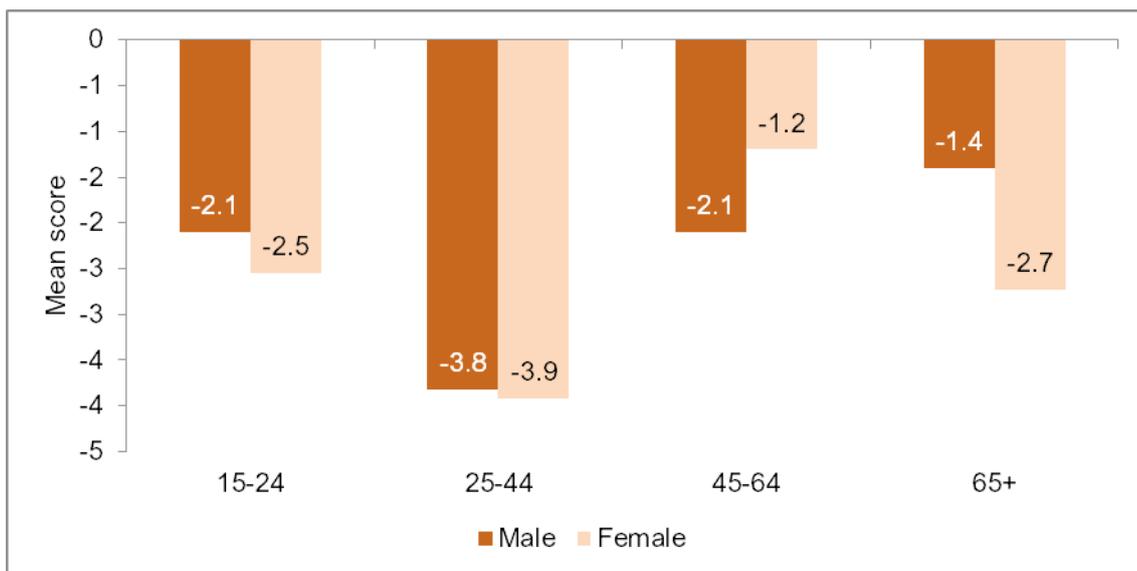
6.3 Quality of life

The following indicators of quality of life in Table 6.3 were considered.

Table 6.3 Quality of life indicators in the HILDA Survey data

Domain	Indicators
Physical health	• SF36 Physical component summary scores
Mental health	• SF36 Mental component summary scores
Stress	• Proportion in high or very high risk categories on the Kessler Psychological Distress Scale (K10)
Self-esteem/ personal efficacy	• I have little control over the things that happen to me There is really no way I can solve some of the problems I have
	• There is little I can do to change many of the important things in my life
	• I often feel helpless in dealing with the problems of life
	• Sometimes I feel that I'm being pushed around in life What happens to me in the future mostly depends on me
	• I can do just about anything I really set my mind to do

Health

For all years, carers are more disadvantaged compared to non-carers across three indicators of health and wellbeing – the SF-36 Physical Component Summary (PCS), SF-36 Mental Component Summary (MCS), and the Kessler Psychological Distress scale. In 2013, both male and female carers aged 25–64 years had lower scores than their non-carer counterparts in both physical and mental health summary indicators (Figure 6.9 and Figure 6.10). Male and female young carers aged 15–24 years had lower scores compared to young non-carers only in the mental health summary indicator (Figure 6.10). Older male carers aged 65 years and above were more disadvantaged than male non-carers in the physical summary indicator than female carers in this age group.

Figure 6.9 Gap between carers and non-carer, SF-36 PCS, by age and gender, 2013 (mean score differences)
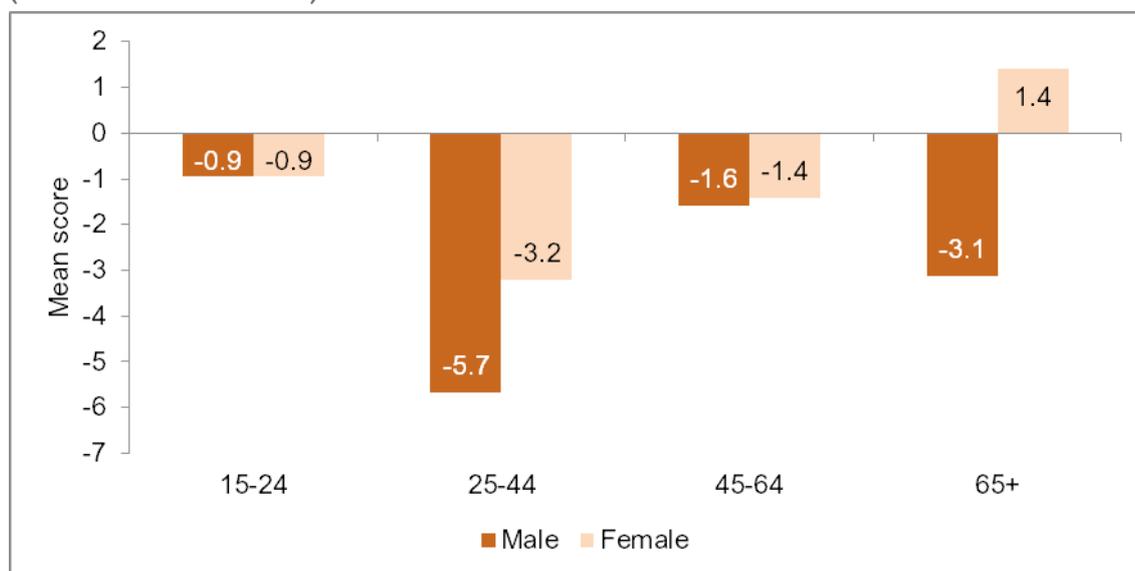
Figure 6.10 Gap between carers and non-carer, SF-36 MCS, by age and gender, 2013 (mean score differences)
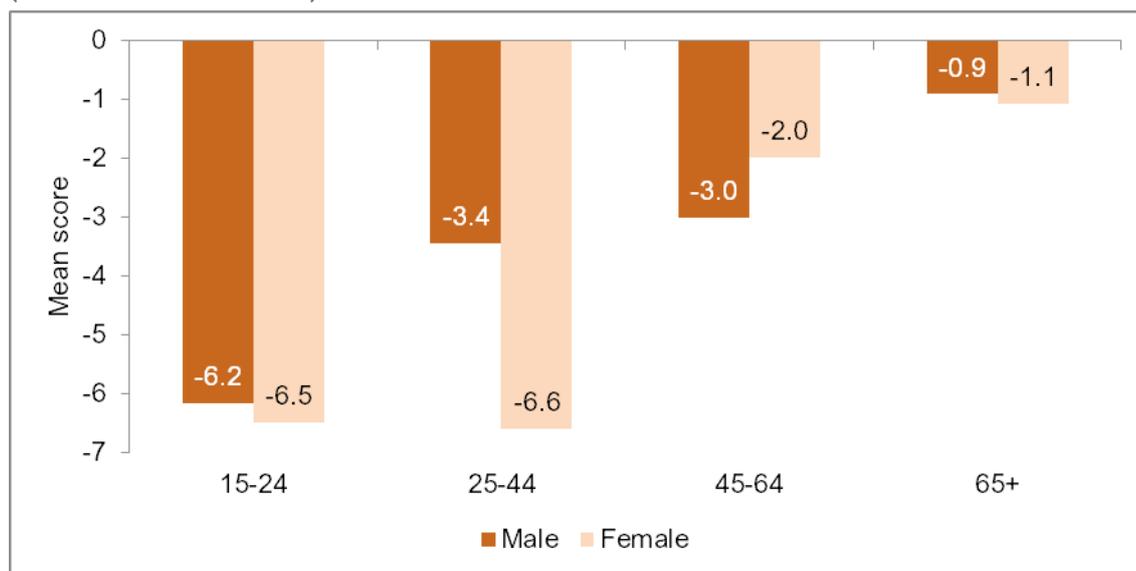
Stress

The analysis of the Kessler Psychological Distress scale indicator shows a statistically significant difference for female carers and non-carers only, with a relatively high proportion of female carers under aged 45 years reporting high levels of stress (42.9 per cent of young female carers aged 15–24 years and 35 per cent of female carers aged 25–44 years).

Efficacy

The indicators in the HILDA relating to sense of efficacy were only available in 2007 and 2011. In both these years, carers reported lower levels of perceived efficacy on all the indicators listed above.

Life satisfaction

Overall, carers report lower life satisfaction than non-carers in all years (Figure 6.11). In 2013, this finding holds for female carers in all age groups, but only for young male carers (Figure 6.12).

Figure 6.11 Carer and non-carer life satisfaction mean scores, 2005–2013 (mean score, scale 0–10)
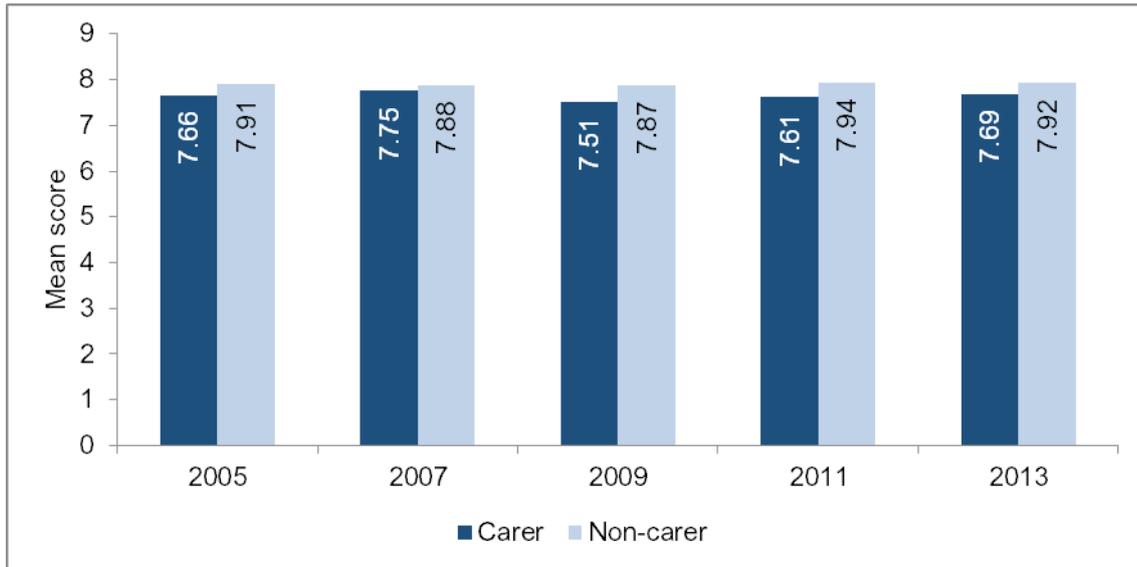
Figure 6.12 Gap between carers and non-carer, life satisfaction mean scores, by age and gender, 2013 (mean score differences)
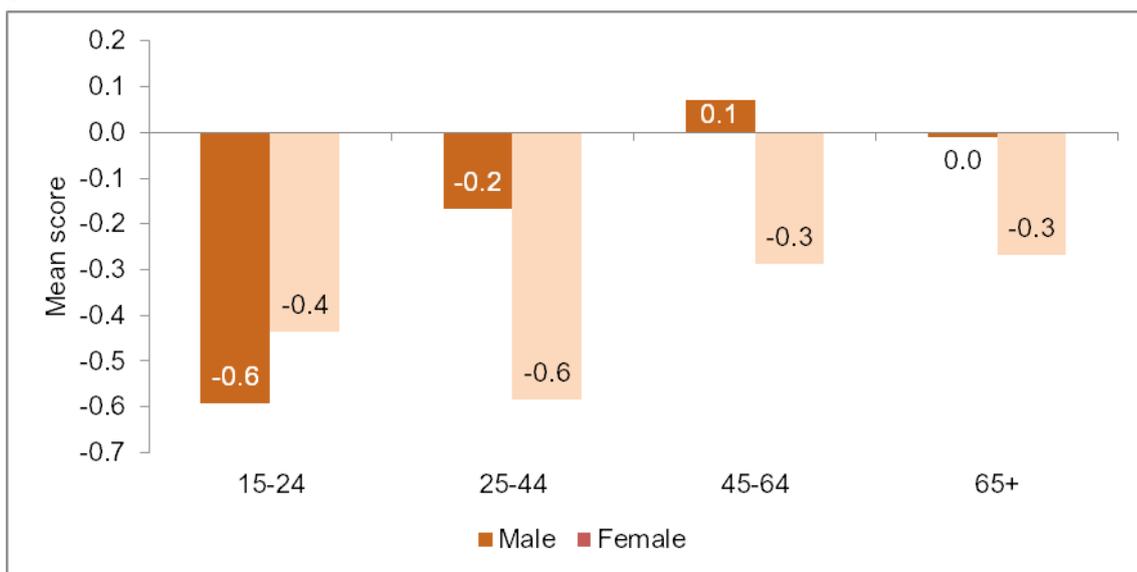
6.4 Additional indicators

Additional indicators based on those proposed in Section 3.5 and outlined in Table 6.4 were also examined to the extent that it was possible in the HILDA survey data.

Table 6.4 Additional indicators in the HILDA Survey data

Domain	Indicators
Quality of participation – time pressure	Always or often feel rushed or pressed for time
Spillover effects	Work family strains and gains indicators for a subsample of carers who are parents in the following domains: • Work family facilitation • Work family conflict • Parenting gains • Parenting
Cumulative effects	• Work history – proportion of time employed since left school

Time pressure

Overall, carers were more likely to say that they felt rushed or pressed for time compared to non-carers in all years from 2005 to 2013 (Figure 6.13). In all years, around two in five carers report time pressure. In 2013, this finding holds when comparing female carers and their non-carer peers. In 2013, female carers over 25 years and male carers over 65 years were more likely than non-carers to feel rushed and pressed for time.

Figure 6.13 Proportion of carers and non-carers who always/often felt rushed for time, 2005–2013 (%)
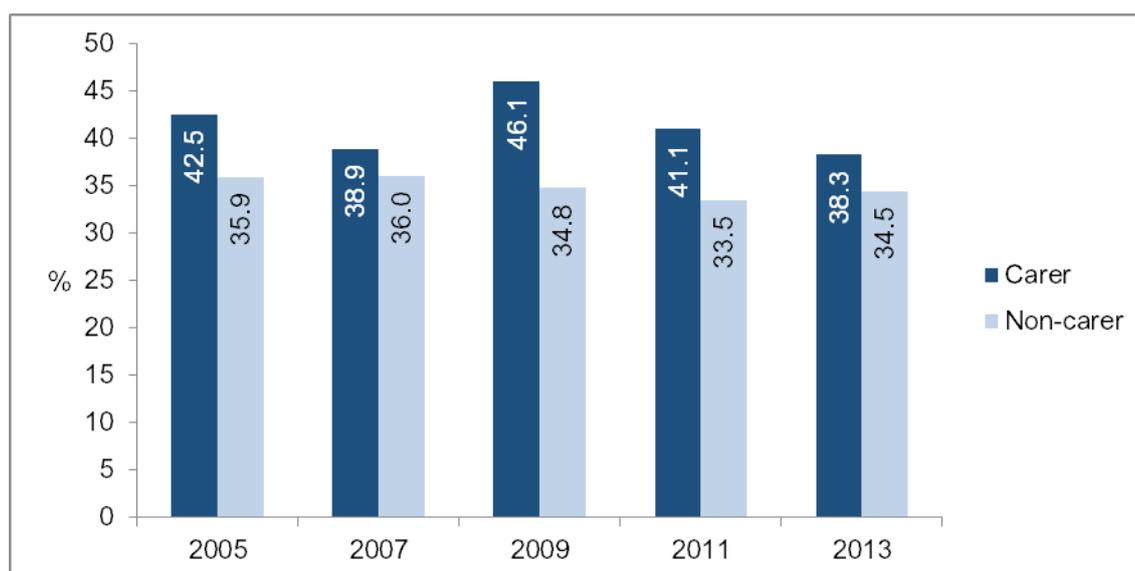
Work/family strains and gains

There were no consistent differences in work/family gains and strains variables for carers who were also parents. However, there could be some suggestion that female carers (who

were parents) report more work-family conflict and male carers report lower levels of work family facilitation.

Effects over time

There were no statistically significant differences overall between carers and non-carers in the proportion of time employed in their work history. Female carers had a lower proportion of time in the labour force than their non-carer peers, which is likely to be explained by caring for children with disabilities.

6.7 Summary

The HILDA data provided the opportunity to explore aspects of quality of economic and social participation, a wider definition of resources (social as well as economic) and quality of life indicators (including physical and mental health, stress and life satisfaction), as well as some of the additional indicators proposed in this report. This panel data also provided the opportunity to consider changes over the time between 2005 and 2013.

Participation

The results show that, after 2009, carers were more likely than non-carers to report wanting to work but being unable to do so (being marginally attached). In all years, carers were more likely than non-carers to be working long hours (over 40 hours per week), but only in 2013 were carers employed full-time more likely to report that they wanted to work fewer hours. Workplace conditions and workplace entitlements were fairly similar for employed carers and non-carers. Key differences in reported job characteristics between the two groups were that carers reported higher levels of stress and lack of time to do everything in their job. Carers were more likely than non-carers to report low levels of social participation in all years.

Resources

Carers had higher rates of poverty and financial stress. The latter finding is most likely to be a result of the combination of low incomes and additional costs of disability and care. Compared to their non-carer peers, female carers were more likely to say that they were poor and also unable to save. Carers were, however, less likely to have high levels of debt compared to non-carers which may be due to the older age of carers. Compared to non-carers, carers – particularly carers aged 25–44 years – lacked social support.

Quality of life

Carers had lower average scores for physical and mental health. The gap between carers and non-carers was greatest on mental health scales for young carers (both men and women) and female carers aged 25–44 years. Females carers aged under 45years were the groups reporting the highest levels of stress. Overall, carers report lower levels of personal efficacy.

Additional indicators

Additional indicators based on those proposed in Section 3.5 were also examined. An

analysis of time pressure, as an indicator of quality of participation, showed that carers experience a greater sense of time pressure than non-carers. The limited data available on work/family strains and gains in the HILDA had inconsistent results, but may suggest that female carers have higher levels of work-family conflict and male carers report lower levels of work-family facilitation.

The findings in this section highlight key areas that impact on carer's social inclusion that need to be addressed: stress in jobs and lack of time at work, lack of capacity for social participation, poverty and financial stress, lack of social support, health, stress and efficacy and lack of time. Additional data on spillover effects and cumulative effect over time should be collected.

7 Research on Indigenous Carers in Australia, New Zealand and Canada
Margaret Raven

The second thematic strand of this project aimed to:

- undertake a comparative analysis of research and policies about carers and indicators of social inclusion in Indigenous communities in Australia, New Zealand, and Canada.

- explore the concepts, meanings, and experiences of informal care and social inclusion for Aboriginal and Torres Strait Islander Australians in urban and regional communities.

- develop indicators of social inclusion for Indigenous carers.

This section (Section 7) summarises findings from the research, policies and programs in Australia, New Zealand and Canada. Section 8 reports on the discussions with key stakeholders in Aboriginal and Torres Strait Islanders communities and Section 9 outlines the proposed indicators of social inclusion.

7.1   Policies for carers and social inclusion

Australia

Launched in 2010, under the previous Labor Government, *A Stronger Fairer Australia* was a key social inclusion policy in operation in Australia until 2013. This policy complemented and supported the reform agenda in Indigenous affairs set out in Closing the Gap (CtG)[16] policy, which aimed at closing the gap between Indigenous and non-Indigenous people in key target areas. The social inclusion policy set closing the gap as its fifth priority (Australian Government, 2009). The fifth priority of the social inclusion policy was driven by three imperatives, which were to:

- overcome decades of under-investment in services and infrastructure

- encourage and support personal responsibility as the foundation for healthy, functional families and communities

- build new understanding and respect between Indigenous and non-Indigenous Australians (Australian Government, 2009).

The fifth priority drew attention to supporting young Indigenous Australians in education and leadership – focused in particular on education and leadership – and programs aimed at parents, carers and community to help young people to engage in education; supporting healthy lifestyles; and improving housing, education, and employment outcomes for Indigenous people.

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16   While CTG was a specific policy framework of the Rudd-Gillard Labour government, some argue that the underlying principles of this framework of emphasising statistical equality is rooted in policies developed through the Hawke-Keating Labor, and the Howard Liberal government (Altman, 2009; Pholi, Black, & Richards, 2009).

The social inclusion policy drew connections with the government's reform agenda on remote service delivery[17] for remote Indigenous communities. Within the third priority on 'reducing the incidence on homelessness', the social inclusion policy also connected to a pre-existing policy[18] on housing for Indigenous peoples in remote communities.

CtG is a framework approach that measures socioeconomic disadvantage of Aboriginal and Torres Strait Islander peoples (Altman, 2009). The *National Indigenous Reform Agreement*, endorsed by the Council of Australian Governments (COAG) in 2008, set out six CtG targets (Australian Government, 2012). Each year the Prime Minister (Australian Government, 2012); Productivity Commission (SCRGSP, 2011); and the Close the Gap Campaign Steering Committee for Indigenous Health Equality (Close the Gap Campaign Steering Committee for Indigenous Health Equality, 2011) produce separate reports on progress towards closing the gap.

Priority four of the social inclusion policy ('Improving outcomes for people living with disability or mental illness and their carers'), did not specifically make mention of Indigenous carers. However, the 2011 *Overcoming Indigenous Disadvantage* (OID) report (produced by the Productivity Commission) recognised that 'Care-givers do not always see care-giving as a burden — carers can draw satisfaction and fulfilment from their role' (SCRGSP, 2011: 4.90). Yet, the report does indicate that the body of research suggests the need for carer support because of stress associated with care-giving.

At the national level, the *Carer Recognition Act 2010* has as its first principle in the Statement for Australia's carers that:

> All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality (Carer Recognition Act 2010 (Cth), Schedule 1).

The Australian National Carer Strategy 2011 aimed to 'give effect to the principles of the *Carer Recognition Act, 2010*' (Australian Government, 2011a). The *National Carer Strategy Action Plan (2011 – 2014)* had six priority areas focused on: recognition and respect; information and access; economic security; services for carers; education and training; health and wellbeing (Australian Government, 2011b). Indigenous carers are specifically mentioned in the action area of priority two – information and access, and in the practical actions under priority six – health and wellbeing.

The second priority sought to 'address the information needs of carers who need particular support such as older carers, young carers, Indigenous carers, carers from culturally and linguistically diverse backgrounds, and carers living in regional, rural and remote areas' (Action 2.2, Australian Government 2011b:14). The strategy sought to do this through the $1.6 million National Awareness Campaign.

The same priority – information and access – also sought to 'educate agencies that are the first point of contact for carers – such as health, community and school-based professionals – about how to quickly link carers with appropriate and relevant information' (Action 2.3, Australian Government, 2011b:14). The strategy sought to, in part, practically implement

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17   The *National Partnership Agreement on Remote Service Delivery*
18   *National Partnership Agreement on Remote Indigenous Housing*

this through the establishment of Aboriginal Liaison Officers (ALOs) through the Helping Children with Autism (HVWA) package (Australian Government, 2011b:14). The Aboriginal Liaison Officers would liaise with HCWA partner agencies, facilitate communication and problem solve with Indigenous organisations and communities, and 'facilitate sharing of effective strategies and products for increasing the knowledge of Indigenous families and communities between HCWA partners' (Australian Government, 2011b:14). Additionally, one of the influencing actions for the information and access priority was to 'consider the needs of Indigenous carers when improving access to disability and mental health supports' (Australian Government, 2011b:15).

Under priority six – health and wellbeing, the second priority direction sought to 'give carers greater opportunities to participate in family, social and community life' (Australian Government, 2011b:29). The practical action for this priority sought to 'expand the National Aboriginal and Torres Strait Islander Flexible Aged Care Program by an additional 200 aged care places to allow more Aboriginal and Torres Strait Islander people with complex high care needs to stay close to their home and country in culturally appropriate care' (Australian Government, 2011b:30).

At the state and territory level, NSW has a Carers Strategy that was developed within framework outlined by the NSW Carers Charter in the *NSW Carers (Recognition) Act 2010*. This charter states that: 'Carers are to be acknowledged and recognised as having their own individual needs within and beyond their caring role. This acknowledgement and recognition is to take into consideration Aboriginal or Torres Strait Islander culture, age, disability, religion, socio-economic status, cultural differences, gender identification and place of residence' (*NSW Carers (Recognition Act) 2010*, Schedule 1).

The *NSW Carers Strategy 2014–2019* has five focus areas: employment and education; carer health and wellbeing; information and community awareness; carer engagement; and improving the evidence (NSW Government, 2014). And the second principle of the strategy states that 'projects will support the diversity of carers including those from culturally and linguistically diverse backgrounds, Aboriginal carers and young carers' (NSW Government, 2014:7).

Aboriginal carers are specifically mentioned in the focus area of information and community awareness of the *NSW Carers Strategy 2014–2019*. In that area the strategy makes a specific commitment to ensure 'information for carers in Aboriginal communities' (Commitment 3.4, NSW Government, 2014:20). This commitment seeks to develop and promote culturally appropriate information for Aboriginal carers. The information resources, as the strategy states, will 'include information on services and supports and tools to assist carers plan ahead and involve other family members in providing care' (NSW Government, 2014:20). The resources will include an emergency care and contacts template for Aboriginal carers, and strategies to encourage Aboriginal people and carers complete wills, powers of attorney and enduring guardianship.

The South Australian carers plan *We Care – Our Plan for South Australian Carers,* was launched in late 2014 (Government of South Australia, 2014). It includes seven priorities: government is an employer of choice for carers; government and government-funded services are addressing the social, emotional and physical needs of carers; carers feel

empowered to make choices within their caring role, and their choices are respected; strategies are in place to address the specific needs of Aboriginal carers; strategies are in place to address the specific needs of young carers; strategies are in place to address the specific needs of carers from culturally and linguistically diverse (CALD) backgrounds; and strategies are in place to support carers in their own right, throughout the caring role and after their transition from the caring role (Government of South Australia, 2014).

The SA carers plan has dedicated priorities to specific populations of people. This is guided, in part, by the SA *Carers Charter* – enshrined in the *South Australian Carers Recognition Act 2005* – that sets out the principles that must guide services for carers. The fifth principle of services in the charter is that 'carers in Aboriginal and Torres Strait Islander communities need specific consideration' (Government of South Australia, 2014:5).

The fourth priority of the SA carers plan is focused specifically on Aboriginal carers. This priority seeks the following four outcomes:

> Outcome 1: Aboriginal carers are consulted in culturally appropriate ways in the development and review of policies and services that affect them.

> Outcome 2: Aboriginal carers' specific needs inform the development and provision of services.

> Outcome 3: Aboriginal carers are supported in the workplace to balance working and caring responsibilities.

> Outcome 4: Supports are available to Aboriginal carers locally in their communities.

New Zealand

The New Zealand social inclusion policy, *Opportunity for All New Zealanders* (Office of the Minister for Social Development and Employment, 2004), was developed by the New Zealand Labour Party and released in 2004. It sought to act as a coordinating framework for sustainable social development, and sat alongside the New Zealand *Growth and Innovation Framework*. The New Zealand social inclusion policy was guided by the vision for:

> An inclusive New Zealand where all people enjoy opportunity to fulfil their potential, prosper and participate in the social, economic, political and cultural life of their communities and nation.

The policy was based on two goals and ten domains of social wellbeing (Table 7.1). The New Zealand social inclusion policy also introduced a number of critical social issues, based on improving educational achievement among low socio-economic groups; increased opportunities for people to participate in sustainable employment; promoting healthy eating and activity; reducing tobacco, alcohol and other drug abuse; and minimising family violence, abuse and the neglect of children and older persons.

Table 7.1 New Zealand Social Inclusion Policy goals and domains

Goals	Ten Domains of Social Wellbeing
• Achieving and sustaining improvements in social wellbeing for all New Zealanders • Reducing disadvantage and promoting equality of opportunity for all New Zealanders	• Knowledge and skills • Employment • Economic standard of living • Health • Social cohesion • Safety • Civil and political rights • National identity • Leisure and recreation • Physical environment

The policy acknowledges actors who contribute to 'social wellbeing' – including families/whanau; neighbourhoods; communities/iwi; community and voluntary sector; private sector; local government; and central government. However, there are clear implications for 'carers' in the family/whanua, whereby the policy describes the family/whanau as:

> **Families/whanau** are responsible for the wellbeing of their members, particularly that of dependent children. While there are and must be exceptions, it is a reasonable expectation that families will, for the most part, 'look after their own'.

This policy indicates a preference for care to be taken on by families. This policy preference may create a burden for families, but will depend on the support provided to the family by the state. Beyond this, the policy is relatively silent on the role of the family/whanau. Rather the policy focuses on the role of the central government's responsibility to sustainable development and equality of opportunity.

The domains of 'employment' and 'economic standard of living' domains are likely to be of particular importance to carers because they seek to, respectively, 'minimise disadvantage in the labour market and enhance the sustainability of employment' and to 'support labour market participation – and help people move into and remain in employment (particularly families with dependent children)'. There are no specific provisions for carers in either of these domains. While there is a discussion on flexible work arrangements, this is focused more on people caring for children.

The *New Zealand Carers' Strategy Action Plan for 2014 to 2018* (Ministry of Social Development, 2014:9), building on the 2008–2013 Carers' Strategy Action Plan, has five objectives focused on whanau, aiga, family and carers to:

1. take a break

2. protect their health and wellbeing

3. provide information

4. improve pathways to paid employment and to support to balance their work, life and caring roles

5. increase awareness and understanding of the carer's role.

While the strategy is not specifically targeted at Māori carers, it does recognise their unique position in relation to other carers, and highlights the overwhelming gendered nature of care. For example, under the guiding principle to 'recognise diversity' the action plan seeks to 'consider the needs of specific groups, eg [sic] young carers and Maori and Pacific carers' (Ministry of Social Development, 2014:10). Under objective three, action 3.2 of the action plan seeks to 'provide information for whanau, aiga and carers at the places where carers visit …' (Ministry of Social Development, 2014:21). Under this action the plan includes 'connecting to networks' that include Maori carers to 'improve access to government information for all carers' (Ministry of Social Development, 2014:21).

Additionally, under objective five, action 5.2 seeks to 'develop promotional information resources about carers and their roles' (Ministry of Social Development, 2014:21). The action plan specifically recognises that:

> Providing information for Mäori may require different approaches, such as effective and meaningful kanohi ki te kanohi (face to face communication) and recognition of the marae as a hub of learning and development. Information will be made available where whänau go, including on Mäori radio and online networks.

Canada

Canada's social inclusion agenda was operationalised conjointly through the notions of 'social cohesion' and 'social inclusion'. In 1998 the Canadian senate requested the *Standing Committee on Social Affairs, Science and Technology* to conduct a study on the impacts of globalisation and technology. The standing committee report, released in 1999, focused *On Social Cohesion*, as a policy response to these influences (Parliament of Canada, 1999). Then in 2001 the Canadian Government sought to explore 'social cohesion' as a policy response for immigration, and released the report *Inclusion for All: A Canadian Roadmap to Social Cohesion* (Government of Canada, 2001). The 'social cohesion' agenda informed policy across a wide range of portfolios[19].

In November 2011 the Canadian senate requested the *Standing Senate Committee on Social Affairs, Science and Technology* 'to examine and report on social inclusion and cohesion in Canada' (Parliament of Canada, 2013: viii). This request continued an earlier study on social conditions in Canadian cities, which was released in the report *In from the Margins: A Call to Action on Poverty, Housing and Homelessness[20]*. The request to examine social inclusion and cohesion was completed in June 2013 as the report *In from the Margins, Part II: Reducing Barriers to Social Inclusion and Social Cohesion* (Parliament of Canada, 2013).

Chapter six of *In from the Margins, Part II* is dedicated to examining social inclusion and cohesion for 'urban Aboriginal Canadians'. This chapter recognises the diversity of Aboriginal Canadians (First Nations, Métis and Inuits), and the differing systems of rights, entitlements and jurisdictional issues that apply to the differing Nations and groups. The chapter also recognised the increasing urbanity of Aboriginal Canadians; lower levels of educational attainment, compared to the broader population; existence and impact of urban Aboriginal gangs; cultural connections for Aboriginal youth; and transitioning from living on

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19   See for example *The Chief Public Health Officer's Report on The State of Public Health in Canada 2008*, in particular Chapter 4 on 'Social and Economic Influences' the section dedicated to 'social support and connectedness' available at: http://www.phac-aspc.gc.ca/cphorsphc-respcacsp/2008/fr-rc/cphorsphc-respcacsp07g-eng.php. See also, for example, the *Report on the Social Isolation of Seniors*, Available at: http://www.seniorscouncil.gc.ca/eng/research_publications/social_isolation/page05.shtml

20   The report was tabled in the Canadian Parliament on December 2009.

reserves to urban centres. Additionally, in a specific discussion on 'economic inclusion', the same chapter recognises the higher levels of unemployment and lower levels of income; that Aboriginal Canadians face barriers to economic inclusion that include racism and prejudice (Parliament of Canada, 2013).

While childcare and foster care (or 'government care') was covered in the report, there was limited (if any) mention of carers or care-givers in the report. A discussion of the role of carers in the report, and specifically the chapters on 'recent immigrants', 'urban Aboriginal Canadians', and 'youth and seniors', highlights the extent to which carers/care-givers are still excluded from policy discussions and development in Canada.

There is a brief possible entry into a discussion on carers in the chapter on 'youth and seniors' where the report makes reference to a submission by Mr Cook, who argues that the State should '… take the money out of hospitals, out of institutions and put it in home care' (Parliament of Canada, 2013:107). In relation to this matter, the report recommends (recommendation 19):

> That the federal, provincial, and territorial governments develop and implement a strategy for continuing care in Canada, which would integrate home-, facility-based long-term, respite and palliative-care services fully within health-care systems. The strategy would establish clear targets and indicators in relation to access, quality and integration of these services and would require governments to report regularly to Canadians on results (Parliament of Canada, 2013:168).

Canada does not have a national carers strategy. The *Canadian Caregiver Coalition* – a network of non-government organisations – introduced the *Canadian Caregiver Strategy* (CCS) in December 2008 (Canadian Caregiver Coalition, 2015). The CCS is guided by the principles of respect, choice, and self-determination for caregivers, and is based on the following five key elements:

1. Safeguard the health and well-being of family caregivers.

2. Minimise the financial burden placed on family caregivers.

3. Enable access to user friendly information and education.

4. Create flexible workplace / educational environments that respect caregiving obligations.

5. Invest in research on family caregiving as a foundation for evidence-informed decision making.

The CCS does not specifically target Aboriginal Canadians, but the *Canadian Caregivers Coalition* suggests that the CCS has contributed to the development and establishment of a number of initiatives, such as the Manitoba *Carer Recognition Act*, the *CareAware* program to raise awareness of Manitoba caregivers.

7.2   Indigenous practices of care: obligations, love and networks

This section explores elements of care discussed in the research literature on Indigenous carers in Australia, New Zealand and Canada. Care is a 'corporeal relation' (Hoppania and Vaittienen, 2015), a 'moral practice' (Kleinman, 2009), a 'moral value' comparable

to justice, or a 'labour of love' (Rummer and Fine, 2012). For Indigenous carers, like non-Indigenous carers, love and commitment are two strong drivers of caring (Wright, 2008). Indigenous carers become carers largely out of family obligation and through default. The Productivity Commission's Inquiry Report on *Disability Care and Support* suggests that Indigenous carers in Australia have a strong cultural belief that is the responsibility of family to provide care and support (Productivity Commission, 2011a). Family carers care for people out of a necessity to keep older people in their community, because older people play a role in keeping family together and in passing on cultural knowledge and language to family (Productivity Commission, 2011a; Smith et al., 2011; Kelly et al., 2011). Not everyone, however, in an Indigenous family provides care. The Australian literature suggests that there are cultural restrictions for some communities on who can care for family members and what types of care they can provide (Palliative Care Australia, 2004).

The New Zealand literature suggests that Maori's with disabilities have strong preference for 'informal care' over formal support systems, and that family obligation plays a role in the caring practices in Maori families (Bevan-Brown, 2012; Collins and Wilson, 2008). Waimarie Nikoa et al. (2004) suggest that many Maori whanau ('family') carers find their way into this role by default. There is, they suggest, a perception held by others of a potential carer having time, being free and able to, and who ought to care (Waimarie Nikora et al., 2004). The New Zealand Carers Strategy, for example, suggests that a Mäori woman is more likely to be a carer than a woman in any other population group in New Zealand, and that Mäori and Pacific peoples are more likely to provide unpaid support than other ethnic groups (Ministry of Social Development, 2014). The same strategy indicates that Maori and Pacific peoples are more likely to be caring for more than one person and across more than one generation (Ministry of Social Development, 2014). This complexity of caring is the result of the average age of Mäori carers being younger than for other groups, and higher rates of severe disability and larger households in Maori communities (Ministry of Social Development, 2014).

In Canada, the literature suggests that providing care was expected, and is a traditional role for women within Aboriginal culture (Crosato, 2007; Parrack and Joseph, 2007). Indigenous women caregivers' experiences, in Canada, occurred in context of the healers, the family, the Aboriginal community and the non-Aboriginal community (Crosato, 2007).

Indigenous carers fulfil an important role. Caring is diverse in nature and facilitates more than just practical aspects of care. Aboriginal and Torres Strait Islander carer roles encompass the provision of care, support for the people they are caring for and the wider community, and 'being attentive' and 'being there' which allows for providing care without being controlling (Hepburn, 2005; Hill et al., 2012; Wright, 2008). Carers traverse a complex landscape of happiness and heartbreak. As Wright (2008:78) argues:

> the unique character strengths involved in caring are not always evident, but occasionally stories are told that offer unique insights into the lives of caregivers that reveal remarkable resilience, strength and resistance. The stories of caregivers are often a mixture of both joy and tragedy.

In the context of caring for someone with a mental illness, the literature for Australia, New Zealand and Canada suggests that care-giving is complex and filled with multiple demands

that can strain relationships, and in some instances the carer is 'sandwiched' between competing demands of childcare and senior care or care responsibilities for a person with a mental illness or disability; which may cause stress to the carer (Collins and Wilson, 2008; Greenstein et al. 2016; Waimarie Nikora et al. 2004; Parrack and Joseph, 2007; Pauktuutit Inuit Women of Canada, 2006). As Wright goes on to argue, while it be difficult and traumatic to care for someone with a mental illness, it can also be transformational for the Indigenous carer and those receiving care (Wright 2008).

In New Zealand, Maori carers provide companionship and personal care, administration of medicine, gatekeepers, advocacy, and community linkages (Waimarie Nikora et al., 2004). Waimarie Nikora et al. argue that caring 'enhances the emotional well-being of the whole whanau (family), ensuring a person with a disability maintains a sense of purpose, independence, dignity, health and connectedness with whanau, hapy and community across the person's lifespan' (Waimarie Nikora et al., 2004:49). Wellbeing, as Bevan-Brown suggest, is interaction of: taha wairua (spiritual side), taha hinengaro (thoughts and feelings), taha tinana (the physical side) and taha wha̅nau (family) (Bevan-Brown, 2012).

Canadian Indigenous 'caregivers' provide ongoing care and assistance without pay to family members and/or friends in need of support (Inuit Family Caregivers Respite Strategy, n.d.). Caregivers also play the role of the conduit to the formal care system to ensure that the care-receiver's basic health care needs are met (Health Canada, 2008; Inuit Family Caregivers Respite Strategy, n.d.).

Policy and statistical definitions of 'carer' have an inclination toward defining one person as a 'primary carer' (for example, the Australian Bureau of Statistics uses the term in its *Survey of Disability, Ageing and Carers* (SDAC) (Australian Bureau of Statistics, 2013).' Yet, defining care as an individual practice, where one person cares for another, risks narrowing the activity of caring in ways that may exclude Indigenous practices of care. Alternative concepts of care could inform policy responses to assist in providing better outcomes for carers. Carers exist as part of a relationship with the people they 'care for' and 'care about' (Ungerson, 2005). While considering the role that individual Indigenous people play as carers, it is also helpful to consider Indigenous caring as 'networks of care' or 'landscapes of care' (Milligan and Wiles, 2010). As Wright argues in the Australian context, 'the experience of care-giving within an Aboriginal context can be a seamless activity involving, individuals, families and communities' (Wright, 2012:107). Additionally, as Biddle et al. (2012:20) argue:

> While the family is traditionally the primary source of care for Indigenous people with disabilities, the extended kinship group and wider community also plays an important role in providing care and assistance. This care can take a range of forms, from informal assistance provided by one person to another, to more formal arrangements in which the community arranges professional care for an individual.

The idea that Indigenous care operates through a 'network of care' is discussed more broadly in the Indigenous care literature. Quinless, for example, argues that Canadian First Nations female teenage lone parent families 'rely on culturally significant "networks of care" to support and care for their children' (Quinless, 2013:3). In that study, Quinless defines 'networks of care' as 'interrelated cultural and social system provided by extended families members and friends to support' teenage lone parents (Quinless 2013:3).

'Landscapes of care', as Milligan and Wiles (2010:740) argue, are 'shaped by issues of responsibility, ethics and morals, and by the social, emotional, symbolic, physical and material aspects of caring'. Considering Indigenous carers, not solely as individuals, but as part of a 'network of care' or a 'landscape of care' will allow policy makers to consider the 'macro and micro-level governance or social arrangements' that can operate at the multiple scales of the international, national, community, family and the interpersonal (Milligan and Wiles, 2010: 738). Considering 'carers' as part a network – that extends through and beyond family, friends and community and interacts with the State (e.g. hospitals, specialists, government services) – may allow for innovation in policy responses for carers that can support them as part of a network, a family or a community.

7.3 Indigenous carers' experiences of services

Indigenous carers' experiences of services vary; however, the literature review suggests some broad aspects that are common to Indigenous carers in Australia, New Zealand and Canada.

1. It is crucial for Indigenous carers to receive access to culturally appropriate and timely information, including information on how to navigate the 'systems' for accessing funding and services (Central Australian Aboriginal Congress Inc., 2011; First Peoples Disability Network (Australia), 2011; Hill et al., 2012; Hepburn, 2005; Hunter and Biddle, 2012; Palliative Care Australia, 2004; Treloar et al., 2014). The capacity to navigate the system, prepare for a crisis or process paperwork in good time is reduced, partly due to the inaccessibility of information, which means that Indigenous carers are often socially excluded from receiving payments or services (Central Australian Aboriginal Congress Inc., 2011; First Peoples Disability Network (Australia), 2011; Hill et al., 2012; Hepburn, 2005; Palliative Care Australia, 2004; Collins and Wilson, 2008; Waimarie Nikora et al., 2004). Treloar et al. (2014), in their NSW study, argued that carers (and patients) described 'confusion about financial assistance programs resulting in the lack of uptake of support for transport, temporary accommodation and housing expenses (Treloar, 2014: 377). Information was instead acquired ad-hoc through family and peers (Treloar, 2014). Lack of adequate information is likely to have a disproportionately larger financial impact on Indigenous carers who have higher levels of receipt of income support. This impacts on the carers' ability to provide transport and accommodation that influences their ability to provide care (Central Australian Aboriginal Congress Inc., 2011; Kelly et al., 2011; Krieg and Martz, 2008; Palliative Care Australia, 2004; Waimarie Nikora et al., 2004).

2. Indigenous carers need to feel that the services they are seeking, and engaging with, are culturally safe (Aboriginal Disability Network New South Wales, 2007). As Treloar et al. (2014:376) argue 'Aboriginal Australians may face exclusionary processes or choose not to engage with these institutions for fear of future negative treatment'. Carers, and the person receiving care face barriers to accessing services due to isolation, lack of services (including specialists and community care), racism, discrimination and intolerant attitudes, language barriers, and the inability of existing services to meet needs of local population (Greenstein et al.,

2016; Krieg and Martz, 2008; Parrack and Joseph, 2007; Teloar et al., 2014). The recruitment, training and retention of staff, who are culturally equipped to work with Indigenous people, the use of interpreters, and more flexible models of service delivery are important steps towards making services more culturally safe for Indigenous carers (O'Neill et al., 2004).

3. There is a need for contribution of Indigenous carers to be recognised by the health and disability system, family members and society (Waimarie Nikora et al., 2004). Service provision is uncoordinated with little involvement of Indigenous clients (or their carers) (O'Neill et al., 2004).

4. Not only is the contribution not recognised, but Indigenous carers may not see themselves as carers as they see that they role they play is just the extension of their parent, spouse, child, or grandparent role (Health Canada, 2008). Carers using services, as a carer, for example may not have their voices heard when advocating for the people they are caring for.

5. Additionally, there is a need for improved communication and coordination among service providers, communities and caregivers (Goldstein et al., 2016; O'Neill et al., 2004). The study by Goldstein et al. (2016:47), on the experiences of Indigenous children with a disability and their carers in northern Australia, for example argued for an approach in which physiotherapists adopt a 'person/family-centred, context-specific approach … [which] involves developing relationships and effective communication skills in collaborative pathways, in which knowledge is understood, shared and valued by both therapist and client'.

7.4 Indigenous carers experiences of caring

The capacity of carers to offer care and support is affected by socio-economic disadvantage, carer's own health problems, family dynamics, and employment (Australian Government, 2011a; Productivity Commission, 2011a; 2005; Hill et al., 2011; O'Neill et al., 2004). It includes a diverse range of aspects such as:

1. Care includes financial burdens for the carer. The higher levels of welfare receipt in Indigenous populations impacts on the ability of Indigenous carers to provide some aspects of care, such as the cost of transport and accommodation (Central Australian Aboriginal Congress Inc., 2011; Kelly et al., 2011; Palliative Care Australia, 2004). This may also influence the ability of carers to plan for their futures such as holiday or retirement.

2. There is, as such, need for adequate financial support available to whanau carers (Waimarie Nikora et al. 2004). For instance, lower income levels make it more difficult to gain access to privately purchased care (Parrack and Joseph, 2007) or pay increased costs associated with transportation (Krieg and Martz, 2008).

3. The rates of chronic illness are high among Indigenous populations. Indigenous carers may also have a chronic illness or mental illness themselves while caring for someone else with a chronic illness or mental illness (Biddle et al., 2012). Governments have both economic and social incentives to supporting unpaid

family carers. Challenges faced by family caregivers include the 'burden of bearing witness to the cognitive and physical deterioration of a close family member, and the associated burden of providing increasing amounts of physical care' (Andrews, 2008:27). Strain placed on carers, whanua, relationships and resources, and the need for social and emotional support (Collins and Wilson, 2008; Waimarie Nikora et al., 2004) increase carer's risk of becoming physically and mentally ill themselves. As such, there is a need for social and emotional, spiritual and ceremonial support for carers or they either become physically and mentally ill themselves, or exacerbate any existing illnesses they may have (Collins and Wilson, 2008; Waimarie Nikora et al., 2004). Such outcomes will affect their capacity to provide care.

4. The support for carers should include the need for time-out/respite from carers' duties, physical strength, transportation and diagnosis (Central Australian Aboriginal Congress Inc., 2011; Commonwealth of Australia, 2011a; Hill et al., 2012; Waimarie Nikora et al., 2004).

5. Care giving has implications for Indigenous carers on their ability to hold a job (Palliative Care Australia, 2004), while also meeting cultural and caring obligations. Caregivers take time away from work to care, which leads to absenteeism and greater strains on employment and general wellbeing (Palliative Care Australia, 2004; Parrack and Joseph, 2007).

6. Due to cultural restrictions on who is able, allowed or expected to play the role of the carer (Crosato et al., 2007; Palliative Care Australia, 2004; Parrack and Joseph, 2007; Waimarie Nikora et al., 2004); it can be difficult to find the 'right' people to care or to share the caring role (Waimarie Nikora et al., 2004).

7. The limited availability of community housing can lead to caregivers being unable to continue to care for a person with disability or chronic illness, resulting in admissions to town-based residential care (Aboriginal Disability Network New South Wales, 2007). There is a need for additional housing options in the community (Aboriginal Disability Network New South Wales, 2007; Health Canada, 2008).

8. Ongoing caregiving (for a person with dementia) results in emotional and physical costs, as families attempt to keep the individual with dementia at home as long as possible. Income levels are lower for Indigenous carers making it more difficult to gain access to privately purchased care (Parrack and Joseph, 2007).

9. Some literature suggested that there was little or no community-based training or education for carers and the community (Andrews, 2008; O'Neill et al., 2004; Walker et al., 2010). Carers could benefit from such training that could assist with, inter alia, early intervention and diagnosis.

10. Dispossession from traditional lands and the history of Indigenous child removal has fractured the networks that once supported those in need of care. This has impacted on the ability of people to care for their families, but also to care for the 'carers' in the family (Palliative Care Australia, 2004).

11. Participation in 'the community' can bring relief to carers and their family, and have positive impacts on carer's personal development, and strengthen family cohesiveness (Collins and Wilson, 2008; Waimarie Nikora et al., 2004).

7.5 Summary

The policies of social inclusion in Australia, New Zealand and Canada focus on opportunity and wellbeing and contain reference to the uniqueness and circumstances of peoples in Indigenous communities. While the social inclusion policies in all countries recognise the need to address disadvantages experienced by Indigenous peoples, the particular circumstances of carers and how their inclusion might be supported are not explicitly mentioned.

New Zealand has an overarching national carer strategy and in Australia there are state-based strategies. All the strategies in Australia have been developed within the framework of respective Carer Recognition Acts and provide for explicit recognition of the circumstances of Aboriginal and Torres Strait Islander carers, although they differ in how they approach the implementation of the principles within the Acts. The New Zealand Carer Strategy also recognises the unique position and information needs of Māori carers.

In Australia, New Zealand and Canada the literature suggests that love, commitment, obligation and sense of family responsibility are key factors underpinning caring in Indigenous communities, and that Indigenous carers fulfil an important role. Caring is diverse in nature and facilitates more than just practical aspects of care. Defining care as an individual practice, where one person cares for another, risks narrowing the activity of caring in ways that may exclude Indigenous practices of care. While considering the role that individual Indigenous people play as carers, it is also helpful to consider Indigenous caring as 'networks of care' or 'landscapes of care'. Considering 'carers' as part a network – that extends through and beyond family, friends and community and interacts with the State (e.g. hospitals, specialists, government services) – may allow for innovation in policy responses for carers that can support them as part of a network, a family or a community.

Indigenous carers' experiences of services vary; however, the literature review suggests some broad aspects that are common to Indigenous carers in Australia, New Zealand and Canada:

- The need for access to culturally appropriate and timely information.
- Culturally safe services.
- Recognition by health and disability systems and broader society of the contributions of Indigenous carers.
- Support for carers to identify as carers.
- Communication and coordination among service providers, communities and caregivers.

The capacity of carers to offer care and support is affected by socio-economic disadvantage, carers' own health problems, family dynamics and employment. Care includes financial burdens for the carer and, as such, there is a need for adequate financial support. Many carers may have chronic illnesses which affect their capacity to care. Carers require support in terms of: access to respite; a job that enables them to balance cultural and caregiving obligations; community housing; and training and education. Dispossession and earlier government policies have impacted on the cohesion and connections of family

and communities. The literature suggests that supporting and strengthening communities and community participation has benefits for carers.

8 Reports on the Stakeholder Consultations with Communities
Margaret Raven

To explore the meanings and experiences of informal care and social inclusion for Aboriginal and Torres Strait Islander Australians in urban and regional communities, two 'yarning circles' were held in South Australia. Through these circles, carers were given an opportunity to talk more broadly about their experiences as carers and were also prompted to by a series of questions. The section below provides an overview of their experiences and responses to the questions.

8.1 How Indigenous people became carers

In the consultations the carers indicated that caring for family members is just something that carers 'naturally' did, or is part of Aboriginal 'culture' and 'way of life' as Aboriginal people. Caring for people with disability, old people, and people with chronic illness or long-term health needs is a part of Aboriginal kinship networks and is not distinct from caring responsibilities for children and other family members, nor is it distinct from 'alternative care'[16]. As some of the participants said:

> Family orientated with our culture it has always been there. It's in our culture.

Indigenous carers became carers through a mix of wanting to care, out of obligations and responsibilities to culture and family, and limited choices, opportunities and alternatives. As one participant said:

> I did it because I wanted to. You know, if you're needed you're needed.

In some cases Indigenous people took on the carer role because there was no-one else in the family who could care, no-one else wanted to do it, and they knew that someone had to provide care. As one participant indicated:

> How most carers came about to being a carer is because most of the time they're pushed into it because they're seen as well, that's your family. You deal with it'. And there's no one else around to … Yeah, they might do it out of love, you know. They see there's a family obligation. But, you know, most of the time carers are put, you know, pushed into it basically.

8.2 Recognition as a carer

Indigenous carers do not always recognise themselves as 'carers'. The role they play, as they indicated in the 'yarning circles', is part of their normal role as spouses, parents, grandparents, children, sisters, brothers and friends. As two participants said:

> We don't call it caring. That's part of our culture.

16   The term 'alternative care' was given by the carers in the discussion as an alternative term to 'foster care'.

> Some of them don't even recognise they're carers because of the marriage vows 'till death do us part'.

The term 'carer' is also a term that the Aboriginal carers themselves said that they do not always identify with. The Aboriginal carers suggested that the term comes across as a very medical term, and not one that Aboriginal people readily and easily identify with. For instance, they suggested that some Aboriginal people who care for their grandchildren more easily identify with the term 'grannies'.

When Indigenous carers have recognised themselves as 'carers', this has occurred through a 'facilitator' or another person (e.g. a service provider, a family member, a stranger in the shops) pointing out that the relationship we have to the people we care for would be considered as a 'carer' role. As one participant indicated:

> A lot of people that we meet and we say 'oh you're a carer', 'no I'm not', and you go 'you are'.

8.3 Who we care for and what we do as Aboriginal carers

Aboriginal carers care for people in their families who have disabilities, chronic illness and long-term health needs, mental illness, and who are elderly. This includes children, parents, in-laws, spouses, grandchildren and grandparents. Some of the carers indicated that they also take on the carer role for more than one person at a time, or are in carer arrangements where people are carers for each other.

Aboriginal carers play a large number of roles from household chores to transport, filling in paperwork, decision-making, monitoring changes, being on-call and protecting the care-receiver. As the participants indicated:

> I care for my son … he lives on his own. I'm forever telling him … because he lives in a rental they can kick him out any time, that sort of thing. I mean he's not dirty, dirty, but he just doesn't put things away.

> She does rely on mum and dad to – to do things now because she can't. Like, they've taken her licence away. So, no, mum and dad now have to transport her if she needs to go to medical appointments or just, well basically go anywhere you know.

> When it's a family member, you don't expect them to go and apply for Centrelink because that's to get assistance. But then when the carers do go to get assistance it's the written role … and they get told, 'Fill in this paper'. Don't ask whether or not you can read and write. 'Are you able to fill this form in'".

These roles are ongoing and do not stop when someone reaches a milestone (such as turning 18 or reaching retirement age). Each of these roles requires a certain level and kind of knowledge and skills (e.g. how to change dressing, medications) and includes the ability to be able to navigate conflict (e.g. with family members, service providers and the care-receiver). As one participant indicated:

> I still go to the doctors with him because I need to know what's going on. I need to know that he understands what they're saying. So it doesn't stop.

The more recent move by Centrelink to move service delivery to an online model, as discussed in one of the 'talking circles', is likely to adversely impact carers with lower levels of general literacy and computer literacy.

8.4   How has the carer role affected the lives of Aboriginal carers?

Being an Aboriginal carer is both rewarding and challenging. Aboriginal carers have opportunities to care for the people they love, and spend time with those they care for.

Being an Aboriginal carer is rewarding, and as the Aboriginal carers indicated, it affords them opportunities to spend time with the people they are caring for. In their carer roles they get to know the people they care for very well. They come to understand and know their feelings, goals, aspirations, and dreams for their own lives. Being an Aboriginal carer is also healing, because it gives Aboriginal people opportunities to spend more time with their families and to pass on and receive cultural knowledge.

Being an Aboriginal carer also has challenges. The participants indicated that some of them had to leave school to care for their relatives, and this has had longer-term impacts on their education.

Some of the carers had to give up employment in order to care for the people they love. Many of the participants indicated that they come from large families and navigating the responsibilities and obligations to care for someone within their family also brings with it conflict and complex challenges.

Being an advocate for the people they care for can be difficult and time-consuming when they are faced with situations, services and individuals who do not understand what it means to be a carer and the responsibilities they have to the people they care for, or where racism exists, which means that carers cannot have their voices heard and accepted.

Participants commented that negotiating with family, service providers and government can be tiresome. Watching some of the changes and how they impact on them, as the participants indicated, can be worrisome, and it makes them tired and sick. When funding is cut to carer and disability support, such as to respite care, then they do not get time out to look after themselves. Without adequate support some of the carers are choosing to give up their roles as Aboriginal carers. As one participant said:

> What's happening is a lot of people are thinking about relinquishing their care of their people that they're looking after because they don't have the support structures and they don't have the financial backing.

Additionally, as the carers discussed, if a carer is receiving a Centrelink carer payment there are restrictions on how much time-out they can take. As one of the participants indicated:

> Being a carer, too, you're only allowed so many hours away from that person. I think you're only allowed what, four hours away … and yet when you look at if you had a doctor's appointment for yourself on some occasion there's four hours gone just there, depending on the doctor you've gone to see, you know. So there's your time gone. So don't worry about doing shopping in that four yours, you know, that week or that you know, or anything else because your four hours has gone.

For young Aboriginal carers, the policy associated with carer payments can adversely impact their education. As two participants said, based on experience and perception:

> It's the same for young carers. Young carers, now, they should be at school. They should be at school full-time. But if they care for somebody they – and because, I mean, they have to apply for Centrelink payments. They have to. Being a young carer they actually meet the criteria. However, they're not allowed to attend school full-time. They can't do anything. They can't go up and say, 'I'd like to go away for a couple of days', because they definitely don't have anybody there. That's the reason they're being a young carer.

> For young carers, caring responsibilities can impact on schooling, and it can be difficult for young carers to speak up and have their needs met.

Lastly, the carers indicated that caring is not distinct from healing. Aboriginal carers carry trauma that is the direct result of colonisation. In their roles as Aboriginal carers they are faced with the challenges of supporting people who carry trauma, while also trying to heal their own trauma.

8.5 What things do Aboriginal carers do outside of their caring roles?

Many of the Aboriginal carers in the 'yarning circles' indicated that they had limited opportunities to do things outside of their caring roles. Some of carers said that they had have no activities outside of their caring roles, and found it difficult to find time away for themselves. As one care-receiver said:

> If she wants to go around and see them we can't because I – I have to go with her. If I don't want to go with her, well, she can't go. That's what sort of, you know, ties you down kind of thing.

For the carers who did do things outside of their caring roles, they indicated that they attend 'carer support groups', spend time with friends and relatives, or engage in other activities such as painting, playing lawn bowls or spending time playing pokies.

Lastly, for some of the carers attending a 'carer support group' was the only thing that they did outside of their caring roles. But the support groups did not work for everyone. As one participant indicated:

> We do the retreats where we take them for a week … You know, they go away and they relax. They do basically what they want to do, but the staff are there to support them. But it still doesn't fit everybody … some can't go because they just won't leave the caree – because they don't want to be in that situation, or you know, relying on others or they haven't got the assistance there to do it, you know.

The participants at the 'yarning circles' indicated that 'carer support groups' are important for Aboriginal carers because they provide opportunities to meet with other Aboriginal carers, to hear about changes to carer and disability policy, services and funding (such as the introduction of the NDIS , changes to aged care and state funding of carer support services), and to discuss and share some of the challenges they each face as carers. Carer

support groups also give them opportunities to meet with like-minded people and share some of the great things about being a carer.

8.6   Who helps Aboriginal carers in their caring roles?

In their role as Aboriginal carers, the participants indicated that they get support from families, friends and neighbours, and the people they are caring for. They rely on their families to assist with household chores or look after the care-receiver, which allows them to do other activities, such as shopping.

The Aboriginal carers suggested that their families and friends support them emotionally through being available to talk on the phone when they need someone to talk to, or taking over some of the responsibilities of their carer role to give them some personal time.

For some carers, with strong relationships with their neighbours, they indicated that their neighbours also support them through watching out for them, or checking in with them to make sure that they are okay.

Aboriginal carers also indicated that they get support from government and other service providers, such as carer and disability support organisations, which support them with respite or through providing home cleaning services.

Lastly, there were some carers who indicated that they received no support. For the most part, they undertook all of the caring responsibilities and received no support from family, friends, government or service providers.

8.7   What is important for Aboriginal carers?

Carers were asked specifically what is important for them as Aboriginal carers, and what would they like to tell the government. Their responses were broad in nature and included (in no particular order) the following points:

1.   It is important that governments recognise the roles that Aboriginal carers play in caring for their family members, and cost-savings that this role brings to the government.

2.   Human rights should be upheld and respected. Carers need their human rights to be upheld and respected, which includes the right to adequate housing and health care.

3.   Ongoing and continuous funding for Aboriginal carers support groups and services, which provide carers with the opportunities to meet other Aboriginal carers, discuss how they can care for the people we love, and to learn more about changes to government policies, programs and funding that affect us. This includes the need for appropriate counsellors, respite, and appropriate education programs to support carers who are providing full-time care.

4.   Carers need support in their caring roles, such as assistance with household chores and respite for the people we are caring for. They need opportunities to engage in activities outside of their caring roles, and support with some of the caring responsibilities to allow this to happen. This type of assistance provides them, as

carers, with opportunities to strengthen their own social and emotional wellbeing. This enables carers to continue to provide the much needed care that their family members need. The participants also indicated that they need support with how to work through their own trauma, and the trauma of the people they are caring for.

5. For carers located in regional and remote locations, services need to understand that some Aboriginal carers have to drive long distances to access them, and this takes time and money. In addition, the criteria for funding to support carers in regional and remote areas needs to take account of the extra costs associated with caring 'out here'. As some of the participants indicated:

We went to an Aboriginal hostel in Adelaide. The next time we went down that wasn't available and we went to the cancer research place on North Terrace and we got – it cost us $80 for two. We got back $60. Then you've got your meals. They don't give you everything everybody else has got, which is understandable. But they don't give you what you lose; you're out of pocket expenses.

It's, like $184 every time we go to the doctor ... So you've got to fork out all this money.

Yeah, but this is through the hospital now. This is Medicare Local through the hospital, will assist but you have to meet their criteria. And if you don't meet their criteria then you don't get assisted. But then when they do assist you, you only get a certain amount.

And they don't care in Adelaide, you know, they don't think you've got to drive three hours to get there so you can go early.

6. Advocates are needed – people who are employed on full-time and on an ongoing basis, who can advocate for Aboriginal carers, and assist carers with advocating for their own rights and needs.

7. Aboriginal carers have their own needs as carers. They need to be able to access affordable health and dental services.

8. Access to information about changes to policies, services and funding. In order to make informed decisions about the choices before them, Aboriginal carers need timely access to information about proposed changes to Aboriginal, carer, and disability policies, services and funding.

9. There are a lot of layers to being a carer. Government and service providers need to listen to Aboriginal carers when they devise and implement policies and programs that will impact directly upon them, or the people they care for.

10. Some of the participants indicated that increasing the number of volunteers may provide support for Aboriginal carers. Many Aboriginal people want to become volunteers, but for some, with criminal records from the past, this is difficult. They indicated that there needs to be an easier process that can still provide the adequate checks and balances, for Aboriginal people to become volunteers. As two participants indicated:

Make it easy for volunteers to be brought in. Because as an Aboriginal person it's very daunting to come in and fill all that paperwork in, you know. Then we have to – then

they have to do have a police check done. The minute you say police check, 'No don't worry about it. Not going any further'. But it's having, you know, a volunteer come in whose Aboriginal to be able to help hang your washing out or, you know, do your gardening, you know, mow your lawn for you.

And it's the carers who want to be able to become those volunteers because they've been to us. Especially the past carers. They've been there, they've done that. They know, you know, they've worked that, well, not worked, in it, but they've – the person that they cared for were in that same situation. So bringing them in as a volunteer to support them as a carer would be great.

11. Government needs to set the relationship right between Indigenous and non-Indigenous peoples in Australia. The participants in one 'yarning circle' suggested the relationship could be reset through a treaty, which sets out the rights and responsibilities that the State has for Indigenous Australians.

9 Indicators of Social Inclusion for Aboriginal and Torres Strait Islander Carers

Margaret Raven

This section outlines indicators of social inclusion as developed from the policy and literature review and consultations. Any attempt to establish indicators of social inclusion for Indigenous carers must be based on the views and needs of carers. As a starting point, some of these indicators could include: recognition as a carer, health and wellbeing of the carer, and access to culture and heritage.

9.1 Recognition as a carer

Some Aboriginal and Torres Strait Islander people take on the role of caring for others, but do not see themselves as being carers[16]. This means that some carers can miss out on services and workplace provisions (e.g. carers leave), which are specifically available for carers. In a similar way, some services, workplaces, family members and friends, and communities may not see the role they play as a carer. This means that they may be not receive the support they need, or may not be able to participate in things which gives them meaning. Indicators could include: self-recognition as a carer, and recognition as a carer by workplace, family and friends, community, and services.

9.2 Health and wellbeing

The health and wellbeing of Aboriginal and Torres Strait Islander carers can impact on the ability to care and the ability to participate in other areas of life. Indicators could include social, emotional, physical and spiritual health and wellbeing.

16   NSW Government. (n.d). Hidden Carers. The Definition. Department of Health, South Eastern Sydney Local Health District. http://www.swslhd.nsw.gov.au/Carers/content/pdf/HiddenCarers.pdf

9.3 Culture and heritage

Some Aboriginal and Torres Strait Islander carers have indicated that culture and heritage are important aspects for them, and for the people they are caring for. Some possible indicators for this could include: relationships with country; access to cultural events; access to traditional language; participation in life of the family, community and relationships with friends; and balancing cultural responsibilities and obligations with own life aspirations (hopes and dreams).

Country

Language

Culture and heritage

Cultural events

Family and community

9.4 Services

The ability to access services that are culturally safe, with appropriately trained staff and culturally appropriate information can impact on the ability of Aboriginal and Torres Strait Islander carers to provide care. It can also impact on the ability of carers to participate in the broader fabric of society. Some possible indicators for this area could include: culturally appropriate information; cultural safety (experiences of racism or discrimination; appropriately trained staff); access to, and availability of, services; and availability and use of interpreters.

Information

Access to, and availability of, services

Services

Cultural safety

Availability of interpreters
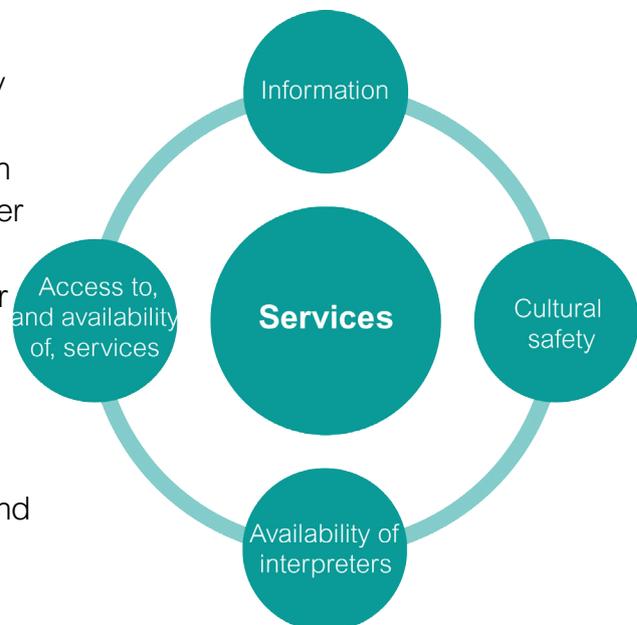
9.5 Education and employment

Being a carer provides opportunities for social connectedness. However, caring may also create barriers to education and employment. Some work places are able to provide flexible work arrangements, while others do not. Some possible indicators include: flexible employment arrangements; community-based education; access to education; and completion of education.

Employment

Education and Employment

Community-based education

9.6 Resourcing

Carers need sufficient resources to be able to take on a caring role and to support the person they are caring for. Some potential indicators include: financial costs of caring (ability to provide care within current income levels); making plans for the future (savings, holidays); access to adequate transport and housing.
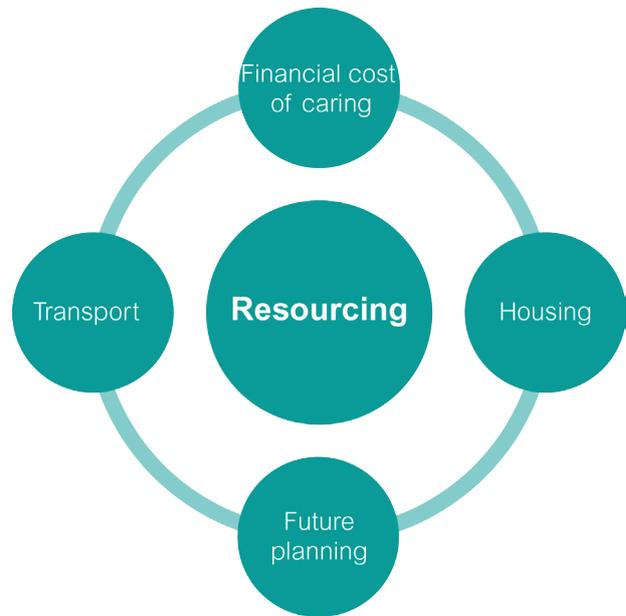
10 Comparative Policy Analysis
Bettina Cass, Sue Yeandle and Trish Hill

Informal care provides the infrastructure that is essential to the care and wellbeing of people who have a disability, or are frail due to ageing, in Australia and England. In both countries the need for care will increase due to the population demographic changes and the preference for independent living in the community. This section outlines policies in Australia and England that support or affect the capacity of carers to continue their role and to be socially included in a range of other activities. Such policies encompass income support, recognition and rights legislation, community and social care support services, social inclusion policies, shifts to consumer directed care, workforce and labour force measures.

Policies that support carers were identified through reviewing key literature and policy documents in Australia and England to identify any policy insights for the Australia context. England has a longer history than Australia of legislation and policies that might support genuine choice for carers to participate in multiple roles, yet also faces different challenges to Australia.

As well as national level policies, States and Territories in Australia, including NSW and SA, also have specific legislation and policies to recognise and support carers. For example, NSW and SA have Carer Recognition Acts. The NSW Act establishes the NSW Carer Advisory Council. NSW also has a Carers Strategy and SA has a Plan for South Australian Carers outlining key policies priorities for carers and both states recognise carers as 'partners in care'. The focus of this study is on national level legislation and policies and differences.

10.1 Policies for carers in Australia

The Australian Census identified 1.9 million carers in 2011 and 1.6 million in 2006. The Census question and collection method of self-completion are likely to lead to an undercount of carers. The ABS *Survey of Disability, Ageing and Carers* (SDAC) has a more comprehensive method for identifying carers. This survey identified 2.7 million carers in 2012 (12 per cent of the population), and 2.6 million in 2003 and 2009 (ABS, 2014; AIHW, 2015). The SDAC identifies primary carers, who are defined as the group who provide the most assistance to a person with a core activity need for assistance (ABS, 2013, Glossary). In 2012 and 2009, the SDAC identified around 770,000 primary carers in Australia (ABS, 2014). Women comprise the greater number of primary carers: in 2012, 537,000 women and 233,000 men were identified as primary carers (ABS, 2014).

10.1.1 Income support for carers

While carers in Australia may be eligible for a range of income support payments, the dedicated payments for carers to maintain their income while caring include: Carer Payment;

Carer Allowance (Adult), Carer Allowance (Child), and Carer Supplement (Australian Government Department of Human Services, 2016a; Australian Government Department of Social Services, 2015a). Other payments include the Carer Adjustment Payment, and the Child Disability Assistance Payment (Australian Government Department of Human Services, 2016a).

In 2014–15, there were 255,542 recipients of Carer Payment, which is a 15.1 per cent increase on the number of recipients (221,954) in 2012–13 (Australian Government Department of Social Services 2015a: 50, Table 4.19). In 2004–5 the number of carer payment recipients was 95,446 (FaCS 2005: 212) (a 167.7 per cent increase over the decade). In 2014–15, the number of recipients of Carer Payment represented 33.1 per cent of primary carers (Australian Government Department of Social Services 2015a: 50, Table 4.19)[16].

The basic rate of Carer Payment for an individual until March 2016 was $788.40 per fortnight (equivalent to the Age Pension) (Australian Government Department of Human Services, 2016b:13). Carers may work, study or train for up to 25 hours per week and remain eligible for Carer Payment. Carer Payment is more similar to age pension than other income support payments for people of working age in terms of rates, income and assets testing, and it does not require an activity or work test.

Even though recipients may work (study or train) for up to 25 hours per week, only 9.8 per cent of recipients of Carer Payment reported employment income in 2014–15 (and 10.1% in 2012–13) (Australian Government Department of Social Services, 2015a:50, Table 4.19). In addition, only 24.6 per cent of recipients were on part-rate of payment due to the means test in 2014–15 (25.1% in 2012–13) (Australian Government Department of Social Services, 2015a:50, Table 4.19), indicating the difficulties faced by carers in sustaining employment while meeting their caring responsibilities.

Carer Allowance is an income supplement paid to people 'who provides daily care and attention at home to a person with a disability or severe medical condition' (Australian Government Department of Human Services, 2016b:19). In March 2016 the basic rate of payment was $123.50 per fortnight (Australian Government Department of Human Services, 2016b:19). In 2014–15, there were 601,364 people receiving the Carer Allowance (including both those caring for an adult or a child) (Australian Government Department of Social Services 2015a:50, Table 4.19). The number of recipients in 2014–15 was approximately 6.7 per cent higher than the number of recipients in 2012–13. In 2004–05, 339,478 people received Carer Allowance (233,332 CA (Adult), 102,535 CA (Child), 3611 CA both) (FaCS 2005:211). In 2014–15, the number of recipients of Carer Allowance represented 78.1 per cent of primary carers based on the number of primary carers identified in the ABS SDAC 2012. (Australian Government Department of Social Services 2015a:50, Table 4.19).

Carer supplement is 'an annual, non-indexed, lump sum payment … paid to recipients of Carer Allowance and Carer Payment[17] which is not income or asset tested (Department of Human Services, 2016b:19). Carer Supplement is paid at the rate of $600 for each person being cared for (Department of Human Services, 2016b:19). In 2014–15 there were 614,815

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16 Based on as number of primary carers estimated in the SDAC 2012.
17 As well as to recipients Wife Pension with Carer Allowance, DVA Carer Service pension, DVA Partner Service Pension with Carer Allowance) (Australian Government Department of Human Services, 2016b:19)

recipients of Carer Supplement, an increase of 6.4 per cent since 2012–13 (Australian Government Department of Social Services 2015a:50, Table 4.19).

Although eligibility for income support, in particular Carer Payment, with the augmentation of Carer Allowance and Carer Supplement, is crucial to the financial wellbeing of carers and the people for whom they care, the small proportion of recipients of Carer Payment who earn extra income from employment has raised concerns. Key issues noted by a number of sources are the restrictions on the number of hours (currently 25 hours) that carers may engage in employment, education or training and the interaction of this criteria with the means test (Australian Human Rights Commission, 2013:45; Carers Australia, 2013b).

Carers Australia has highlighted the differences between the definition in the *Social Security Act 1991* of 'constant care' and the policy guidelines provided by the Department of Social Services on the amount of time a carers may 'cease to care' in order to remain eligible for the payment (Carers Australia, 2013b:9–10). The concerns about the impact of the time restriction on carers' capacity to remain engaged in education or attached to the labour market and maintain an adequate income has led to calls for greater flexibility in the guidelines (Australian Human Rights Commission, 2013:46: Carers Australia 2013b).

Concerns have also been voiced about the sustainability of the Carer Payment, with the National Commission of Audit (2014) noting that 'the number of Carer Payment recipients has been growing at 12 per cent each year in the last decade', and calling for better targeting and a review of the eligibility criteria for Carer Payment, income testing the Carer Allowance and limiting the Carer Supplement (Australian Government National Commission of Audit, 2014:142–144). The Department of Social Services is currently undertaking a review of the assessment process for Carer Payment and Carer Allowance, focusing on the 'care-related qualification criteria' and the findings of this review will be implemented in January 2018 (Australian Government Department of Social Services, 2016a).

10.1.2 Recognition and rights legislation

In October 2009 (AIHW 2011:208) Australia introduced a National Carer Recognition Framework, which encompassed recognition legislation and a national strategy including:

- The *Carer Recognition Act 2010 (Cth)*, which contains the Statement for Australia's carers which outlined 10 principles including that 'carers should have the same rights opportunities and choices as other Australians' and that 'carers should be acknowledged as individuals with their own needs in and beyond the caring role' (Commonwealth of Australia, 2010:9). The Act outlines how carers should be treated by public service agencies and providers. As noted by Phillips and Magarey (2010), 'it does not create legally enforceable obligations', although they also note that 'it is arguable that public service agencies will seek to comply with the Bill's provision'. While the statement on carers acknowledges carers have their own needs, it does not provide carers with the right to an assessment of their own capacity and needs (Australian Human Rights Commission, 2013:34–35).

- National Carer Strategy 2011 and the subsequent National Carer Strategy Implementation Plan and the National Carer Strategy Action Plan (2011–2014).

- A national awareness campaign, *Care Aware: National Carer Awareness Initiative*, which was launched in 2012 as part of the Action Plan to promote recognition and respect.

The absence of the right to assessment of carers' needs in Commonwealth legislation is a significant issue because there remains inadequate emphasis on carers' risk of exclusion from full participation in the normal activities of society, which includes evidence of the 'triple penalty' imposed on carers – poorer health, poorer financial circumstances associated with constraints on remaining in and sustaining labour force participation, and social exclusion from participation in social networks (Yeandle et al., 2007a,b; University of Leeds et al., 2014).

Carers are also recognised in other legislation:

- The *Fair Work Act 2009 (Cth)* and the National Employment Standards (Fair Work Act ,2009) provides for paid carers leave and the right to request flexibility.

- The *National Disability Insurance Scheme Act 2013(Cth)* (NDIS Act) has changed the funding arrangements for support services for people with disability, and outlines principles which include that 'the role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected' (*National Disability Insurance Scheme Act 2013 (Cth)* s4.12).

- Provisions within the *Disability Discrimination Act 1992 (Cth)*, which protect again discrimination on the basis of having 'an associate with a disability' (Australian Human Rights Commission, 2013: 33).

- Provisions within the *Sex Discrimination Act 1984 (Cth)* which protect against direct discrimination on the basis of family responsibilities. However, family responsibilities are restricted to 'immediate family members' (Australian Human Rights Commission, 2013:33).

10.1.3 Services for carers

Services in Australia include carer-specific services, such as information, training and respite services provided within the NDIS to people with disability, and aged care services. Significant reforms to the aged care and disability sectors have been occurring and the impact of these reforms on supports and services available to carers is yet to be fully determined. This section outlines some key developments.

Aged care reform

The reforms to aged care were developed after the Productivity Commission (2011b) report *Caring for Older Australians*. In 2012, the Government response to this report was presented in reforms outlined in the *Living Longer, Living Better* document (Australian Government Department of Health, 2012; AIHW, 2013). The reforms in the aged care system are being rolled out over ten years from 2012 and aim to support 'a responsive, integrated, consumer-centred and sustainable aged care system' (Australian Government Department of Health, 2012:19). A key element of the reform is the shift to consumer directed care (Department of Social Services, 2016b). Support for carers outlined in this policy included respite,

information and counselling, and carer support centres (Australian Government Department of Health, 2012:35). As part of the reforms, a range of services, the Commonwealth Home and Community Care (HACC) Program, the National Respite for Carers Program (NRCP), the Day Therapy Centres (DTC) Program, and the Assistance with Care and Housing for the Aged (ACHA), were merged into the new Commonwealth Home Support Scheme in July 2015 (Australian Government Department of Social Services, 2016c).

Carers Advocacy groups have raised concerns about the recognition of the role of carers within the Commonwealth Home Support Program and have argued for their inclusion in policy as 'partners in care as well as individuals with their own needs' (Carers Australia, 2014:1). The Carers Australia submission notes that 'recognition of and support for carers would be in accordance with the Carer Recognition Act 2010, which must be reflected throughout the new Commonwealth Home Support Program' (Carers Australia, 2014:1).

Furthermore, it argues that:

> *Carers must continue to have access to Commonwealth Home Support Program funded respite services as well as residential respite care based on their assessed need. Carer needs should be independently assessed to ensure that a need for respite care that exceeds the provision of consumer directed services within an individual client's Home Care package is able to be accommodated* (Carers Australia, 2014:2).

The reforms for the aged care sector exemplify the state of flux and uncertainty for future service provision for carers of frail older people.

Supports for people with disability

The NDIS was launched in trial sites in 2013 after recognition by a national inquiry by the Productivity Commission that the previous disability support system was 'underfunded, unfair, fragmented and inefficient' (Productivity Commission, 2011a:2). The general principles in the NDIS Act seek to provide 'certainty' for people with disability and their families and carers about long-term care and support, and 'where possible, strengthen and build capacity of families and carers to support participants' (NDIS ACT 2013, s4c, s31d). The scheme is based on individualised plans and funding for the person with disability, taking into account their 'goals, personal circumstances and disability support needs' (NDIS 2016). The amount of funding and support is supposed to take account of what 'it is reasonable to expect families, carers, informal networks and the community to provide' (NDIS ACT 2013, s34(e)).

The NDIS is implemented by the National Disability Insurance Agency (NDIA), which states that 'families and carers are partners in the support of people with disability', and that 'one of the core aims of the NDIS is to better support carers in their caring role' (NDIS, 2016). Carers are perceived to have a role in assisting with the development of participant plans, if requested by the person with disability (NDIS, 2016). While most benefits to the carers may come indirectly through support services for the person being cared for, the NDIA also states that 'supports that maintain a carer's health and wellbeing may also be considered' (NDIS, 2016). The NDIS Operational Guideline for planning and assessment outlines 'supports for sustaining informal supports' (NDIS, 2014).

A report on outcomes in a site after the first year noted benefits to carers such as 'significant improvements in the amount, quality, value and flexibility of support received by NDIS participants' with 'flow on benefits for carers, including the ability to return to work, reduced stress and less financial pressure' (Carers NSW, 2014:4–5). A range of challenges for carers were also identified, such as understanding the NDIS, varying degrees of carer recognition and participation in the assessment process, lack of eligibility for some participants, withdrawal of carer-specific service funding, and lack of capacity to prepare and implement plans (Carers NSW 2014:5–6). Carers Advocacy groups have called for a number of improvements to the NDI, including for the operational guidelines to include a separate formal assessment process for carers with access to services and training in carer recognition for NDIS planners (Carers NSW, 2014:7), and policy recognition that there is a need for carer-specific support services (Carers Australia, 2013b).

Carer-specific programs

In 2015, the Australian Government announced its commitment to develop an 'Integrated Plan for Carer Support Services' (Department of Social Services, 2015b). The Plan has the objective of outlining 'practical actions to recognise, support and sustain the vital work of unpaid carers' (Department of Social Services, 2015b). In the first stages of the plan the Government has launched the Carer Gateway in December 2015. This is a website and phone service that provides information and resources for carers (Department of Social Services, 2015b). A Carer Gateway Advisory Group, comprised of sector representatives, was involved in the development of the Gateway and the terms of reference outline that it may provide other advice to the Department of Social Services, including 'overseeing a collaborative approach with key parties, including carers themselves, to co-design future integrated carer support services' (Department of Social Services, 2015c).

As discussed in Section 2 of this report, carers' interaction with formal support systems can be perceived in a number of ways that seek to maintain the caring role and/or recognise the needs of carers separately (Twigg and Atkin, 1994). Similarly, analysts of long-term care schemes have outlined the different policy logics and actual policies involved in conceptualising and treating carers as either co-producers or co-clients of a policy system (Schneider et al., 2016). It is evident that while the NDIS and aged care reforms are premised on carers as co-producers of care (carers are considered in all relevant public policy documents as partners in the support of people with disability), these reforms do not as yet specifically conceptualise carers as co-clients of the program, with eligibility for services in their own right (apart from participation in support groups or a special interest network).

10.1.4 Workplace and labour force measures

Reflecting policy shifts recognising carers' own aspirations to combine employment and care, and the strong shift in Australian public policy towards increasing rates of women's labour force participation, the *Fair Work Act 2009* (Cth) introduced 10 National Employment Standards (NES), including the right to request flexible work for carers of children with disability under the age of 18 years. In July 2013 this right to request was extended to most (but not all) employed carers, without reference to the ages of the people for whom they care, and reasonable business grounds for refusal of requests were defined. In addition, the

NES provides 10 days paid personal/carers leave per year if a family or household member requires care or support, plus two days unpaid leave on other occasions.

To be eligible to make a request for flexible working arrangement, the employee needs to have completed at least 12 months of continuous service with the employer immediately before making the request, or, in the case of a casual employee, the employee needs to be a long-term casual employee of the employer immediately before making the request and have a reasonable expectation of continuing employment by the employer on a regular and systematic basis. These criteria may exclude employees with a less consistent, more precarious employment history, circumstances likely to be associated with caring responsibilities. In addition, there is no right to appeal if a request is unsuccessful. Further, where employees are defined as 'casual' they are excluded from a number of National Employment Standards rights, such as those relating to paid carers (such as personal leave and annual leave), all of which are crucial to managing work and care (Heron and Charlesworth, 2012). If the NES are to support working carers, annual leave and carer's leave would need to be extended to all employees, including those defined as 'casual'. The Australian Human Rights Commission (AHRC) recommended that the NES provide a dedicated carer's leave allocation separate from personal leave, and extend access to carer's leave to all employees, including casual employees (AHRC, 2013). It should also be noted that research indicates that most workers (and their managers) do not know about the Right to Request legislation in the Fair Work Act (Skinner and Pocock, 2014).

10.1.5 Summary

Social policies to design the future of the policy system for carers in Australia, enabling carers' inclusion into a range of spheres, in particular labour force participation, are in a state of flux and transition. Formal, statutory recognition of the circumstances and needs of carers, and their entitlement to have their needs individually assessed in community-based elder care, and consumer directed disability care under the NDIS require a focus on carer-dedicated policy design. In particular, policy design must be directed to the arrangements, services and resources which enable carers to remain in, enter or return to paid employment. Carers' rights to have their needs assessed and met is a major issue in the development and implementation of these wide-ranging social policy reforms. Of additional policy focus would be the re-design of income support arrangements which enable flexible packages of income support and labour force participation, education and training. And of overwhelming importance are the nature, shape, regulation and culture of workplaces, as encapsulated by the Fair Work Act, where the opportunity exists for strengthening arrangements to ensure carer-friendly workplaces. All of these policy domains are interconnected with respect to their future effects on the capacity and opportunity for carers to maintain, enter or re-enter employment. The domains of workplace flexibility arrangements, elder care and disability care policies, and income support policies need to be addressed if carers who aspire and struggle to combine employment and care, and other forms of social inclusion and care, are to achieve flexible and sustained forms of social inclusion.

10.2 Policies for carers in England

England's censuses of population show that there were 5.4 million carers in 2011 and 4.8 million in 2001, a numerical increase over 10 years of 12.5 per cent. In 2011, 23 per cent of carers (1.24 million people) cared for 50 or more hours per week (compared with 20% in 2001); 13 per cent (624,000 for 20–49 hours per week, compared with 11% in 2001); and 64 per cent (a little over 3 million people) for 1–19 hours per week (compared with 69% in 2001) (Office for National Statistics data).

10.2.1 Income support for carers

The main financial welfare benefit for carers is Carer's Allowance (CA). CA was first introduced in 1976. At that time, it was called 'Invalid Care Allowance' and, initially, married women were ineligible for it. This discrimination was legally challenged in 1986, with the support of a carer's organisation, and subsequently rectified, following a case which was decided in the European Court of Justice.

Between 2004 and 2015, the number of CA 'claimants in payment' (that is, people who meet the non-financial eligibility criteria for CA and who also have earnings or other state benefits, including state pension, below a specified level) rose by 72 per cent to 626,770 people (a figure which represented 11% of all carers in 2015). Most recipients of CA are women (75% of claimants in 2004 and 73% in 2015), and the vast majority are people of working age (95% of claimants in 2004 and 98% in 2015). CA is not paid if a carer has a state pension or other welfare payments of equivalent or greater value, as these are treated as 'overlapping benefits' and adjusted accordingly (HCWPC, 2008).

This arrangement has been widely criticised over many years by carers' and older people's organisations and, in 2008, CA was described by the House of Commons Work and Pensions Committee, in its official report of its Inquiry 'into the effectiveness of the Department of Work and Pension's existing approach to carers' (HCWPC, 2008:10), as 'outdated'. The Committee recommended that CA needed to be 'radically overhauled at the earliest opportunity' (HCWPC, 2008: 38), adding that it wished to see it replaced with a 'two-tiered benefit for carers', which it suggested should comprise a new 'Carer Support Allowance' and a new 'Caring Costs Payment' (HCWPC, 2008: 55). Despite this, the Labour Government of that time, and the Coalition and Conservative Governments which have followed, did not make any significant structural changes to CA, which still remains the major financial benefit available to carers.

The eligibility criteria for CA are another long-standing point of contention. Claimants must care for 35 or more hours per week for one person who is receiving one of a specified list of state disability payments in their own right. Couples (for example, parents of a disabled son or daughter) cannot share this care, nor can they both claim CA (unless that have two disabled children each requiring 35 or more hours of care, as two people cannot claim CA in relation to the same disabled person. In addition, the carer's own earnings from employment (after income tax and National Insurance deductions) must be at or below £110 per week (the 2015 figure). As no taper applies, carers may face sudden loss of CA if their earnings from paid work are close to the limit and rise, even slightly. Recipients of CA may be in education, but cannot be full-time students as they must be studying for a maximum

of 21 hours weekly. CA is not means-tested, except in relation to weekly earnings from the recipient's own paid employment, but it is taxable if the carer's total income is above the limit at which income tax becomes payable.

Average weekly CA payments are low: for people of working age the average in 2015 was £62.59 (compared with £47.59 in 2004), and for those carers who have reached state pension age and receive CA payments (whose numbers are very few), it is even lower (£35.76 per week in 2015). CA is only payable to people above state pension age with nil or a very low pension entitlement, and it in effect 'tops up' an older carer's pension for those carers whose pension entitlement is very low.

Most CA claimants are outside the labour market and it is a benefit which has been criticised for acting as a disincentive to paid work for carers. Official data show that only about nine per cent of all those who claim CA also do part-time paid work (and any carer in full-time paid work, even those on the national minimum wage, would be ineligible as their earnings would breach the upper earnings limit).

Some small additional carer premiums are payable to carers on state income support benefits (excluding CA). In addition, adults caring for 20 or more hours per week can get a 'pension credit' to fill gaps in their National Insurance record, which counts towards their entitlement for their state pension after retirement (under the *Pensions Act 2007*).

10.2.2   Recognition and rights legislation

The first major legislation on carers was the *Carers (Recognition & Services) Act 1995*, which originated as a Private Member's Bill promoted by Labour MP Malcolm Wicks, and was drafted with the support of the national organisation, Carers UK. It introduced the concept of a local authority carer's assessment, the aim of which is 'to identify his or her "ability to provide and to continue to provide care"' (Clements, 2005:31). As Clements notes, official guidance to the Act pointed out that 'if a carer is no longer willing or able to provide help to the disabled person with (for example) bathing, the disabled person's care plan will need to specify how this need is to be met in the future' (Clements, 2005:31). The 1995 legislation did not make provision for any services to be provided for carers, as of right, however, and it took almost another 20 years before that legislative step was taken.

After the successful passage of the 1995 Act, additional legislative recognition and rights followed, originating in both Government and in further successful Private Members' Bills (in 2000 and 2004), for which carers' organisations campaigned vigorously:

- The *Employment Relations Act 1999* gave all employees the right to an unspecified, but short, amount of unpaid 'time off' to deal with family emergencies.

- The *Carers and Disabled Children Act 2000*, introduced by Tom Pendry, MP (later Lord Pendry), introduced optional separate assessment of the carer and the disabled person, and made provision for support services for carers, following assessment, to be accessed if desired through allocation of a direct payment or voucher to the carer.

- The *Employment Act 2002* gave parents of a disabled child under the age of 18 years the right to request flexible working (which an employer was obliged to

consider but could reject on business grounds).

- The *Carers (Equal Opportunities) Act 2004*, promoted by Labour MP Dr Hywel Francis, laid down provisions ensuring that carers' wishes regarding their own employment, education, and leisure should be taken into consideration when local authority carers' assessments were undertaken.

- The *Work & Families Act 2006* extended the right to request flexible working to most carers of adults (a right later extended to all employees with six months' service, irrespective of any care responsibilities, under the *Children and Families Act 2014*).

- The *Equality Act 2010* banned workplace discrimination against an employee in association with a disabled person for whom they provide care or support.

- The *Care Act 2014* introduced a new duty on local authorities to promote 'well-being', defining this to include economic wellbeing. It strengthened carers' rights to assessment and to support and services following assessment if relevant eligibility criteria, which includes an assessment of means/assets, are met.

10.2.3   Community and social care support services

Community support for carers has been in existence in England for many years, although it has always been uneven, with local services varying greatly from one part of the country to another. Much of this support originated in voluntary, charitable or 'self-help' provisions, or in local authority services developed, initially under discretionary powers, by English local authorities. Today, such support mainly comprises: respite care (now usually referred to as 'breaks') provision; sitting services; health and wellbeing support; information and advice services; and various types of emotional support. Some voluntary organisations, and a few local authorities, offer carers help to return to paid work or to manage work and care, and in recent years some have given 'one-off' payments to carers to address specific practical needs, or to enable carers to access leisure or activities consistent with the aspiration that carers should be able to live 'a life of their own'.

The background to this situation includes several important developments: the introduction by central Government, during a Labour administration, of a first National Carers' Strategy in 1999 (followed by a second one in 2008), and the introduction of a Carers Grant, paid to all English local authorities by the Department of Health (beginning in 1999), to stimulate local support for carers. By the 2000s, most local authorities were providing, or at least commissioning, some carers' services (Fry et al., 2009). Some were using their Carers' Grant allocations to fund voluntary sector support; some established and operationalised their own local carers' strategies; and today, under the *Care Act 2014*, all have responsibility for stimulating a market for care and new carers' services.

The *Care Act 2014*, which followed a major review of social care legislation in England, consolidated and replaced almost all previous legislation on adult social care. As mentioned, it introduced new landmark rights to support for carers and gave local authorities responsibility for assessing a carer's support needs in any case where they 'appear to have such needs', potentially making assessment available to many more carers. Under the 2014 Act, local authorities must consider the impact of caring on the carer, what the carer wants

to achieve in their daily life, and their ability or willingness to continue caring. It must then decide if the carer's needs are eligiblefor local authority support and, if so, it must agree a support plan and personal budget for the carer which, if a carer wishes, can be provided as a direct payment to the carer.

Despite this trend towards opening the door to support for more carers, official data show that the number of carers receiving 'carer-specific' services fell by 19 per cent between 2007–08 and 2012–13 (the numbers of carers supported falling from 209,000 to 169,000 between these dates). The number of carers receiving 'information only' rose by 49 per cent between 2007–08 and 2010–11 (from 128,000 to 191,000 carers), but fell back to 185,000 in 2012–13 (Community Care Statistics: Social Services Activity, England, 2012–13, Final release:78).

Carers have also been affected by a decline in local authority funding of services for older people (Yeandle, 2016). Across England, this funding rose annually in real terms between 2003–04 and 2009–10, but fell annually thereafter. Client contributions to the cost of older people's social care have also risen annually for several years, totalling £2.0 billion in 2007–08 and £2.16 billion in 2013–14. However local authority grants to voluntary organisations to support older people fell annually in real terms between 2008–09 and 2013–14 (dropping from £129.7 million in 2008–09 to £114.1 million in 2013–14).

Voluntary provision for carers by charities and other not-for-profit or non-government organisations is locally very variable, and there has never been any stable public funding for it. Some high quality and innovative provision has been developed, at times as a result of temporary funding provided by central government, in other cases through recourse to European Union or charitable funding, but this has mostly been available only in selected localities, and it has often involved short-term funding, rarely exceeding two or three years.

More recently, more effort has been made to increase support for carers in the National Health Service, and an 'NHS commitment to carers', affecting hospitals, general practitioners (GPs) and community health services, was formally set out in April 2014.

10.2.4   Social inclusion policies

Over recent years, successive governments have made policy commitments stating that carers should have 'a life of their own alongside caring' (2008 National Carers Strategy) or 'a life alongside caring' (Carers Strategy 2nd National Action Plan 2014). Their statements have often focused on 'personalised' support (see S5), the importance of carers' breaks, or promoting 'best practice in working with the voluntary sector'.

Between 2008 and 2012 the Department of Health invested £15 million (each) in a major 'Caring with Confidence' training programme for carers, which supported 12,621 carers in various locations in England; and a programme of National Carers Strategy 'Demonstrator Sites' (collaborative projects which brought together local authorities, NHS organisations and voluntary sector agencies, operating in 25 locations that had successfully applied for competitive funding). The sites supported a total of 18,653 carers (Yeandle and Wigfield, 2011). The Demonstrator Sites programme provided health and wellbeing support to carers in a variety of innovative projects, delivering carers' breaks, new NHS support for carers, and health and wellbeing checks for carers (Yeandle and Wigfield, 2011).

10.2.5   Consumer directed care

Local authorities in England were first permitted to make direct payments to carers (to enable them to purchase services to meet their own assessed needs) under the *Carers and Disabled Children Act 2000*. In 2014–15, a national survey found that 77 per cent of local authority-supported carers had received 'self-directed support'.[18]

10.2.6   Workplace and labour force measures

Government has addressed the needs of 'working carers' in its successive National Carers Strategies and provides limited support for carers seeking work through the state job search agency, Jobcentre Plus. Carers are not subject to conditionality as a condition of receiving CA, so are treated differently in the welfare system than most claimants of other state benefits. In 2010, a Memorandum of Understanding was agreed with between the Government and the Employers for Carers Forum, a group of employers, drawn from a variety of employment sectors, which advocate on behalf of carers at work in the belief that there is a strong 'business case' for providing support and flexibility to their employees with caring responsibilities. A Carers in Employment Task and Finish Group (jointly led by the Department of Health and the Employers for Carers Forum) was established by an initiative of the Minister for Care Services in 2012 and met in 2012–13, publishing a report and recommendations entitled *Supporting Working Carers: the benefits to families, business and the economy.* The right to request flexible working was first introduced in 2002 in the *Employment Act* of that year for some carers and in 2014 was made available to all employees with six months' service. However, paid 'carers leave' has never been legislated for in the UK, and it remains merely a voluntary option which is offered by only some employers, entirely at their discretion, and in some cases is available to some, but not all of their employees.

10.3 Comparing policies in Australia and England

This section of the report asks whether the social policy systems for carers in Australia and England are sufficient, appropriate, and flexible enough to enable carers to not only sustain their caregiving obligations, but to combine employment and care, and social inclusion and care in sustainable and fulfilling ways. A useful conceptualisation is to ask whether the logic of carer policy in each country follows either a 'carer as a co-producer' model, or a 'carer as a co-client' model (Schneider et al., 2016).

Understanding carers as co-producers means that policies should aim to:

- 'maintain and develop informal care as an important resource' in the overall mix of informal and formal carer services.

- 'stabilise [and support] informal care arrangements' (e.g. with income support) and avoid 'excessive care burdens' (e.g. with respite care).

- 'support informal caregivers in delivering adequate support' (information, counselling, support networks) (Schneider et al., 2016:223–4).

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18   Source: HSCIC (2015) *Measures from the Adult Social Outcomes Framework*, p12.

Understanding carers as co-clients means that policies should aim to:

- recognise that informal care 'is associated with a variety of social risks and challenges to the caregiver's wellbeing' (Schneider et al., 2016:224).

The latter could be facilitated by promoting rights-based access to services which enable combinations of care and employment, and care and social inclusion, in a range of social and economic domains (Schneider et al., 2016).

With respect to financial benefits paid by national governments in each country, it is evident that the proportion of benefits recipients who are also able to be in the labour force is low: in Australia only 9.8 per cent of recipients of Carer Payment reported employment income in 2014–15; while in the UK in 2015 the large majority of recipients of CA were in not in the labour force, and only 9 per cent of recipients were employed part-time. In both countries the rate of income support for carers is not sufficient to enable recipients to escape the carer penalty of material insecurity. Although it is essential that carers have eligibility to claim various forms of financial benefit in order to sustain a livelihood while providing informal care which greatly restricts their employment, the financial penalty of care is evident for those who must rely on benefits.

With respect to recognition and rights legislation, the Australian *Carer Recognition Act 2010 (Cth)* aims to increase recognition and awareness of the role that carers play in providing daily care and support to people with disability, medical condition or mental illness, or those who are frail aged. The Act places a number of obligations with respect to carers on Commonwealth public agencies and their contractors, directing them to take account of the requirements and needs of carers in a range of programs and services delivery. However, the Act does not, unlike similar legislation in the UK, involve a right to assessment of carers' needs to receive services or 'place any enforceable obligations' on service providers to meet carers' needs.

In the UK, the *Care Act 2014* gives carers the right to support and services, as well as to assessment of their needs for various services. The Act introduced new landmark rights to support for carers and gave local authorities (LAs) responsibility for assessing a carer's support needs – LAs must consider the impact of caring on the carer, what the carer wants to achieve in their daily life, and their ability/willingness to continue caring. It must then decide if the carer's needs are 'eligible' for LA support and, if so, must agree a support plan/personal budget for the carer which, if a carer wishes, can be provided as a direct payment. Services for carers mainly comprise respite/breaks/sitting services; health/wellbeing support; information and advice; and emotional support. Some LAs offer carers help to return to work, and to manage work and care. However, the number of carers receiving 'carer-specific' services fell by 19 per cent between 2007–08 and 2012–13. Carers have also been affected by a decline in LA funding of services for older people since 2009–10.

It is evident, therefore, that even though carer recognition and rights legislation, which carries entitlements for carers to be assessed for services (in their own right as co-clients) as in the UK, is of great importance, the corollary needs to be sufficient government funding and provision of appropriate caregiver support policies. In Australia, on the other hand, the *Carer Recognition Act 2010* does not carry entitlement for carers to be assessed as co-clients with respect to their service needs. Considering the situation in both countries, a

discussion paper prepared by the University of Leeds, the Social Policy Research Centre at University of New South Wales, and the University of Alberta in Toronto, Canada (May 2014, p. 7) noted that ongoing issues and challenges in developing support for carers in the three countries under examination included 'inadequate emphasis on carers' risk of exclusion from full participation in the normal activities of society and evidence of the triple penalty which carers pay-poorer health and financial circumstances, social exclusion'.

With respect to carer-specific support services, the co-design of a new integrated carer support service system will continue to be undertaken throughout 2016. The policy information for carer support services, as evident from an examination of the newly established Carer Gateway, suggests that services for carers remain embedded in a model of carers as co-producers of care, whose access to services is limited to short-term and emergency respite support, and who do not have explicit rights under the *Carer Recognition Act 2010* to be entitled to receive various services – in particular those which would effectively facilitate combinations of care and employment.

While the UK *Care Act 2014*, in contrast to the Australian legislation, does give carers the right to assessment of their needs for various services, including help to return to work and manage work and care (provided in some but not all LAs), insufficient funding to LAs has resulted in a fall in the number of carers receiving 'carer-specific' services between 2007–08 and 2012–13. It is evident that recognition and rights legislation needs to be accompanied by a recognition of carers as co-clients of services, requiring assessment and service provision in their own right, and services which mitigate the triple penalty of caregiving.

With respect to workplace and labour force measures in both countries, Australia's *Fair Work Act 2009 (Cth)* and the UK *Work & Families Act* from 2014, provide the right to request flexible working arrangements after a period of employment to establish entitlement (in the UK the right to request flexible working arrangements is provided to employees without reference to caregiving responsibilities). However, in comparison with the Australian legislation, in the UK there is no established right to paid 'carers leave', which remains a voluntary option offered by only some employers. Also, the Australian Fair Work Act imposes restrictions on employees defined as 'casual' in relation to the right to request flexible working arrangements and paid care leave. It is of considerable importance that workplace and labour force measures provide rights to request flexible employment arrangements for all employees with caregiving responsibilities, including paid leave. This is essential to effectively mitigate for carers the difficulty of combining employment and care, and with that the financial penalties imposed by caregiving.

In Australia and England, all of these policy domains under analysis are interconnected with respect to their future effects on the capacity and opportunity for carers to maintain, enter or re-enter employment and engage in other modes of social inclusion. The domains of income support policies, rights and recognition legislation, workplace flexibility and paid leave arrangements, the right to be assessed for dedicated carer-specific services (following the carer as co-client logic), need to be addressed if carers who aspire and struggle to combine care and employment and other forms of social inclusion are to achieve their legitimate aspirations.

11 Social Inclusion Outcomes for Carers in England and Australia
Melissa Wong, Lisa Buckner and Trish Hill

This section examines indicators of participation and resources in the censuses from Australia and England to assess the relative rates of social inclusion. Full results are outlined in the Technical Appendix. Key results are outlined below. The analysis first considered differences in outcomes for carers in 2011 in the two countries. It then explored similarities and differences in changes over time in participation indicators for Australia between 2006 and 2011 and for England between 2001 and 2011. Differences between the definitions of carers in the two censuses and the different time periods over which changes are analysed should be borne in mind when interpreting the results.

11.1 Outcomes for carers in 2011

11.1.1 Participation

Education: Young carers aged 20–24 years who have Year 12 (or equivalent) attainment

Overall, carers in both countries had lower rates of Year 12 (or equivalent) attainment compared to their non-carer peers (Figure 11.1). However, the gap between carers and non-carers is larger in Australia than in England. This is especially true for young female carers in Australia. In this case, the gap was twice the size of all other groups (Figure 11.2).

Figure 11.1 Proportion of carers and non-carers aged 20–24 who have completed Year 12 or equivalent in Australia and England, 2011 (%)
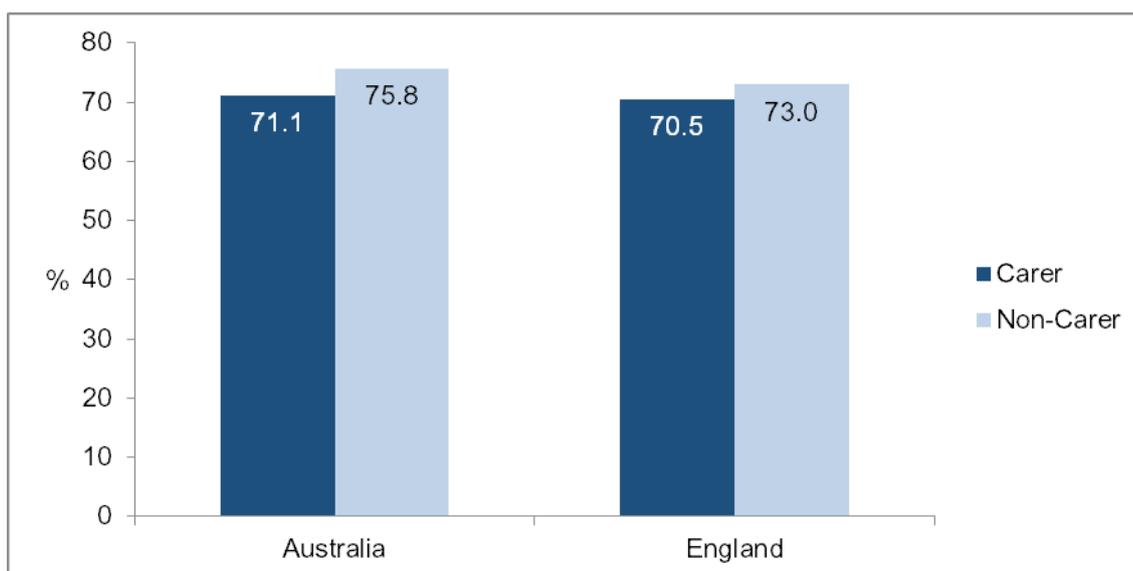
Figure 11.2 Gap between carers and non-carers who have completed Year 12 or equivalent in Australia and England, by gender, 2011 (% point difference)
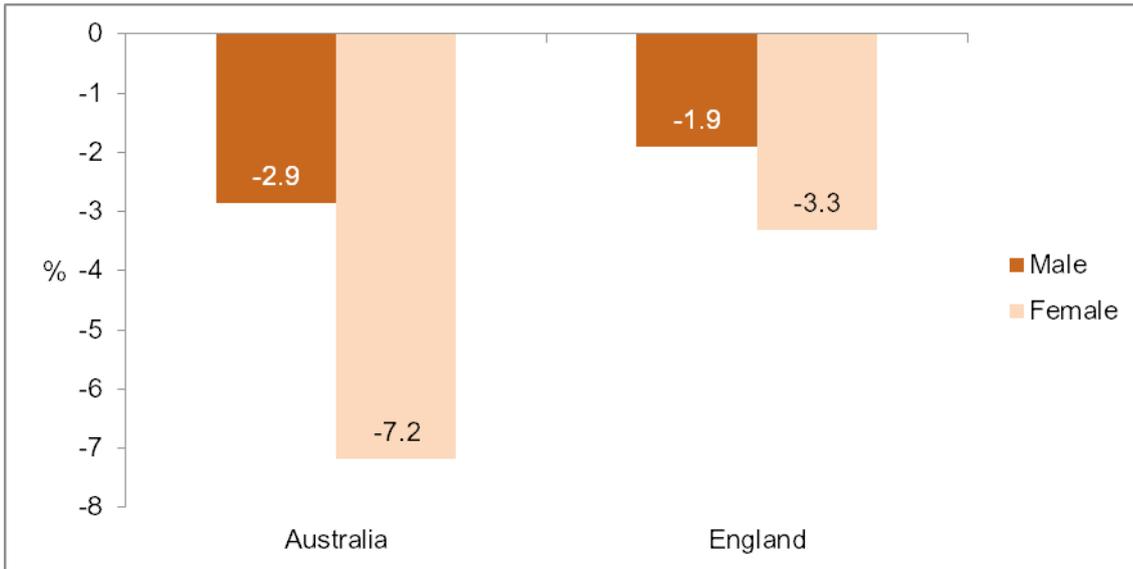
Engagement: Young carers aged 15–24 years who are not in employment, education or training (NEET)

The proportion of young carers who were not in employment, education or training (NEET) was higher in England than in Australia in 2011 (20.7% compared to 18.2%) (Figure 11.3). For both countries, the rates of disadvantage on this indicator were markedly higher for young carers than non-carers, with the gap greater in Australia. Young female carers were more disadvantaged than young male carers in both countries, with young female carers in Australia having the largest gap in NEET rates compared to their non-carer peers (Figure 11.4).

Figure 11.3 Proportion of carers and non-carers aged 15–24 in Australia and 16–24 in England who are NEET, 2011 (%)
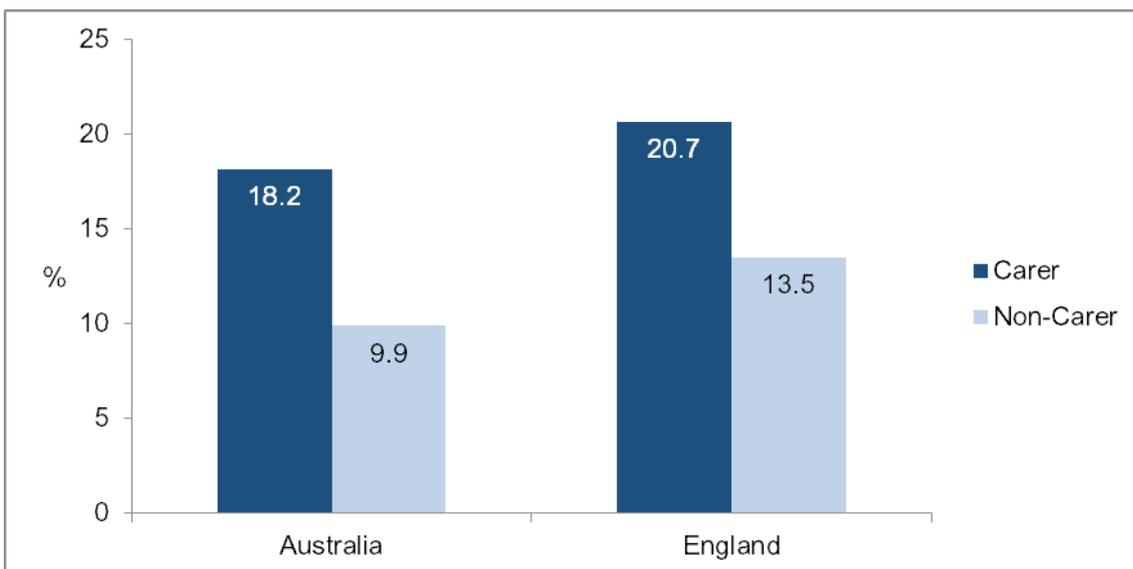
Figure 11.4 Gap between carers and non-carers aged 15–24 in Australia and 16–24 in England who are NEET, by gender, 2011 (% point difference)
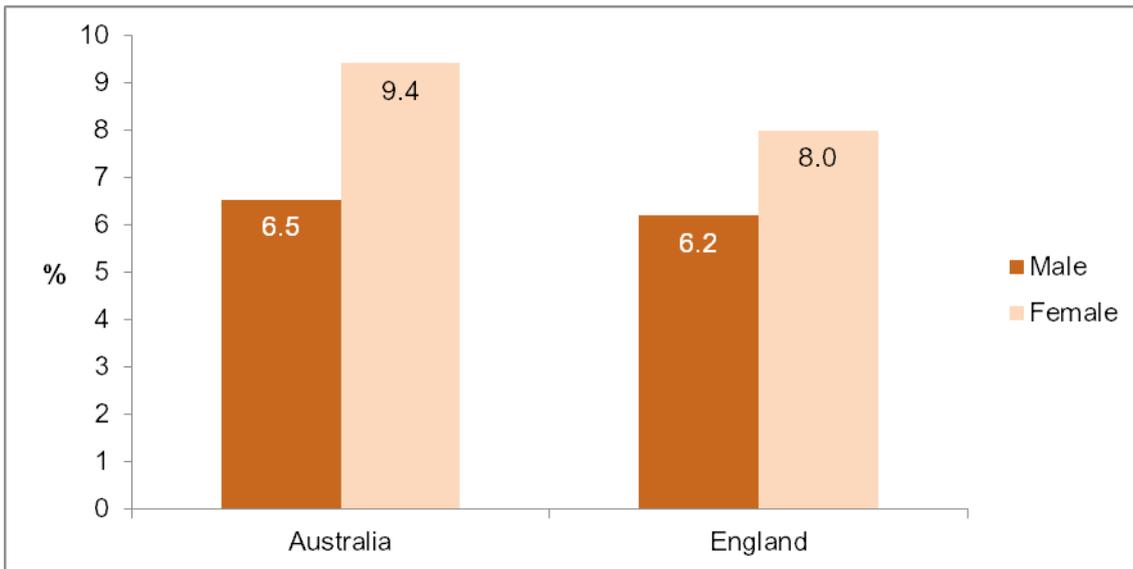
Employment: Working-age carers (15–64 years) who were engaged in paid employment

Carers in England had a slightly higher rate of paid employment compared to Australia in 2011 and employment in full-time work was also higher in England than Australia for male and female carers (Figure 11.5). For both countries, women who were carers in the 25–44 year age group were most disadvantaged compared to their non-carer peers (Figure 11.6). This is possibly due to withdrawal from the labour market due to the compounded effects of informal care and childcare responsibilities. It may also be the case that women in this age group are caring for children with disabilities, rather than parents, and therefore have had long-term constraints on their participation in both education and employment.

Figure 11.5 Proportion of carers who were employed in Australia and England, by gender, 2011 (%)
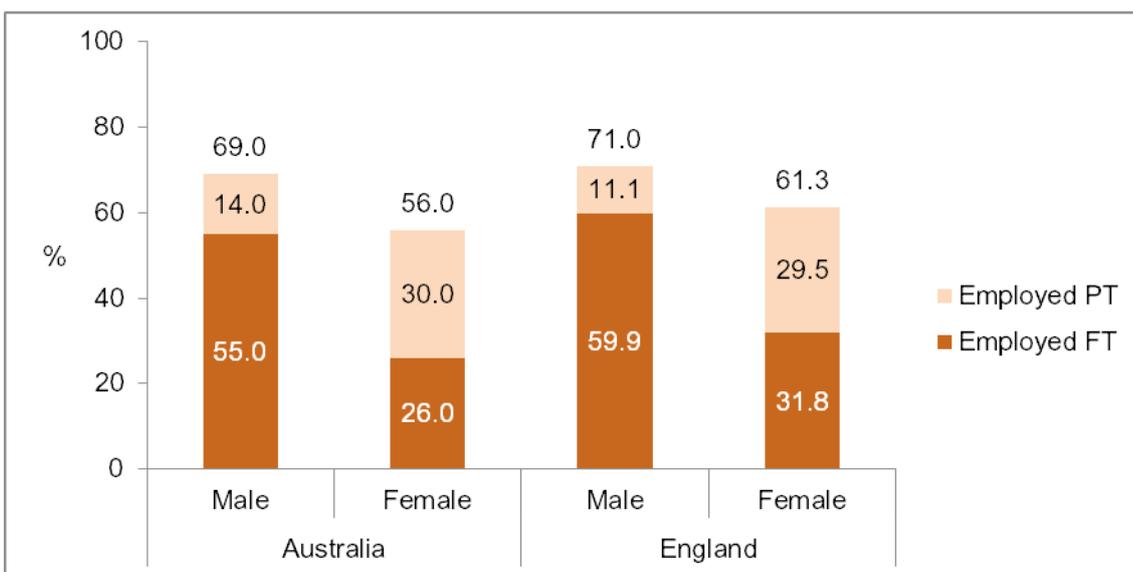
Figure 11.6 Gap between carers and non-carers who were employed in Australia and England, by gender, 2011 (% point difference)
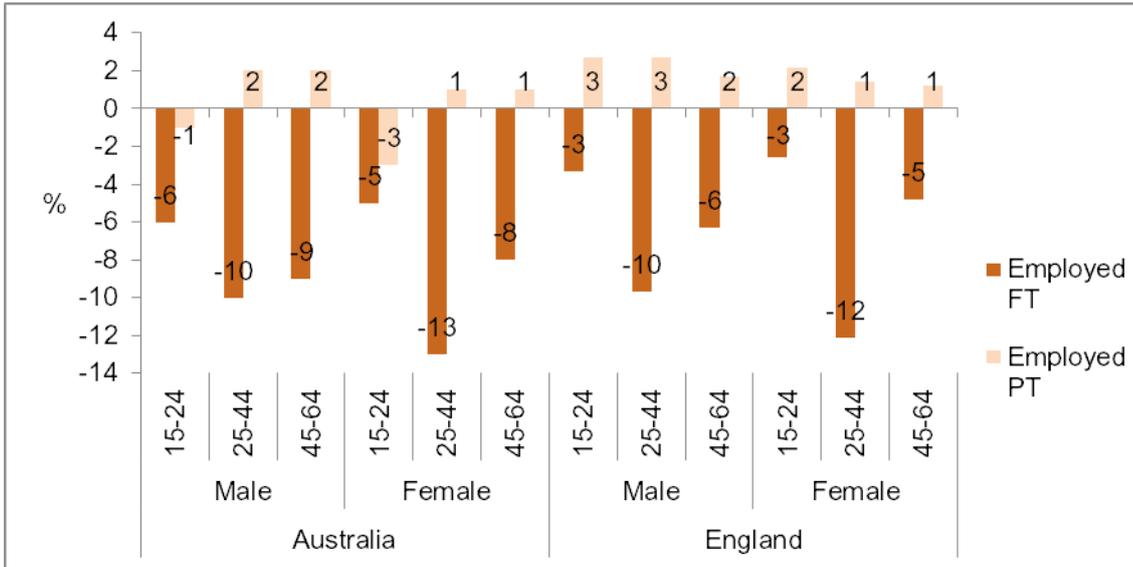

11.1.2 Resources

Material resources: Motor vehicles

Overall, the proportion of carers who lived in a house with access to a motor vehicle was higher in Australia than in England (around 95% in Australia compared to 85% in England). This may be explained by geographical and transport differences. However, carers in England were more likely to have access to a motor vehicle compared to their non-carer peers than carers in Australia. This was especially the case for carers aged 65 years and over. Young carers in both countries were less likely to live in a household with access to a motor vehicle than their peers (Figure 11.7).

Figure 11.7 Gap between carers and non-carers who have at least one motor vehicle at home in Australia and England, by age, 2011 (% point difference)
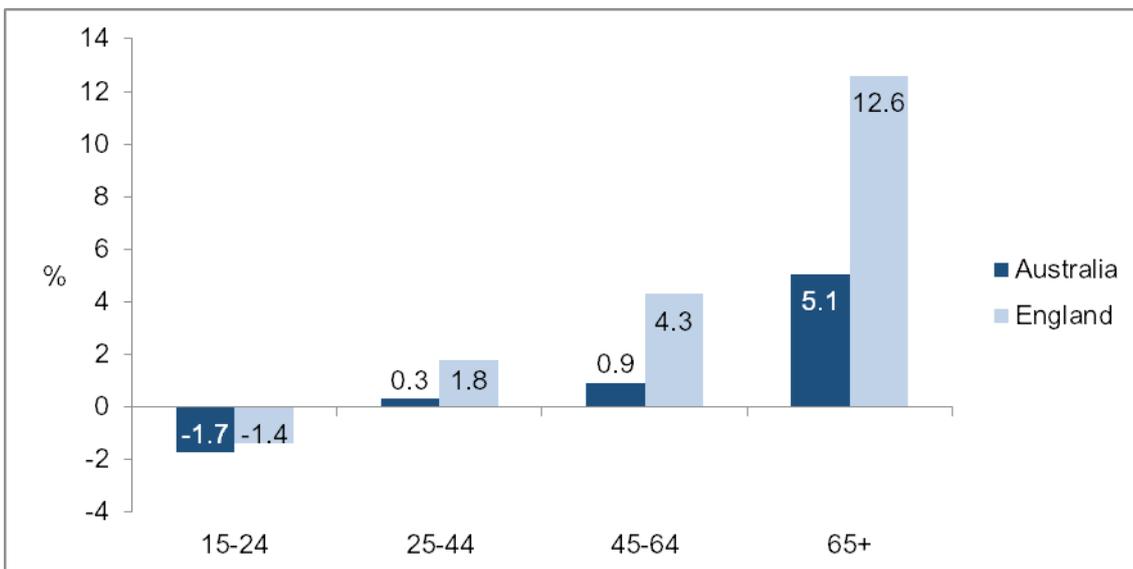
Material resources: Home ownership

Carers had a higher rate of home ownership compared to their non-carer peers in both Australia and England. This finding is likely to reflect the older age profile of carers and the accumulation of assets. The rates of owning a home outright or with a mortgage are quite similar in the two countries. However, renting profiles were very different. Carers were more likely to rent privately in Australia than England (22.5% compared with 7.9%) and there was a higher rate of renting from the public sector for carers in England compared to Australia (16.3% compared to 4.1%) (Figure 11.8).

Figure 11.8 Proportion of carers who are homeowners in Australia and England, by tenure type, 2011
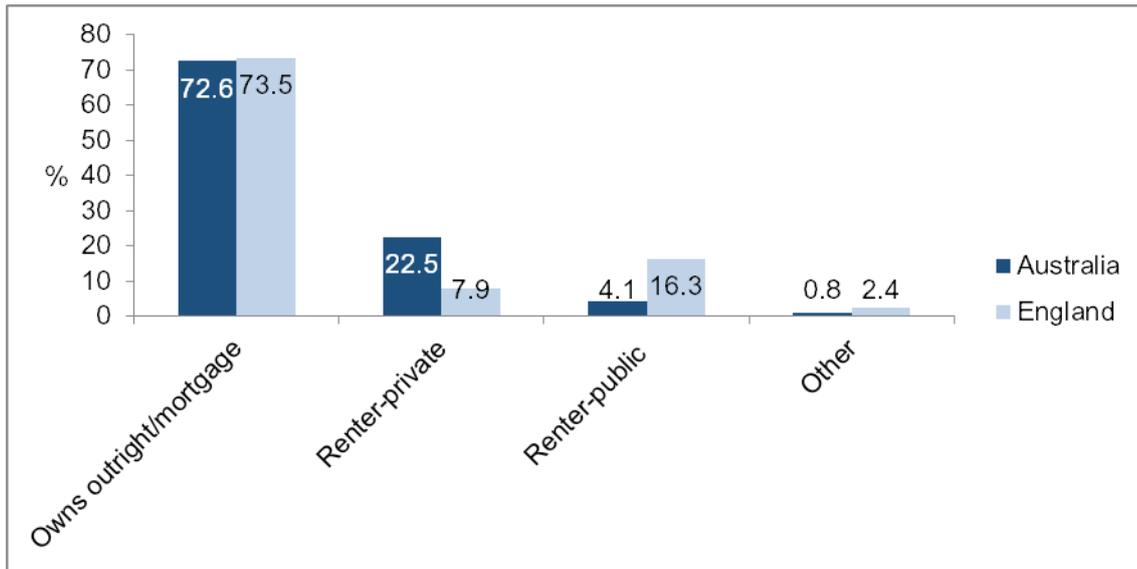
11.2   Changes over time in participation indicators

11.2.1   Education

In both England and Australia, the proportion of young people, including young carers, who had completed Year 12 increased over the time periods considered (Figure 11.9 and Figure 11.10). The gap between carers and non-carers was higher for young women in both years and in both countries. In Australia, between 2006 and 2011, the gap between carers and non-carers reduced by a small amount for both men and women (Figure 11.11). However, in England, between 2001 and 2011 the gap increased slightly for young men and reduced significantly for young women (as it was halved over the decade) (Figure 11.12).

Figure 11.9 Year 12 completion rates by gender, aged 20–24 years, Australia 2006 and 2011
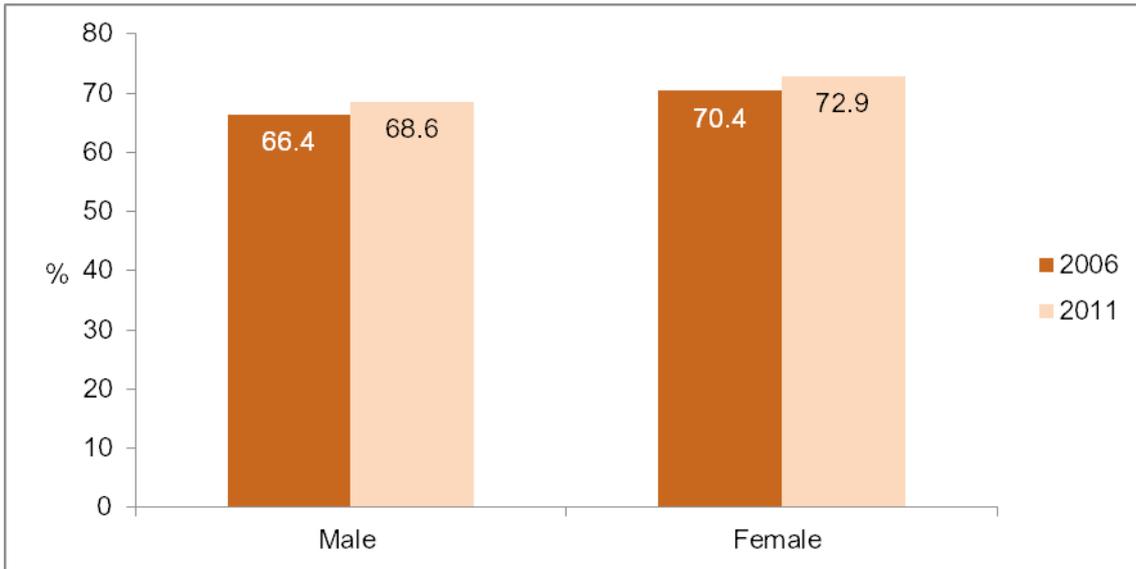

Figure 11.10 Year 12 completion rates by gender, aged 20–24 years: England 2001 and 2011
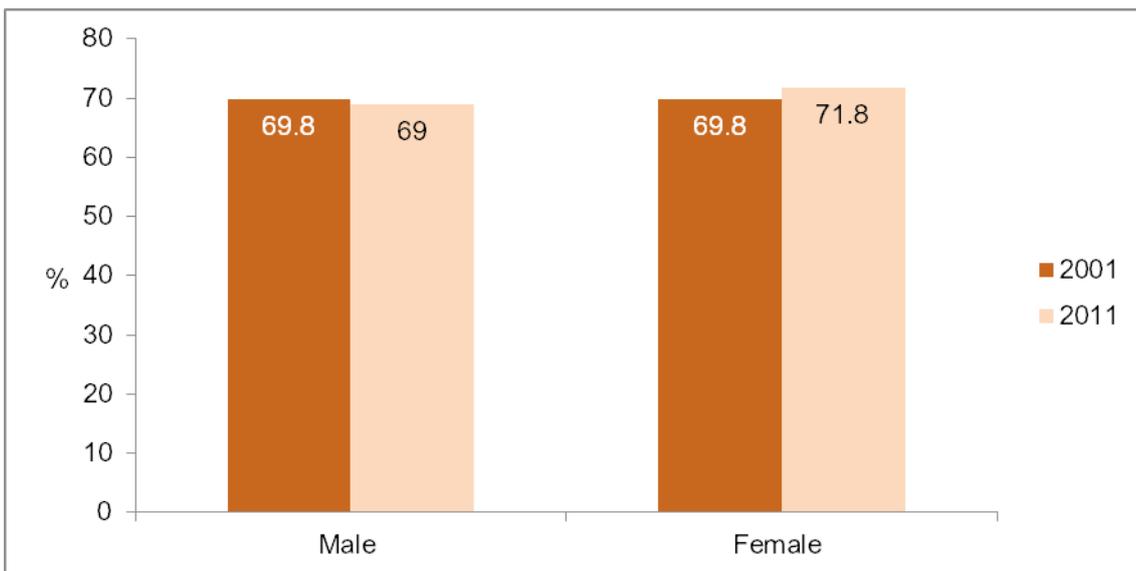
Figure 11.11 Gaps in year 12 completion rates by gender for young carers, aged 20–24 years, Australia 2006 and 2011 (percentage points)
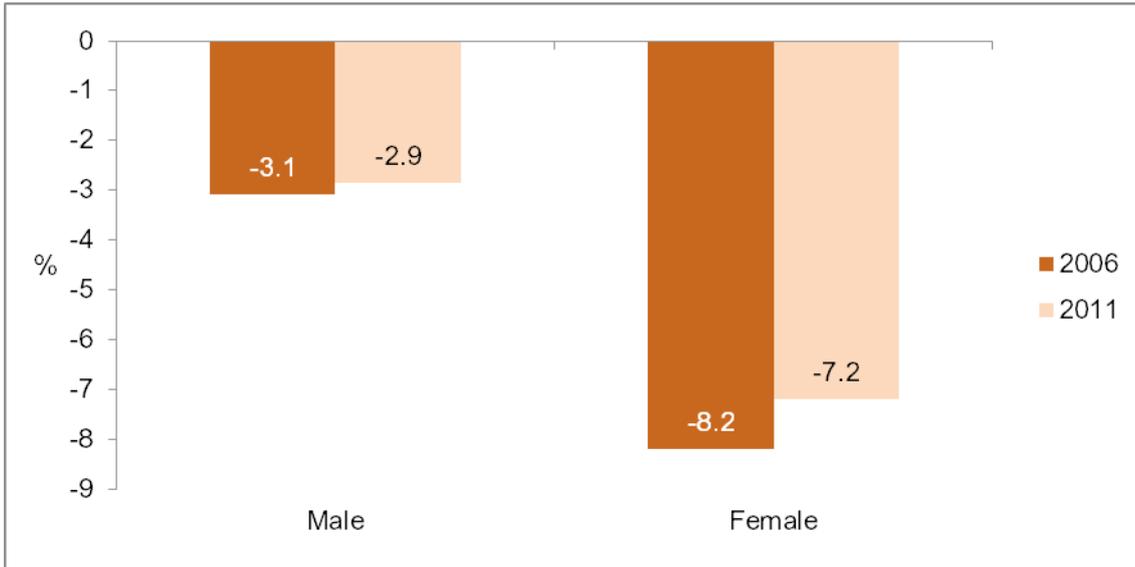
Figure 11.12 Gaps in Year 12 completion rates by gender for young carers, aged 20–24 years, England 2001 and 2011 (percentage points)
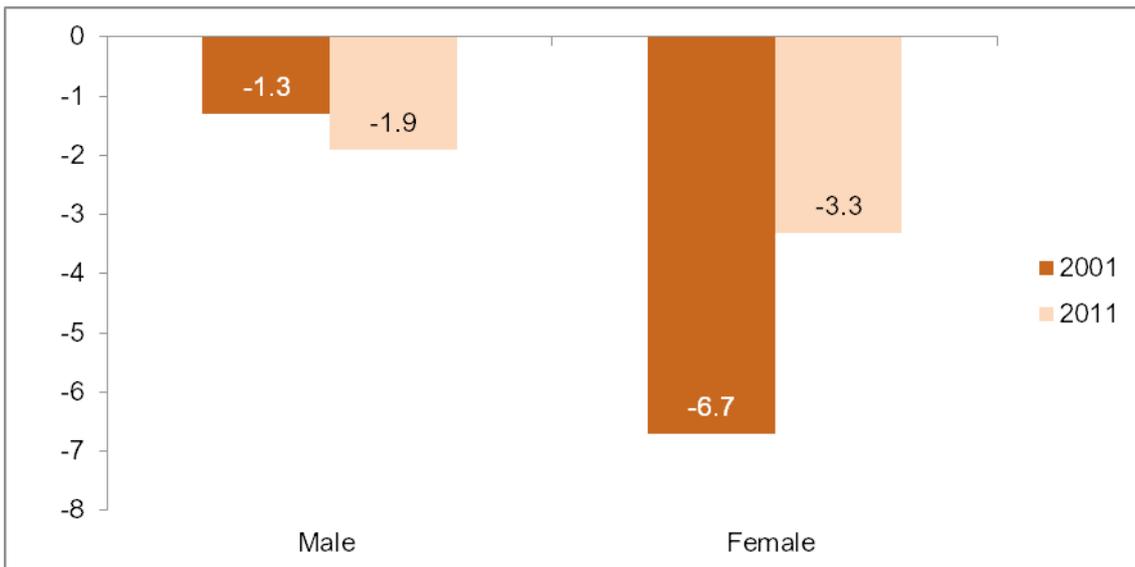
11.2.2 Not in employment, education or training (NEET)

In England and Australia, the proportion of young people, including young carers, who were in the NEET category reduced over time. In both countries, at both times, young female carers had the highest rate of NEET: between one in five and one in four young female carers are not participating in any education or employment. This outcome holds in both years, even though the rates decreased for young female carers, and increased slightly for young male carers (Figure 11.13 and Figure 11.14). A similar finding occurred in regard to the young carer disadvantage in NEET rates: the gap was highest for young women and the gap between carers and non-carers decreased for young women and increased for young men (Figure 11.15 and Figure 11.16).

Figure 11.13 Rates of NEET by gender: young carers aged 15–24 years Australia 2006 and 2011
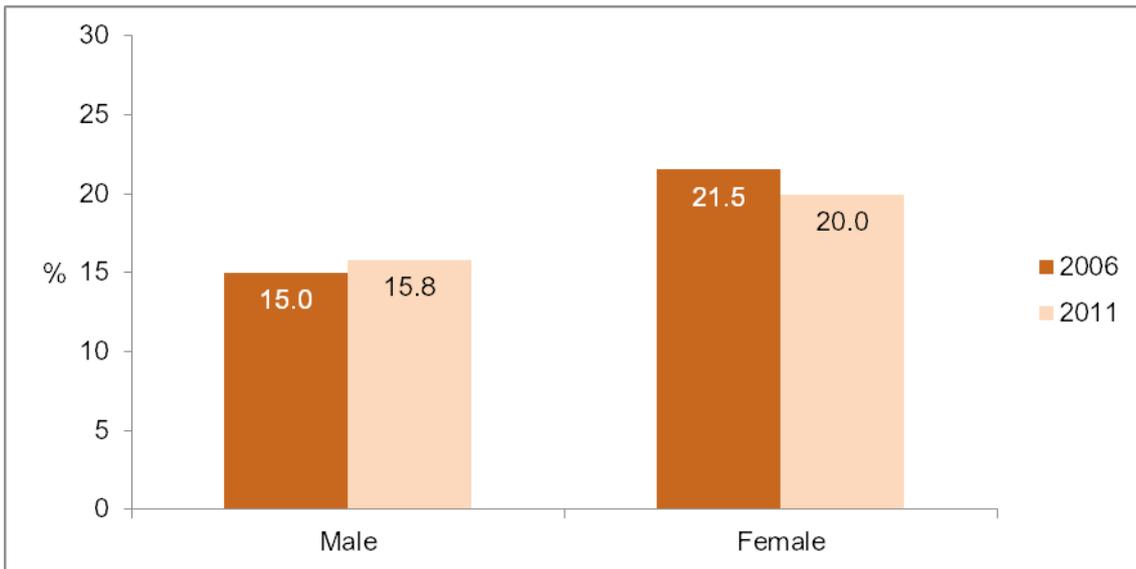
Figure 11.14 Rates of NEET by gender: young carers aged 15–24 years, England 2001 and 2011
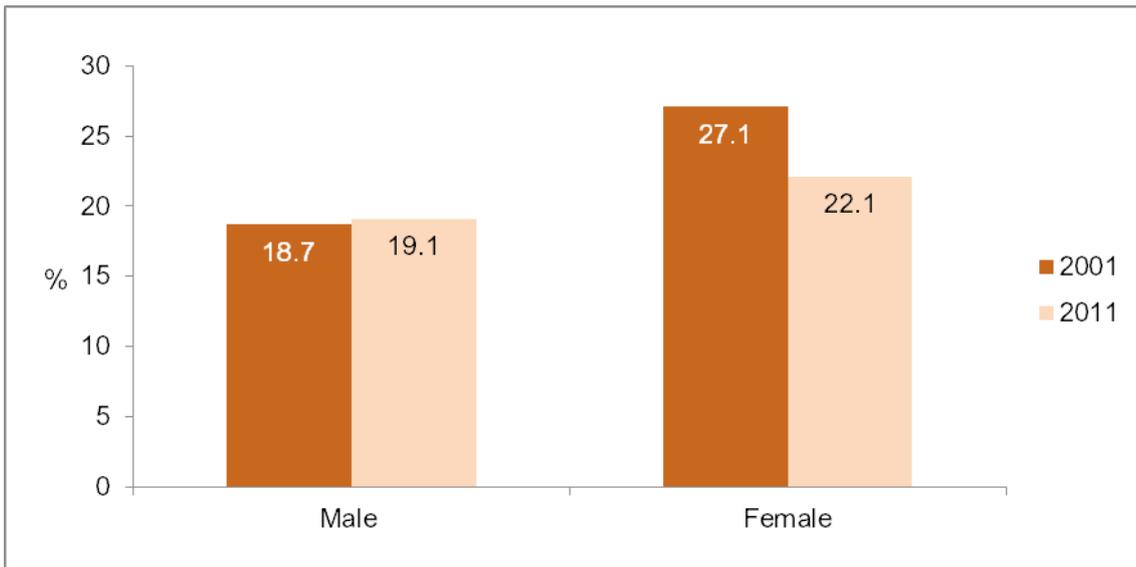
Figure 11.15 Gaps in NEET rates between carers and non-carers by gender: young carers aged 15–24 years Australia 2006 and 2011 (percentage points)
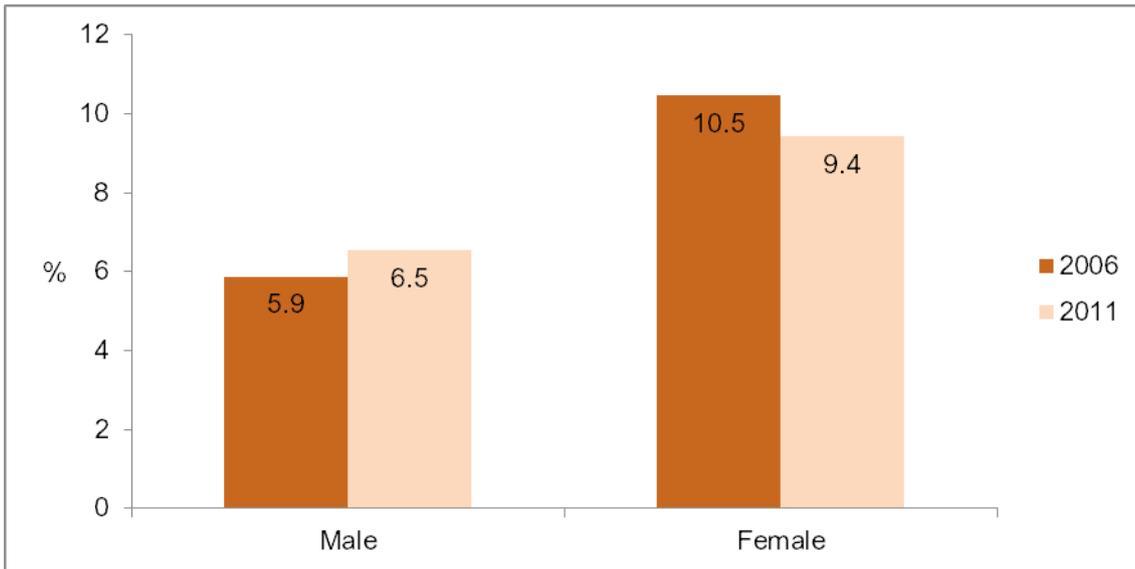
Figure 11.16 Gaps in NEET rates between carers and non-carers by gender: young carers aged 16–24 years, England 2001 and 2011(percentage points)
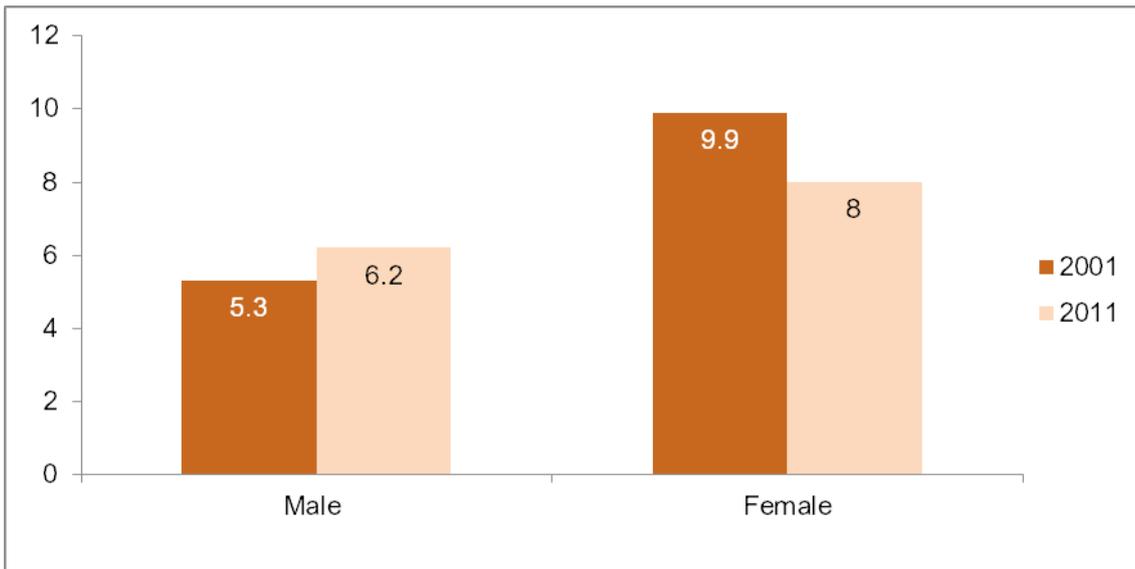
11.2.3 Employment

Overall, employment rates for carers stayed fairly constant over the time periods in each country. In Australia and England, female carers employment increased slightly over the time period, while male carers maintained the same rate in Australia and decreased slightly in England (Figure 11.17 and Figure 11.18).

Figure 11.17 Proportion of carers and non-carers who were employed by gender, Australia, 2006 and 2011
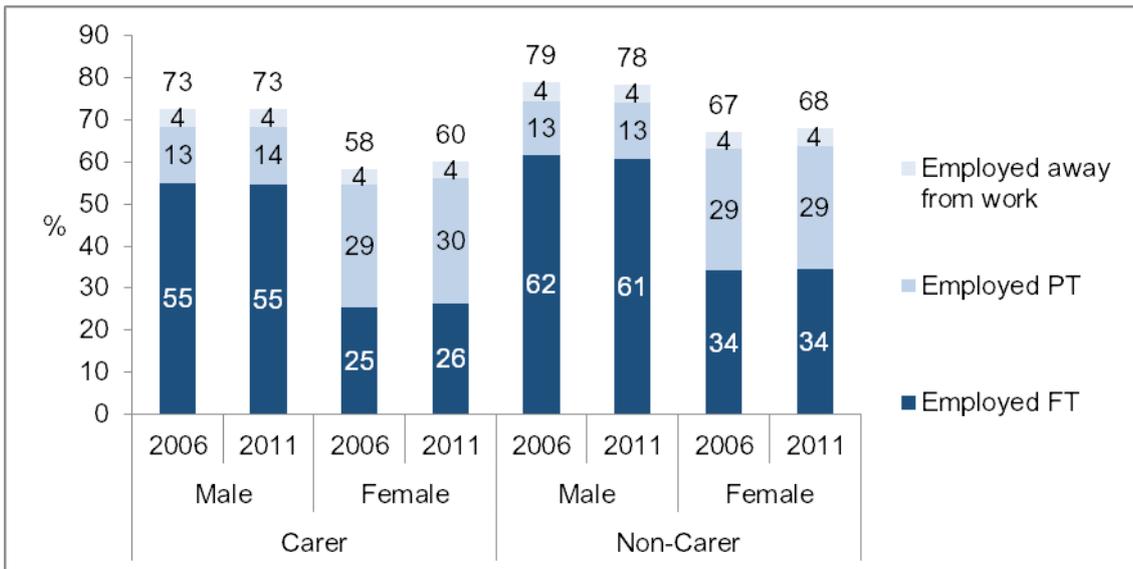
Figure 11.18 Proportion of carers and non-carers who were employed by gender, England 2001 and 2011
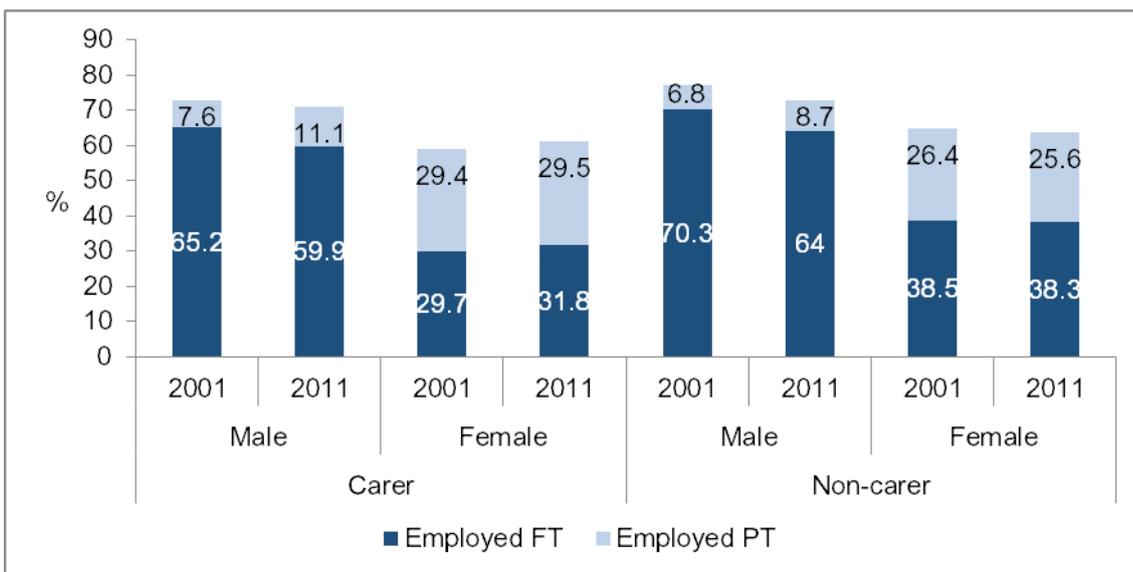
11.3 Summary

Overall, there were many similarities in the social inclusion outcomes for carers in Australia and England. However, there are also salient differences.

Young carers in Australia, particularly females, experienced more educational disadvantage than young carers in England in 2011. The disadvantage in Year 12 completion rates for young women who are carers has reduced in both countries over time, but especially in England. The gendered disadvantage of caring in education is reinforced in the finding that young female carers have the highest rates of NEET. This disadvantage has lowered over the time periods considered in both countries. However, in 2011, in both countries, one in five young women with caring responsibilities did not participate in education or employment.

Carers in England had slightly higher rates of paid employment and full-time employment compared to Australia in 2011. In both countries, women who were carers in the 25–44 year age group were most disadvantaged when compared with their peers. Employment rates for carers stayed fairly constant over the time periods in each country, with slight increases for female carers.

Young carers in both countries were more disadvantaged in terms of access to resources than older carers, reflecting pathways into caring and opportunities to accumulated resources at different points in the life course. The housing profile of carers in both countries also reflects differences in the age profile of carers, with carers being older and therefore more likely to own their homes. The national differences in the structure of the housing market are evident in the higher rates of private and lower rates of public rental for carers in Australia compared with England. A further question to be explored is the significance of the quality of housing and security of tenure for renters on other aspects of carers' social inclusion in Australia and England.

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Reconceptualising social inclusion to acknowledge informal care stakeholder and carer focus group

The aim of this component of the research was to develop a framework for understanding the potential contradictory status of informal care in social inclusion theories, empirical analyses and policies, and develop indicators of social inclusion most relevant to carers.

A review of academic and policy literature on social exclusion and social inclusion was conducted to inform the development of a new theoretical framework for analysing carers and defining social inclusion. Key literature and policy documents were located via the internet, government websites and bibliographic databases using key words, such as carers and: social inclusion, social exclusion, poverty, disadvantage and wellbeing.

The literature informed the development of a new theoretical framework for defining and analysing social inclusion to take account of the contradictory and competing aspects of carers' lives and possible indictors of social inclusion more relevant to carers' lives. To test the framework and possible indicators of social inclusion focus groups with key stakeholders and carers were conducted.

Fieldwork sites

The sites for the focus groups were identified in consultation with the research partners in NSW and SA. The fieldwork sites in NSW were Parramatta and the Lake Macquarie region, and in SA, the South East metro and Northern metro in Adelaide and the Yorke Peninsula, Lower North and Barossa.

Focus groups with key stakeholders

Originally workshops with key stakeholders were to be conducted in SA and NSW in a metropolitan and non-metropolitan location. In response to discussions with research partners the fieldwork methodology for Theme 1 was modified. Age- specific focus groups for carers and separate focus groups with other key stakeholders were conducted in place of the workshops.

Focus groups with key stakeholders, including service providers, policy makers and advocacy representatives from metropolitan and non-metropolitan regions, were held in the above fieldwork sites prior to the focus groups with carers. Three focus groups were conducted in NSW and one in SA. In addition, interviews were conducted with service providers who were unable attend the focus groups in each state.

The topics areas discussed in the focus groups were:

- Service provision perspective and funding and policy context
- How carers' social inclusion is supported by service providers

- Barriers to carers' social inclusion
- Facilitators of carers' social inclusion
- Aspects of funding arrangements that support and/or hinder carers' social inclusion
- Alternative indicators of social inclusion and how policy might support this in the domains of:
  - Recognition of the caring role
  - Opportunities for choice of taking on the caring role
  - Quality of participation in different activities
  - Spillover effects that different activities have on other activities
  - Aspects of services that support carers to juggle multiple roles
  - Cumulative impact of caring over time.

Focus groups with carers

Eleven focus groups with carers have been held in SA and NSW. As the types of activities carers are involved in outside of providing support can vary according to age the focus groups were organised accordingly:

1. young adult carers aged between 18 and 25 years
2. mid-aged carers aged 26 and 64 years
3. older carers aged 65 years and over.

In all fieldwork sites three age specific focus groups were conducted with the exception of Parramatta, where attempts to recruit young adult carers through local services failed to identify any potential participants. A total of 66 carers were involved in the focus groups. The number of participants per areas by age groups are listed below in Table A1.

Table A1 Composition of Focus Groups for Theme 1

	Metro	Non-metro
SA		
Older carers	10	8
Mid-age carers	7	6
Young adult carers	5	3
NSW		
Older carers	3	9
Mid-age carers	2	11
Young adult carers		2

The topics areas discussed in the focus groups with carers were:

Background

- Caring situation
- Recognition as a carer
- Choice about taking on caring

Participation

- Activities that carers are involved in (caring, paid work, social activities and volunteering)
- Factors that assist carers to take part in different activities
- Factors that make it difficult for carers to take part in different activities

Spillover

- How carers juggle different roles e.g. carer, friend, parent, employee, community member
- The effects of taking part in one activity on other activities

Alternative way to think about carers' social inclusion

- Suggestions for policy makers and service providers to assist carers to be socially included
- Alternative measures of social inclusion relevant to carers

Check-back focus groups with carers

Two check-back focus groups were conducted in December 2015 with mid-age and older carers in NSW. Feedback from young adult carers in SA was obtained via Skype and email in January 2016. The topics areas discussed in the focus group included:

- Introduction and overview of the progress of the project
- Summary of the findings of the focus groups
- Comments on the feedback document
- Suggested changes and gaps
- Summary and next steps in the project.