



**Submission to the Senate  
Inquiry into Regional and Remote  
Indigenous Communities**

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## Table of Contents

<b>Introduction...</b>	<b>1</b>
<b>About Australia's Carers .....</b>	<b>1</b>
<b>About Carers Australia .....</b>	<b>1</b>
<b>Indigenous Carers: a forgotten demographic .....</b>	<b>2</b>
Incidence of disability and illness in Indigenous communities.....	2
Ageing in Indigenous communities.....	3
<b>Supporting Regional and Remote Indigenous Carers .....</b>	<b>3</b>
Measuring the impact .....	3
Considering young Indigenous carers.....	4
Research into carer needs .....	4
Indigenous carer programs.....	5
<b>Conclusion...</b>	<b>5</b>
<b>References...</b>	<b>6</b>



## **Introduction**

Thank you for inviting Carers Australia to respond to the Inquiry into Regional and Remote Indigenous Communities. Our submission focuses on a very often forgotten group in Indigenous communities— family carers. This submission does not directly address the terms of reference for the inquiry, but focuses on bringing attention to the very real presence of this group. We believe that the health and wellbeing of family carers is crucial to the long-term health and wellbeing of these communities.

The health and wellbeing of Indigenous Australians requires considered action. We would like to draw the committee's attention to the need for reviewing gaps in support within regional and remote Indigenous communities that impact on family carers.

## **About Australia's Carers**

Australia has almost 2.6 million carers, and nearly 500,000 of these are primary carers – the people who provide the most care<sup>1</sup>. Carers are from all walks of Australian society and come into the caring journey at various stages throughout their life.

Carers are the foundation of our aged and community care system, and the annual replacement value of the vital care they provide is over \$30.5 billion. It is estimated that in 2005 carers provided 1.2 billion hours of unpaid care and the productivity loss of this care is approximately \$4.9 billion.<sup>2</sup>

### **Diversity of carers**

Carers are from all walks of Australian society and come into the caring journey at various stages throughout their life. The Australian Bureau of Statistics has identified:

- 350,000 Australians under the age of 25 provide care to a family member who has a disability, or a mental or chronic illness<sup>3</sup>
- 170,000 carers under the age of 18<sup>4</sup>
- 31,600 Indigenous carers over the age of 15<sup>5</sup>
- 620,000 of Australia's carers born outside Australia<sup>6</sup>
- 366,700 of those born in other than main English-speaking countries<sup>7</sup>.

## **About Carers Australia**

Carers Australia is the national peak body representing those Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Carers Australia's members are the Carers Associations in each state and territory that deliver specialist information, counselling and others services to carers in the community. Carers Australia is informed about carer issues through its member Carers Associations (the Network of Carers Associations) and its participation in national and international forums.

We believe that all carers are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education.

## **Indigenous Carers: a forgotten demographic**

The characteristics of Indigenous carers are similar to other caring groups across the country: they are young, they are old, and they are of working age. They can be single parents and they can be caring across the generations. But most importantly, they are doing it tough and caring is having an impact on their health and wellbeing.

According to the 2006 Census of Population and Housing, the Health and Welfare of Australia's Aboriginal and Torres Strait Islander People:

- there were 11,600 Indigenous male carers (9%) and 20,000 Indigenous female carers (14%) in 2006
- the proportion of Indigenous carers ranged from 8% of people aged 15-24 years, increased to a peak of 15% for people aged 24-54 years, and then decreased to 10% of people aged 65 years and over
- Indigenous Australians were more likely than non-Indigenous Australians to care for another person with disability, long-term illness or problems related to old age
- Indigenous people aged 15–34 years were almost **twice as likely to be carers** as non-Indigenous people of the same age
- Indigenous carers were up to three times as likely as non-Indigenous carers to need assistance with core activities themselves. Around 2,100 Indigenous carers needed help with core activities.<sup>8</sup>

Wellbeing can be determined in part based on an individual's exposure to stressful life events such as disability, illness or death. Unfortunately, these are issues faced by many carers on a regular basis. Indigenous Australians as a group have been found to have low social and emotional wellbeing, and a high level of exposure to life-stressors, resulting in a reduced ability for individuals to cope with the stress of life and reach their full potential.<sup>9</sup> Carers have been found to have the lowest overall wellbeing of any group,<sup>10</sup> and the wellbeing of Indigenous carers may be worse still.

The very real presence of Indigenous family carers and their reduced wellbeing must be taken into account in the government's action on Indigenous issues.

## **Incidence of disability and illness in Indigenous communities**

There is a high level of need for caring roles in Indigenous communities. The level and type of disability and illness for Indigenous Australians would require significant support to be provided by carers.

In 2008 the Australian Institute of Health and Welfare carried out a comparison of data from sources such as the 2006 ABS Census, the 2002 ABS NATSISS (National Aboriginal and Torres Strait Islander Social Survey), and the AIHW Databases for Hospital Morbidity, Mortality and Mental Health Care. This report showed:

- in 2002, 102,900 (36%) of Indigenous people aged 15 years and over had a disability or a long-term health condition. Of these, 21,800 had a profound or severe core activity limitation
- Indigenous people had a higher rate of profound and severe core activity limitation than non-Indigenous people in all age groups and had a higher rate of need for assistance with core activities than non-Indigenous Australians across all age groups
- the rate of disability or long-term health condition increased with age. Approximately 70% of Indigenous people aged 55 years and over had a disability or long-term health condition
- male and female Indigenous children aged 5–18 years were 1.3 and 1.5 times as likely to have a profound or severe disability as non-Indigenous children of the same age
- Indigenous Australians were almost twice as likely as non-Indigenous Australians to report their health as fair or poor
- both Indigenous males and Indigenous females had higher hospitalisation rates for mental health related conditions than other males and females across all age groups.<sup>11</sup>

Often, the caring role begins at the point of discharge from hospital following an incident of diagnosed illness or injury. The hospital discharge rate last year was 3.2 times higher for Indigenous males and 5.3 times higher for Indigenous females than the rest of the population.<sup>12</sup> These figures suggest a need for family carers to step in sooner to provide care. These carers need to be prepared and supported to take on caring responsibilities.

### **Ageing in Indigenous communities**

The need for aged care support will occur much earlier in the lives of Indigenous Australians given the 17 year gap in life-expectancy. 50 years and over is generally used to identify 'older' Indigenous Australians. Further, the Indigenous age-dependency ratio (number of people aged 65 years and over for each 100 people of working age) has also gone up in regional centres.<sup>13</sup> These factors will place significant strain on regional and remote communities to care for their older people in the years to come.

Older Indigenous Australians have low levels of access to government services according to the *Report on Government Services 2009*. Indigenous people aged 50 and over were under-represented in accessing government supported aged care facilities, CACP and HACC programs when compared to their presence in the general population. The report also showed that Indigenous people have lower rates of use for aged residential care compared with the general population (21.4 as compared with 79.6 per 1000 people).<sup>14</sup> We believe that Indigenous family carers are stepping in to care for older people who are not accessing these services. Support for these carers is essential.

## **Supporting Regional and Remote Indigenous Carers**

### **Measuring the impact**

Has the Emergency Response improved the quality of life for Indigenous family carers? This must be explored as a matter of urgency.

Carers Australia believes that any government policy regarding Indigenous communities must include a *carer impact statement*. This action would avoid negative outcomes for carers who are

already struggling. A carer impact statement is essential as the Response moves forward— the vital role that carers play has consequences for the wellbeing of entire communities.

We know that currently for carers in Australia there is confusion as to the responsibility of state/territory and the Commonwealth in the delivery of services. And on the ground, people are unsure where and how to access services. Navigating the system is often a demanding task for time-poor and financially-stretched carers. Assisting Indigenous families to know how and where to access services in regional and remote areas would have significant benefits for carers.

### **Considering young Indigenous carers**

Young carers are a particularly vulnerable group. The impact of caring on young carers can have long-term consequences in the areas of education, employment and health and wellbeing.

Education, and the transition from education to employment is a significant issue for young carers— many find that their caring responsibilities significantly disrupt or curtail their education.

- Only 4 per cent of primary carers between the ages of 15-25 years are still in education compared to 23 per cent of the general population in that age group.
- 60 per cent of young primary carers aged 15-25 are unemployed or not in the paid workforce compared to 38 per cent of the general population of 15-25 year olds.

There is an even higher risk of young Indigenous carers not making the transition from education to employment based on the low participation rates for this group.<sup>15</sup> The caring responsibilities of young carers often take precedence over school attendance and achievement. Education interventions in the Northern Territory must accommodate young carers.

*We're living these lives, we're facing this turmoil and discouragement every day. We're battling through every day and facing these circumstances which are phenomenal to so many.*

—Young Indigenous carer, QLD

Carers Australia held a National Young Carers Forum in November 2008. 32 young carer delegates took part in the forum, including several young carers who identified as Aboriginal. These young people provided an insight into the concerns and needs of the broad cross-section of young carers in Australia. Education, identification, access to government services, and respite were all identified as areas in need of attention. Improvements in these areas could make a significant difference in the lives of young people, including those carers in regional and remote communities.

### **Research into carer needs**

There is currently little research about Indigenous carer support needs and this is crucial to successfully improve their lives. Carers Australia believes that statistical analysis of the Indigenous carer population must inform the type and nature of the service delivery to carers and their communities. It is essential that the approach to Indigenous carers and communities be guided by



the age of the target group, their connection to family and community, the types of services that work in particular areas and the geographical region where the person lives.

More broadly, a recent study on *Effective Caring* undertaken by the Centre for Health Service Development at the University of Wollongong found that identifying the needs of Australian carers, and using the best evidence to meet their needs, is a national priority.<sup>16</sup> This also applies to identifying and meeting the specific needs of Indigenous carers.

More evidence is needed to understand the way in which caring is occurring within Indigenous Australian communities. This can only be achieved as a result of funding for research that provides a sound and reliable evidence base for good practice. The Carers Australia Budget Submission for 2009-10 called for carer health and wellbeing to be designated a national public health research priority and identified the need for research into specific caring groups such as Indigenous carers.

Information about the vital role played by carers would assist the government in improving the health and wellbeing of regional and remote Indigenous communities.

### **Indigenous carer programs**

Indigenous carers can be assisted through targeted programs that provide a break from caring and an opportunity to discuss their experiences with other carers.

The Network of Carers Associations currently delivers a number of successful Indigenous carer programs in regional and remote communities. Two successful Carers NT programs have been tailored to the needs of remote and regional Indigenous carers: the Troopy respite program and Ti-Tree carer education program (see Appendix A for further information). These innovative remote programs have insufficient funding to meet the demand in NT and to have more communities benefit from the program.

These programs would promote community development and community engagement. They could easily be incorporated in more regional and remote communities to support Indigenous carers in their caring role.

### **Conclusion**

Indigenous carers need recognition and assistance. The extent of the impact of the Northern Territory Emergency Response on carers in regional and remote communities is as yet unknown, and has been overlooked. It is essential that this is understood to prevent further disadvantaging the already vulnerable demographic of family carers within these communities.

Further, the government's measures to improve the health and wellbeing in regional and remote communities can only be improved by the consideration of, and response to, the needs of Indigenous carers. The needs of vulnerable young carers warrants particular attention. Family carers support the health and wellbeing of a vast proportion of society. We believe improvements to carer health and wellbeing will increase the long-term outcomes of the programs being introduced in regional and remote communities.

## References

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- <sup>6</sup> Australian Bureau of Statistics (2003) Migrants, Disability, Ageing and Carers, Australia, 2003 Cat No 34150DS004, Canberra November 2007
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- <sup>9</sup> AIHW (2009) Measuring the social and emotional wellbeing of Aboriginal and Torres Strait Islander peoples, Australia, Canberra
- <sup>10</sup> Deakin University (2007) Australian Unity Wellbeing Index Survey 17.1: The Wellbeing of Australians— Carer Health and Wellbeing, Australia, Melbourne
- <sup>11</sup> Australian Institute of Health and Welfare (2009) Aboriginal and Torres Strait Islander Health Performance Framework 2008 Report, Australia
- <sup>12</sup> Steering Committee for the Review of Government Service Provision (2009) Report on Government Services 2009, Productivity Commission, Canberra
- <sup>13</sup> Bureau of Rural Sciences (2009) Country Matters: Social Atlas of Rural and Regional Australia, 2008, Australia
- <sup>14</sup> Steering Committee for the Review of Government Service Provision (2009) Report on Government Services 2009, Productivity Commission, Canberra
- <sup>15</sup> Australian Bureau of Statistics (2008) The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples, 2008, Australia, Canberra
- <sup>16</sup> Centre for Health Services Development (CHSD) (2007) Carers Information Needs, Literature Review, August 2007, Wollongong

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## Appendix A

### Troopy and Ti-Tree programs

The Troopy program has been running for six years and is currently delivered to 36 communities in the Northern Territory. The program involves the loan of a 'troopy/troop carrier' 4-wheel-drive, camping and picnic gear to a community organisation for 4-6 weeks to allow carers to take a break from the caring role for a short time and in some cases to 'return to country'. Where the 4wd cannot be left in the care of an organisation, Carers NT staff organise camps allowing 6-10 of a community's older men or women to have time away in a nearby location of their choice. It is delivered through Government funding for the National Respite for Carers Program. This initiative provides a base of practice knowledge about the delivery of respite in remote Indigenous communities.

The Ti-Tree program, is a carers education program. It was introduced in 2007 in the Ti-tree community (north of Alice Springs) and was funded by the Australian Government. The program's aim was to promote and support carer health through 'self care' education principles and the development of a 'Looking After Me' action plan. The project involves a Carer Education Course (CEC) with resources, modified for use with the local Indigenous people. Language, concepts and strategies of the CEC are modified, Indigenous resources are used and where possible, Indigenous staff deliver the program. In the project delivered in Ti-Tree the community's activities (for example gospel singing), and cultural practices (bush tucker included in considerations of healthy eating and nutrition), were incorporated to develop culturally appropriate supports that would improve the health and wellbeing of carers.