



# Carers and Social Inclusion Summary Report

Never Stand Still

Art & Social Sciences

Social Policy Research Centre



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**This report is a summary document of the main research report of the Australian Research Council Linkage project (LP110400160) on Carers and Social Inclusion which can be found at**

<https://www.sprc.unsw.edu.au/research/projects/carers-and-social-inclusion/>

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**Disclaimers**

The views expressed herein are those of the authors, and not necessarily those of the Australian Research Council or the above departments or the responsible Ministers.

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# 1 Introduction

Carers are people who provide support and assistance to people with disability, mental health issues, chronic illness, frailty due to ageing, or alcohol and other drug dependencies.

Carers make enormous contributions to society and experience significant challenges. This research project focused on how we might assess the social inclusion of carers.

Any person can become a carer, and most people will provide, and all will receive, care at some point over their life course. People usually become carers because of an existing relationship with the person they care for. An accident, event or health condition arises which may change the nature of that relationship, as new support needs emerge.

Carers are also members of the broader society. Social, political and economic arrangements affect carers' relationships, the activities carers are able to do and how they spend their time. Caring may affect the roles that people normally undertake: being a paid worker, studying, contributing to the community and supporting family and friends.

## Social Inclusion

The idea of **social inclusion** is that all members of a society should have the opportunity to participate in activities that are recognised and valued in that society<sup>1</sup>. The term **social exclusion** is used to describe groups that miss out on, or are left out of, some forms of participation<sup>2</sup>. In research, there are different ideas about:

- the nature of the people who are 'excluded' and 'included'
- why people are 'excluded' or 'included'
- how we can measure 'exclusion' or 'inclusion'
- whether the ideas of social inclusion and exclusion can be useful in assessing social disadvantage and promoting policies that seek a more inclusive and just society.

Existing measures of social inclusion are not adequate to account for carers' lives. They do not take into account the contributions of carers, their complex relationships, and their competing responsibilities. To date, concepts and measures of social inclusion are limited in that they focus mainly on participation in employment and education and also do not address the terms of inclusion. Alternative ideas, measures and indicators of social inclusion for carers are discussed further in **Section 4**.

## 1.1 Why did we do this research?

To date, research has described carers' lives and situations based on conventional measures of disadvantage or social exclusion. The research in this project sought to address a number of gaps in what we know:

- 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?
- How is care and social inclusion perceived in Aboriginal and Torres Strait Islander communities in Australia?
- What changes are needed to make the idea and indicators of social inclusion more relevant to carers' lives and experiences?
- What policies might support carers' social inclusion?
- What lessons we can learn about policies from countries such as England?

## 1.2 How did we do the research?

Literature &  
policy review

Discussions with  
carers

Data analysis

### Literature and policy review

The research had three themes:

#### 1. Reconceptualising social inclusion to account for care

This theme explored research and policy about:

- Concepts and measures of social inclusion.
- Social care and ethics of care theories.

#### 2. Care and social inclusion in Indigenous communities

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

#### 3. Care and social inclusion in Australia and England

This theme explored similarities and differences in policies for carers in Australia and England over the last two decades to identify any policy lessons for Australia.

## Discussions with carers

### Focus groups

Focus groups were conducted with 66 carers at different points in the life course (young adult carers aged 18-25 years<sup>3</sup>, mid age carers aged 26-64 years, older carers aged 65 years and older) and with service providers in South Australia and New South Wales in metropolitan and non-metropolitan locations. Carers were invited by service providers in their area to participate in the focus groups. Stakeholders were contacted through organisations who were research partners in the project. Carers and service providers were asked to consider their perspectives on a range of questions:

- What activities do carers do and what do they miss out on?
- What helps carers 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?

### Yarning circles

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

## Data analysis

### Carers and social inclusion in Australia

Two sources of data were used to analyse the extent of social inclusion and social exclusion of carers in Australia:

(1) *Australian Bureau of Statistics (ABS) Census of Population and Housing (Census)* data for 2006 and 2011 to analyse social exclusion outcomes in the domains of participation and resources for:

- male and female carers of different age groups for:
  - all carers
  - carers from Aboriginal and Torres Strait Islander communities
  - Culturally and Linguistically Diverse (CALD) carers
  - carers in geographical areas (Local Government Areas) in New South Wales and South Australia

## Data analysis (cont.)

- social exclusion indicators for carers in geographical areas (Local Government Areas) in New South Wales and South Australia

Comparisons were made between carers and their non-carer peers in each age and gender group to measure overall levels of carers' social exclusion and gaps or the relative disadvantage of carers compared to non-carers.

(2) *The Household, Income and Labour Dynamics in Australia (HILDA) Survey* (2005-2013) to analyse other social inclusion indicators in the domains of:

- participation (employment status, nature of working life; quality of working life, social participation)
- resources (economic and social resources)
- quality of life (physical and mental health, stress, self-esteem, efficacy and life satisfaction)
- additional indicators (time pressure, spillover effects and cumulative effects).

### Comparative analysis: Australia and England

The Censuses from Australia and England were analysed to assess the relative rates of social inclusion in each country. The analysis explored:

- differences in outcomes for carers in 2011 in the two countries.
- similarities and differences in changes over time in participation indicators for Australia between 2006 and 2011 and for England between 2001 and 2011.

Differences in 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.

# 2 Research Findings

## 2.1 What does a socially inclusive society mean for carers themselves<sup>4</sup>?

### Carers told us that a socially inclusive society would provide:

- recognition for carers of their roles, relationships and responsibilities and the impact of caring on their lives
- support through information, services, and financial assistance for carers to manage their caring roles
- opportunities for choices about participating in other aspects of their lives: employment, school, community and social activities
- greater community awareness about ageing, illness and disability and better understanding of carers' lives: what they value and what they need.

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.

Existing ideas and measures of social inclusion do not address many of these aspects of carers' lives. **Section 4** explores an alternative way of thinking about and measuring carers' social inclusion that focuses on carers' roles, relationships and responsibilities.

### What a socially inclusive society means for:

#### Young adult carers

- Recognition of young adult carers' knowledge, skills and expertise in their caring role from health professionals and other service providers.
- Access to information, individualised and flexible support services and carer-friendly educational structures and employment conditions.

#### Mid-age carers

- Public awareness of disability and caring to enhance a sense of belonging in the community.
- Access to information about services and assistance to develop 'service literacy' to enable them to access the support they needed.

## What a socially inclusive society means for:

### Mid-age carers (cont).

- Flexible employment conditions, such as working part-time and understanding and supportive management.
- Time away from their caring role in the form of retreats or respite services to facilitate social connections to other carers.

### Older carers

- Access to flexible and high quality respite and well-developed support networks, such as those found in retirement villages and from extended family.
- Accessibility in public spaces for carers and their relatives.

## 2.2 What aspects of life are most important or challenging for carers<sup>5</sup>?

- Carers started caring for different reasons and in different ways – sometimes as a result of a dramatic event or sometimes due to slow deterioration of their relatives' health over time.
- Carers provide 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' relationships were very important and rewarding but also affected other parts of their lives.
- 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 the own 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.

## What aspects of life are most important or challenging for:

### Young adult carers

- Young adult carers faced many challenges completing school, studying at university or TAFE or finding work that accommodated their caring responsibilities.
- Young adult carers' future choices and transition to adulthood often were constrained by their caring roles and may set them on a pathway to disadvantage and social exclusion.

### 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 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.

### 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 for their mental and physical health.
- Policies that redirect support away from carers in their own right may pose a risk to carer's social inclusion if services for carers are reduced.

## 2.3 How are care and social inclusion perceived in Indigenous communities?

### Literature review<sup>6</sup>

#### Caring

- 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.

### Services<sup>7</sup>

Indigenous carers’ experiences of services vary. However, 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.

### Yarning circles<sup>8</sup>

In the ‘yarning circles’ in Aboriginal communities in South Australia, 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.

**Yarning circles<sup>8</sup> (cont.)**

- 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 to pass on and receive 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.

# 3 What Does Existing Data Tell Us About Carers' Social Inclusion?

## 3.1 Data analysis<sup>9</sup>

Analysis of the *Census* and the *HILDA Survey* was conducted to examine what existing data tells us about carers' social exclusion and inclusion. This analysis drew on existing indicators of social exclusion for the *Census* in the areas of participation and resources. It examined geographical variations in rates of social exclusion for carers and their outcomes compared to their peers. Outcomes for carers and changes over time in Australia (2006-2011) and England (2001-2011) were compared using *Census* data for each country. The project also explored a wider range of indicators, including elements of quality of life and some aspects of the new indicators proposed in this project, in the *HILDA Survey* data (2005-2013).

## 3.2 Australia

### Participation

#### Education and employment<sup>10</sup>

- 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<sup>11</sup>.

## Participation (cont.)

### Quality of work<sup>12</sup>

- 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.

### Social participation<sup>13</sup>

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

### In Aboriginal and Torres Strait Islander communities<sup>14</sup>

- 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 less than 45 years were more disadvantaged in rates of employment.

### Among carers from culturally and linguistically diverse (CALD) backgrounds<sup>15</sup>

- Young women were more disadvantaged with regard to Year 12 completion compared to their non-carer peers.
- Female carers aged 25-44 years and male carers aged over 45 years were more disadvantaged with respect to employment participation.

## Resources

- Overall, young carers were more disadvantaged with respect to household income, homeownership 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<sup>16</sup>.
- 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<sup>17</sup>.
- Compared to their non-carer peers, female carers were more likely to say that they were poor and also unable to save<sup>18</sup>.
- 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<sup>19</sup>.
- Compared to non-carers, carers, particularly carers aged 25-44 years, lacked social support<sup>20</sup>.

### Aboriginal and Torres Strait Islander carers:

- Young male carers were more disadvantaged with respect to access to the internet and income<sup>21</sup>.

## Quality of life

- 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<sup>22</sup>.
- Female carers aged under 45 years had the highest rates of stress compared to their peers.
- Overall, carers report lower levels of life satisfaction and personal efficacy.
  - Female carers in all age groups and young male carers reported lower levels of life satisfaction than their non-carer peers<sup>23</sup>.
- Carers reported a greater sense of time pressure than non-carers<sup>24</sup>.
- Female carers who are also parents report higher levels of work-family conflict and male carers report lower levels of work-family facilitation than their non-carer parent peers<sup>25</sup>.

### Geographic disadvantage<sup>26</sup>

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 than metropolitan areas.
- Carers had lower rates of employment than non-carers in nearly all LGAs in NSW and SA, especially carers without a non-school qualification.
- Carers in regional areas in NSW and SA were most disadvantaged compared to non-carers 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.

## 3.3 Comparing carers' social inclusion outcomes in Australia and England

- 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<sup>27</sup>.
- The gendered disadvantage of caring in education is reinforced in the finding that young female carers have the highest rates of not being in employment or education or training (NEET) in both countries. Although the rates have 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<sup>28</sup>.
- Carers in England had slightly higher rates of paid employment and full-time employment compared to Australia in 2011<sup>29</sup>.
- In both countries, women who are carers in the 25-44 years age group are most disadvantaged when compared with their peers<sup>30</sup>.
- Employment rates for carers stayed fairly constant over the time periods in each country, with slight increases for female carers<sup>31</sup>.
- Young carers in both countries are more disadvantaged in terms of access to resources than older carers, reflecting pathways into caring and opportunities to accumulate resources at different points in the life course<sup>32</sup>.
- The national differences in the structure of the housing market are evident in the higher rates of private rental 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 their social inclusion in Australia and England<sup>33</sup>.

# 4 Changes to the Idea and Indicators of Social Inclusion

## 4.1 Reconceptualising the idea of social inclusion<sup>34</sup>

### **The idea of social inclusion**

The idea of social inclusion needs revising to:

- account for carers' lives and relationships
- have greater emphasis on the structural inequalities and social practices that include or exclude carers
- pay more attention to terms on which carers are included in activities, such as the equality of participation in paid work.

The idea of social inclusion should focus on carers' roles, relationships and responsibilities:

- carers' roles need to be understood in relation to the broader health, aged and disability care systems as both a co-worker (partner in care) and co-client (having needs and a life of their own)<sup>35</sup>
- care relationships need to be understood in the context of the histories, complexities, obligations and responsibilities of different types of relationships and how this might affect carers' decisions and social inclusion<sup>36</sup>
- attention needs to be paid to the allocation of responsibility to care and the distribution of care in society<sup>37</sup>.

### **Explaining social inclusion and exclusion**

Explanations for social exclusion in existing research include those that:

- focus on individual deficits
- assume inclusion through any form of paid work, and
- examine distributional issues and structural inequalities<sup>38</sup>.

Explanations for carers' social inclusion and exclusion should focus on social structures and whether these create an equitable distribution of responsibilities to provide care and help or hinder carers' participation in other aspects of their lives.

### Measuring social inclusion<sup>39</sup>

Existing measures of social inclusion are not adequate to account for carers' lives. To date, concepts and measures of social inclusion are limited in that they:

- focus mainly 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.

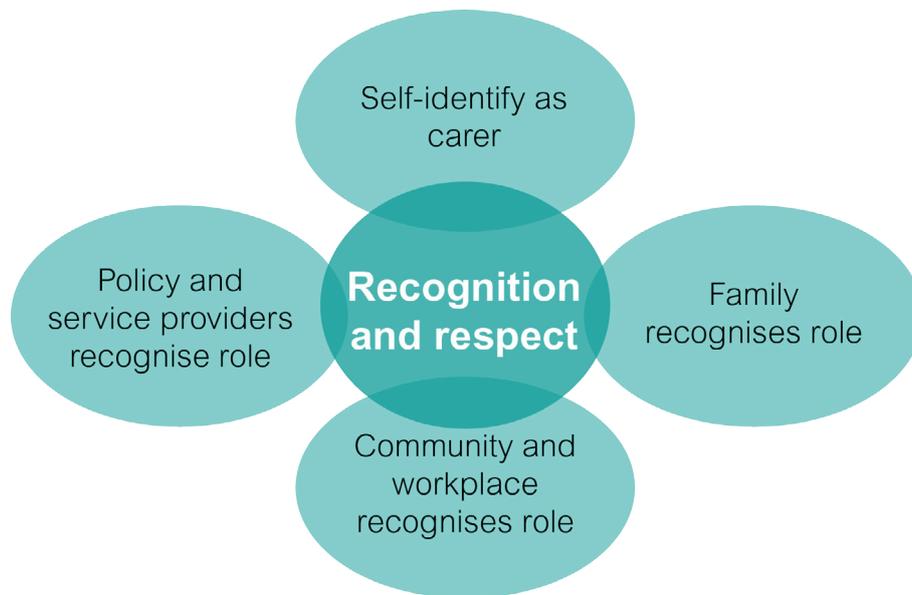
## 4.2 New indicators of social inclusion<sup>40</sup>

New indicators of social inclusion that have relevance for carers' lives were developed based on a review of existing ideas and measures of social inclusion and the focus groups with carers and service providers. These indicators address the following aspects of:

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

### 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.



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 that carers' views and knowledge are taken into account in the assessment process conducted 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 a threshold measure. If a person falls above or below a certain point on a scale, they are categorised as 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.



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.

Examples of possible indicators (cont.):

**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.

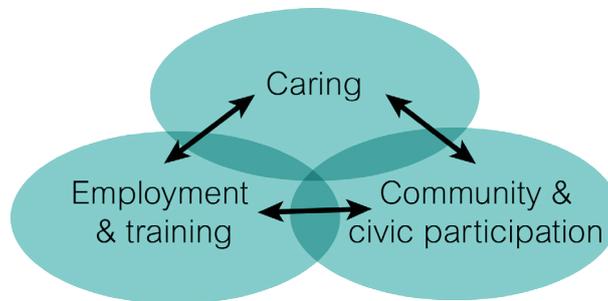


Examples of possible indicators include:

- 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 reduced 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.

## 4.3 Suggestions from carers and stakeholders for indicators of social inclusion

### Young adult carers<sup>41</sup>

#### *Multiple activities*

- Percentage of young adult carers who are doing more than one activity at a time in addition to caring.
- Percentage of young adult carers 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 young adult carers can get away from their caring responsibilities.
- Types of activities young adult carers are involved in when they are not caring.

#### *Health*

- Ratings of physical health and mental health.

## **Young adult carers (cont.)**

### ***Services and support***

- Young adult carers' satisfaction with their access to respite services.
- Percentage of young adult carers who access support groups.
- Percentage of young adult carers with access to family support.

### ***Transport***

- Percentage of young adult carers who have a driving licence.
- Young adult carers' access to transport – public and private.

### ***Employment and education***

- Percentage of young adult carers studying their preferred course.
- How easy or difficult was it for young adult carers to find paid work?
- Percentage of young adult carers accessing on-the-job training

## **Mid-age carers<sup>42</sup>**

### ***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 choice.
- Percentage of carers who access training to re-enter the workforce.
- Percentage of carers with access to flexible employment conditions, such as job sharing.

**Older carers<sup>43</sup>*****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.

**Stakeholders<sup>44</sup>**

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

## 4.4 Social inclusion indicators for Aboriginal and Torres Strait Islander carers<sup>45</sup>

Social inclusion indicators relevant to the lives of carers in Aboriginal and Torres Strait Islander communities were developed after the review of the literature and the yarning circles.

These indicators encompass aspects of:

- **Recognition**
- **Health and wellbeing**
- **Culture and heritage**
- **Services**
- **Education and employment**
- **Resourcing**

### 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<sup>46</sup>. 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 not receive the support they need, or may not be able to participate in things that give them meaning. Indicators could include: self-recognition as a carer, and recognition as a carer by workplace, family and friends, community, and services.



### 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.



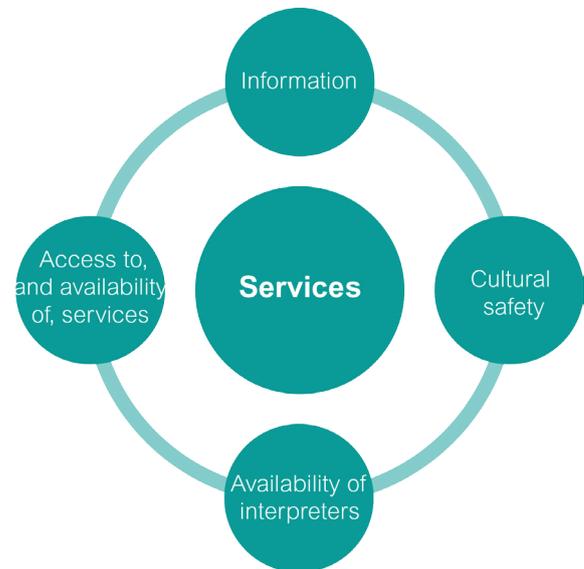
## Culture and heritage

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).



## 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.



## 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.



## 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.



# 5 Policies to Support Carers' Social Inclusion

## 5.1 What policies support carers' social inclusion?<sup>47</sup>

Policies that support carers were identified through reviewing key literature and policy documents in Australia and England to identify any policy insights for the Australian 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. Suggestions for policies for carers in Australia were also discussed with carers and services providers.

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.

Policies to support carers' social inclusion should be based in understanding that carers have a life and needs of their own, that are both separate and intertwined with the person or people they care for.

Key policies that are required are:

- Income support that is adequate and flexible.
- Carer recognition and rights legislation, which carries entitlements for carers to be assessed for services (in their own right).
- Workplace and labour force measures that provide right to request flexible employment arrangements for all employees with caregiving responsibilities, as well as 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.
- Services that are adequately funded to provide support for carers and the people they care for.

## Carers' suggestions to policy makers and service providers

### Young adult carers<sup>48</sup>

#### **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 young adult carers.
- 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 young adult carers through financial support or discounted membership.
- Improved access to mental health support and counselling for young adult carers and their families using a holistic approach.

#### **Transitions**

- Increased support, such as case management or advocacy for young adult carers, through key transitions periods eg. 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 young adult carers.

**Rural areas**

- Increased transport options.
- Develop a scheme to help young adult carers 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.

**Mid-age carers<sup>49</sup>****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 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 a key access point to services.
- Access to counselling or support workers to assist with the stress associated with caring and other mental health issues.
- Programs to help carers have the opportunity for exercise, such as gym membership.
- Greater access to services that target different needs ie different types of support groups, appropriate services for care recipient 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 care 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.
- Increase the 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.

### **Older carers<sup>50</sup>**

#### ***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 the 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.
- Increased 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.

## 5.2 What social inclusion policies exist and what would support Aboriginal and Torres Strait Islander carers?

### Literature Review<sup>51</sup>

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.

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.

### Suggestions from the yarning circles for policy makers included<sup>52</sup>:

- Recognition for carers and their cost saving role.
- Human rights should be upheld and respected.
- On-going and continuous funding for Aboriginal and Torres Strait Islander 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 and Torres Strait Islander 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 Aboriginal and Torres Strait Islander and non-Indigenous peoples in Australia.

### 5.3 What lessons we can learn about policies for carers from countries such as England?<sup>53</sup>

Social inclusion is also specific to the national context. England has a longer history than Australia in developing policies that might support genuine choice for carers to participate in many aspects of their lives, including overarching carers' strategies and rights enacted through legislation<sup>54</sup>. The policies have envisaged carers as individuals with multiple roles: partners in social care, employees, service users, and partners in health services<sup>55</sup>. Such policy directions have been challenged by the impact of the Global Financial Crisis and the subsequent austerity measures. This project examined what lessons such policy developments might hold for Australia.

#### **Carer recognition**

In England (and the countries of the UK covered by the Care Act 2014), unlike Australia, carer recognition and rights legislation carries entitlements for carers to be assessed for services (in their own right). However, such legislation needs to be supported by sufficient government funding and provision of appropriate caregiver support policies to be effective.

#### **Income support**

Income support in both countries is paid at a low rate and eligibility criteria make it difficult for carers to combine employment and receipt of carer benefits.

#### **Services**

At the national level, services in Australia for carers primarily focus on information, respite, counselling and support, training for carer role, peer support groups, support for young carers to remain in education and training, and a website to support skills recognition for carers seeking employment. Other supports for carers may be provided at the local, and state and territory level. Unlike England, Australia has no right to an assessment of carers' own needs for various services established at the national level. While rights provide a framework, they are only effective if supported by adequate funding for services.

## Employment

Both countries have a right for carers to request flexible work. In England, this right is available to all employees, which may reduce the stigma of taking up flexible work. In Australia, unlike England, carers have a right to paid carers leave. In Australia, however, casual employees are excluded from eligibility for flexible work and carers leave.

## Policy frameworks to support carers

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<sup>56</sup>. 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<sup>57</sup>.

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' (eg with income support) and avoid 'excessive care burdens' (eg with respite care)
- 'support informal caregivers in delivering adequate support' (information, counselling, support networks)<sup>58</sup>.

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'<sup>59</sup>.

## Policies in Australia and England<sup>60</sup>

This study focused on national level legislative policy similarities and differences, and notes that States and Territories In Australia have their own legislation and policies recognising and supporting carers.

### **Recognition legislation:**

- In Australia, *Carer Recognition Act 2010 (Cth)*:
  - Aims to increase recognition and awareness of the role that carers play in providing support. The Act also places a number of obligations with respect to carers on Commonwealth public agencies and their contractors.
  - However, the Act does not, unlike similar legislation in England, involve a right to assessment of carers' needs to receive services or 'place any enforceable obligations' on service providers to meet carers' needs.
- In England, the *Care Act 2014*:
  - Gives carers the right to support and services as well as to assessment of their needs for various services.

- Gives Local Authorities 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/well-being support; information and advice; emotional support. Some Local Authorities offer carers help to return to work/manage work and care.

### **Income support:**

At the national level, services in Australia for carers primarily focus on information, respite, counselling and support, training for carer role, peer support groups, support for young carers to remain in education and training, and a website to support skills recognition for carers seeking employment. Other supports for carers may be provided at the local, and state and territory level. Unlike England, Australia has no right to an assessment of carers' own needs for various services established at the national level. While rights provide a framework, they are only effective if supported by adequate funding for services.

### **Services:**

In Australia:

- The co-design of a new integrated carer support service system will continue to be undertaken through 2016.
- The information provided to carers through the 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, neither of which facilitate combining care and employment.

In England:

- The Care Act 2014 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 Local Authorities). However, insufficient funding to Local Authorities has resulted in a fall in the number of carers receiving 'carer specific' services between 2007-08 and 2012-13.

### **Employment**

- In Australia the *Fair Work Act 2009 (Cth)* and in England the *Work & Families Act* from 2014 provide the right to request flexible working arrangements after a period of employment to establish entitlement (in England the right to request flexible working arrangements is provided to employees without reference to caregiving responsibilities).
- However, in comparison with the Australian legislation, in England there is no established right to paid 'carers leave', which remains a voluntary option offered by only some employers.
- It is of considerable importance that workplace and labour force measures provide the right to request flexible employment arrangements for all employees with caregiving responsibilities, as well as paid leave.

In Australia and England, 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 and engage in other modes of social inclusion.

# 6 Conclusions

## **What does a socially inclusive society mean for carers themselves?**

Carers told us that a socially inclusive society would provide recognition of their roles, relationships and the impact of caring on the rest of their lives, support, opportunities for choice and greater community awareness and accessibility. Carers often prioritized the social inclusion of those they care for over their own social inclusion. A socially inclusive society for carers would aim to eliminate the need to make that choice.

## **What aspects of life are most important or challenging to carers?**

Carers' roles and relationships are both rewarding and challenging. A key challenge is the lack of recognition of their contribution to society by governments and the broader community. The often unpredictable demands of caring may lead to disengagement from education, employment, community and social activities, usually contrary to the wishes and aspirations of carers themselves. Service providers suggested that carers need more support to access appropriate services and to relieve guilt feelings about asking for help.

## **How are care and social inclusion perceived in Aboriginal and Torres Strait Islander communities?**

Caring is part of love, obligation, responsibility and reciprocity. Caring is diverse in nature and facilitates more than just practical aspects of care. Considering carers as part of a network that extends through and beyond family, friends and community and interacts with services and policy makers may suggest innovative policy responses.

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

Carers are disadvantaged with respect to participation: Overall, carers, particularly female carers, have lower rates of education and employment participation and social participation. Young male carers in Aboriginal and Torres Strait Islander communities and female carers in CALD communities experience significant disadvantages.

Carers lack economic and social resources. Overall, carers report higher levels of poverty and financial stress. Young carers live in households that are more disadvantaged with respect to resources. Carers also lack social support.

Carers have lower quality of life: lower average scores for physical and mental health, high rates of stress, lower levels of life satisfaction and personal efficacy, and greater time pressure. Carers who are also parents face challenges in reconciling time spent in work and life.

Geographical location matters for carers' outcomes: carers in regional areas are more disadvantaged with respect to education, employment and income.

National context may matter for carers' outcomes: young carers in England are less disadvantaged than young carers in Australia with respect to education although in both countries, female carers are more disadvantaged than male carers in relation to not being in education, training or employment.

### **What changes are needed to make the idea and indicators of social inclusion more relevant to carers' experiences?**

The idea of social inclusion needs revising to:

- account for carers' lives and relationships
- have greater emphasis on the structural inequalities and social practices that include or exclude carers
- pay more attention to terms on which carers are included in activities, such as the quality of participation in paid work.

New indicators of social inclusion for carers need to encompass:

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

New indicators of social inclusion for Aboriginal and Torres Strait Islander carers should include:

- Recognition
- Health and wellbeing
- Culture and heritage
- Services
- Education and employment
- Resourcing

### **What policies might support carers' social inclusion?**

Key policies that are required are:

- Income support that is adequate and flexible.
- Carer recognition and rights legislation, which carries entitlements for carers to be assessed for services in their own right.
- Workplace and labour force measures that provide the right to request flexible employment, as well as paid leave, regardless of employment type.

- Services that are adequately funded to provide appropriate and affordable support for carers and the people they care for.

For Aboriginal and Torres Strait Islander carers, policies need to address recognition, rights, resources, services and support, information, listening to carers, and the relationship between Aboriginal and Torres Strait Islander and non-Indigenous peoples in Australia.

### What lessons can we learn from countries such as England?

England has a longer history than Australia in developing policies that might support genuine choice for carers to participate in many aspects of their lives, including overarching carers' strategies and rights enacted through legislation. Key among these has been the assessment of carers' needs in their own right. Legislation, however, needs to be supported by adequate resources, if it is to be effective. This includes adequate income support and services designed to help carers remain in and return to employment. In England, the right to request flexible work is available to all employees, while in Australia some categories of employees, such as casuals, are excluded.

# Endnotes

<sup>1</sup>Silver, H. (2010). Understanding social inclusion and its meaning for Australia. *Australian Journal of Social Issues*, 45(2), 183–211; Silver, H. (2015). *The contexts of social inclusion*, viewed on 31 December 2015 at SSRN:<http://ssrn.com/abstract=2641272> or <http://dx.doi.org/10.2139/ssrn.2641272>

<sup>2</sup>See for example Levitas, R. (1998). *The Inclusive Society?: Social Exclusion and New Labour*: Palgrave Macmillan, Basingstoke; Daly, M. & Silver, H. (2008). Social Exclusion and Social Capital: A Comparison and Critique. *Theory and Society*, 37(6), 537–566.

<sup>3</sup>Young carers who participated in this research were aged between 18-25 years. We refer to this group as young adult carers as it does not include all young carers.

<sup>4</sup>See Section 3 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>5</sup>See Section 3 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>6</sup>See Section 7.2 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>7</sup>See Sections 7.3 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>8</sup>See Section 8 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>9</sup>See Section 4 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>10</sup>See Section 4.1.1 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>11</sup>Jobless households are defined as having no adults (15 years and over) in employment.

<sup>12</sup>See Section 6.1 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>13</sup>See Section 6.1 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>14</sup>See Section 4.2 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>15</sup>See Section 4.3 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>16</sup>See Section 4.1.2 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>17</sup>See Section 6.2 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>18</sup>See Section 6.2 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>19</sup>See Section 6.2 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>20</sup>See Section 6.2 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>21</sup>See Section 4.2 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>22</sup>See Section 6.3 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>23</sup>See Section 6.3 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>24</sup>See Section 6.4 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>25</sup>See Section 6.4 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>26</sup>See Section 5 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>27</sup>See Section 11.1.1 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>28</sup>See Section 11.1.1 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>29</sup>See Section 11.1.1 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>30</sup>See Section 11.1.1 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>33</sup>See Section 11.1.1 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

<sup>32</sup>See Section 11.1.2 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.

- <sup>33</sup>See Section 11.1.2 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>34</sup>See Section 2.1 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>35</sup>Twigg, J. & Atkin, K. (1994). *Carers perceived: Policy and practice in informal care*. Buckingham: Open University Press. See Section 2.2 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>36</sup>E.g. Sevenhuijsen, S. (1998). *Citizenship and the Ethics of Care. Feminist Considerations on Justice, Morality and Politics*. Routledge, London and New York; Sevenhuijsen, S. (2000). Caring in the Third Way: The Relationship Between Obligation, Responsibility and Care in Third Way Discourse. *Critical Social Policy*, 62, 5-37; Tronto, J. (2013). *Caring Democracies: Markets, Equality and Justice*. New York University Press, New York. See Section 2.2 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>37</sup>Tronto, J. (2013). *Caring Democracies: Markets, Equality and Justice*. New York University Press, New York. See Section 2.2 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>38</sup>Levitas, R. (1998). *The Inclusive Society?: Social Exclusion and New Labour*. Palgrave Macmillan: Basingstoke; Levitas, R. (2003). *The Idea of Social Inclusion*. Social Inclusion Research Conference, 'What do we know and where do we go? Building a social inclusion research agenda, Canada at [www.ccsd.ca/events/inclusion/papers/rlevitas.htm](http://www.ccsd.ca/events/inclusion/papers/rlevitas.htm). See Section 2.3 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>39</sup>See Section 2.4 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>40</sup>See Section 3.5 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>41</sup>See Section 3.1 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>42</sup>See Section 3.2 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>43</sup>See Section 3.3 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>44</sup>See Section 3.4 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>45</sup>See Section 9 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>46</sup>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>
- <sup>47</sup>See Section 10 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>48</sup>See Section 3.1 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>49</sup>See Section 3.2 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>50</sup>See Section 3.3 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>51</sup>See Section 7.1 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>52</sup>See Section 8.7 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>53</sup>See Section 10 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.
- <sup>54</sup>Yeandle, S., Bennett, C., & Buckner, L. (2007). *Carers, Employment and Services in their Local Context*, Carers UK. <http://www.carersuk.org/Policyandpractice/Research/CarersEmploymentandServices/1201172496/2650-carersukreport4.pdf>.
- <sup>55</sup>Yeandle, S., Bennett, C., Buckner, L., Fry, G., & Price, C. (2007). *Managing caring and employment: Carers, Employment and Services Report no. 2*, Carers UK. <http://www.sociology.leeds.ac.uk/assets/files/research/circle/carers-uk-report-2.pdf>
- <sup>56</sup>Twigg, J. & Atkin, K. (1994). *Carers perceived: Policy and practice in informal care*, Open University Press, Buckingham.
- <sup>57</sup>Schneider, U., Sundstrom, G., Johannson, L. & Tortosa, M. (2016). Policies to support informal care. In Gori, C., Fernandez, J-L. & Wittenberg, R. (Eds.), *Long-term Care Reforms in OECD Countries*, Policy Press: Bristol, 219-244.
- <sup>58</sup>Schneider, U., Sundstrom, G., Johannson, L. & Tortosa, M. (2016). Policies to support informal care. In Gori, C., Fernandez, J-L. & Wittenberg, R. (Eds.), *Long-term Care Reforms in OECD Countries*, Policy Press: Bristol, 223-224.
- <sup>59</sup>Schneider, U., Sundstrom, G., Johannson, L. & Tortosa, M. (2016). Policies to support informal care. In Gori, C., Fernandez, J-L. & Wittenberg, R. (Eds.), *Long-term Care Reforms in OECD Countries*, Policy Press: Bristol, 224.

<sup>60</sup>See Section 10 in *Carers and Social Inclusion: Final project report*. Sydney: SPRC, UNSW Australia.