



# Research Brief

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## **Who cares? - Profiling carers in the Northern Territory**

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## RESEARCH AIM

*Following the inclusion of the variable “unpaid assistance to a person with a disability” in the 2006 and 2011 Australian Censuses of Population and Housing, this research brief profiles carers in the Northern Territory (NT) based on socio-demographic and geographic characteristics. The brief answers the question of ‘who cares?’ and creates a baseline profile of NT carers.*

## KEY FINDINGS

- A ‘typical’ NT carer can be summarised as female, aged between 40 to 44 years old, with an income less than \$16,000 per year and living in the Darwin suburbs.
- Carers in the NT are comparatively younger than the rest of Australians providing unpaid assistance.
- 9% of the population in the NT 15 years or older provided unpaid assistance, compared with 11% for the rest of Australia.
- 38% of carers in the NT were not in the labour force, compared to 40% in the rest of Australia.
- 42% of carers in the NT were Indigenous (11% of the total NT Indigenous population) compared to 2% in the rest of Australia (at 8% of the Indigenous population in the rest of Australia).
- Significant regional differences in the composition of carers are noticeable within the Territory with up to 90% of those providing assistance in remote areas being Indigenous, indicating that Indigenous carers provide a vital community role.
- A significantly higher proportion of people in the NT (14%) did not provide a response to questions on providing assistance in the Census compared to the rest of Australia (8%), thus potentially understating the actual number of carers.

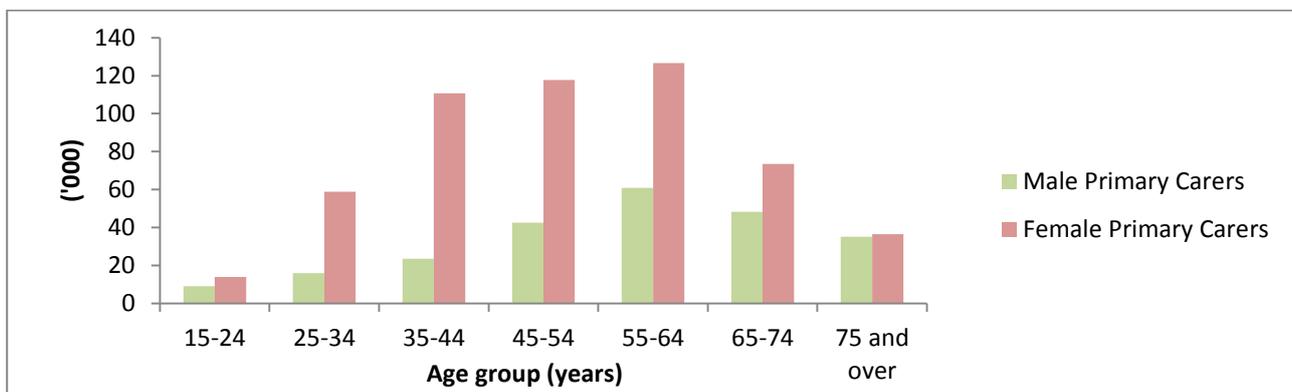
## 1. Introduction

‘Share the care’ or ‘Be Care Aware’ are just two examples of the slogans of Australia’s annual national Carer Week, which took place in late 2014 with the aim of ‘...recognising and celebrating the outstanding contribution unpaid carers make to our nation’ (Carers Australia, 2014a). The event is organised by Carers Australia, the national peak body representing Australia’s carers. Their recently released 2013-14 annual report highlighted 1 in 8 Australians have an unpaid caring role, and 34% of primary carers (the carer who provides the most informal assistance) have been caring between 10 to 25+ years (Carers Australia, 2014b). The latest national survey on this matter was the Australian Bureau of Statistics Disability, Ageing and Carers Survey (ABS, 2014a), which was conducted in 2012 and gives insights into the provision of unpaid assistance in Australia. The survey collects information from three target populations: people with disability, seniors (those aged 65 years and over), and people who care for people with disability or older people. The survey defines carers as “a person of any age who provides any informal assistance, in terms of help or supervision, to persons with disability or long-term health conditions or persons who are elderly (i.e. aged 65 years and over)” (ABS, 2014b, para. 15). The assistance has to be ongoing or likely to be ongoing for at least six months to meet the definition. Before profiling carers in the NT based on the 2011 Census, we look at the issue of informal caring on a national level including an investigation of current issues and challenges found in the literature.

## 2. Informal caring in Australia

Of the almost 2.7 million Australians that were identified in the ABS survey as carers in 2012, around 770,000 (29%) were found to be primary carers. Notably, there were almost 75,000 carers aged less than 15 years identified. In 2012, as was the case in previous surveys, females made up the majority of carers, representing 70% of primary carers and 56% of carers overall. Figure 1 provides an overview of primary carers by age and sex. It shows that most primary carers were aged 55 to 64 years. There were almost equal numbers of male and female primary carers in the 75 years and over age group.

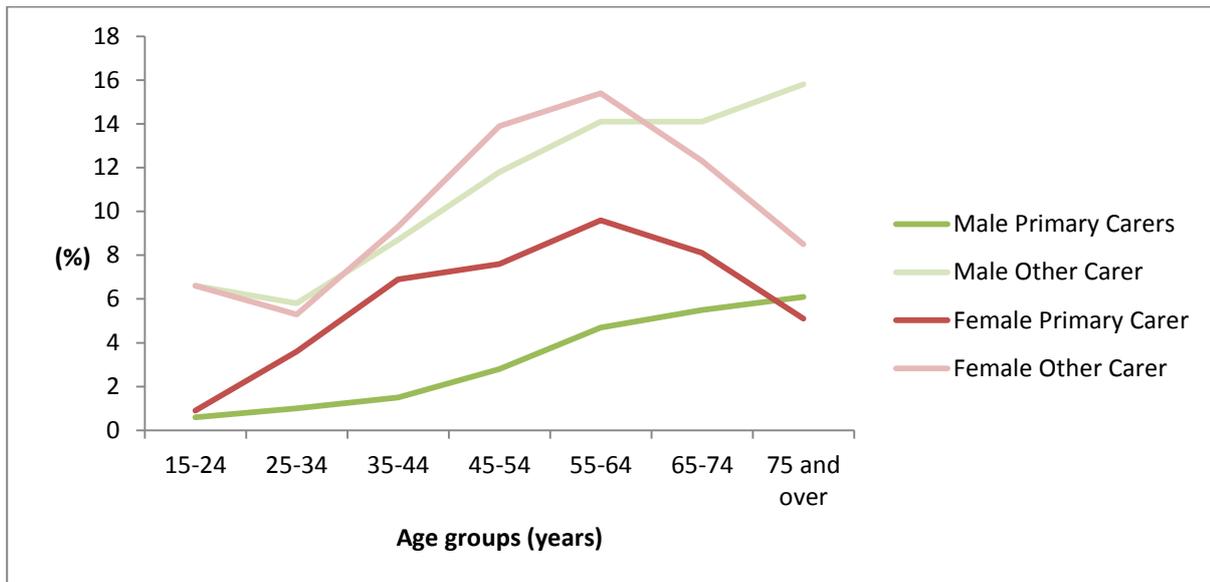
**Figure 1: Primary Carers by Age & Sex, Australia 2012**



Source: ABS, 2014a

The proportion of Australians who were carers increased with age until 65 years, rising from 1.7% of those aged less than 15 years to 22% of those aged 55 to 64 years. After the age of 65 years, the proportion of female carers declined, while the proportion of male carers increased. This was the case for both primary carers and non-primary (other) carers. After the age of 75 years, the proportion of male non-primary carers almost doubles compared with female non-primary carers. This compares to around 91,000 male and 61,500 female, non-primary carers aged 75 years or more.

**Figure 2: Carer Status by Age & Sex, Australia, 2012**



Source: ABS, 2014a

The Survey of Disability, Ageing and Carers furthermore identifies characteristics of the main recipient of the unpaid assistance. Results for 2012 revealed primary carers were more likely to be the partner of the main recipient, compared with any other relationship (43%). One in five primary carers were aged 65 years or more and caring for a partner. Of the primary carers who were caring for a parent, most were aged 45 to 64 years (14%), whereas those who were caring for their child were most likely to be aged 25 to 44 years (13%).

Addressing the Indigenous population in particular, the ‘Health and Welfare of Australia’s Aboriginal and Torres Strait Islanders’ report (ABS, 2008) provides details on the situation within the Indigenous Australian community. The 2008 report draws on data from a variety of sources with the latest being the 2006 Census for Population and Housing.

The report reveals in the 2006 Census a total of 19,600 Indigenous people (4.3%) were identified as needing assistance with core activities (self-care, mobility or communication) some or all of the time, compared to 2011 where the number of Indigenous people requiring assistance with core activities increased to 5.4%. Moreover, the prevalence of disability among Indigenous people was slightly higher at all ages compared to the non-Indigenous population. The median age for those needing assistance was 41 years for Indigenous males, and 49 years for Indigenous females. The

corresponding median ages for non-Indigenous males and females who needed assistance were 61 years and 75 years respectively.

In regards to providing unpaid assistance, the number of Aboriginal and Torres Strait Islanders aged 15 years and over who provided unpaid assistance increased from 11% (in 2006) to 13% (in 2011). There were 11,600 Indigenous male carers and 20,000 Indigenous female carers in 2006. The proportion of Indigenous carers ranged from 8% of those aged 15–24 years, to a peak of 15% aged 45–54 years, and decreasing to 10% for those aged 65 years and over. The report notes the proportion of carers in the Indigenous population is likely to be understated as around 11% of Aboriginal and Torres Strait Islander people aged 15 years and over (in private dwellings) did not answer the questions related to disability and caring.

Given the considerable number of people providing unpaid assistance, valuing carer's contributions in financial terms has been a prominent issue in various debates. *Access Economics* (2010) estimated the cost of informal caring based on two different methods: opportunity cost, and replacement valuation. The opportunity cost of informal care is measured as the income forgone by the carer spending time providing care rather than undertaking paid work. The cost is calculated assuming, in the absence of their caring responsibilities, carers would be employed at the same rate as members of the general population of the same age and gender. Hence, the difference between the standardised employment rates for carers and those of the general population is a measure of the rate of forgone employment due to informal care. Combined, the opportunity cost for all carers was measured to be \$6.5 billion in 2010 (*Access Economics*, p. 18).

The replacement valuation reveals the resources that would need to be diverted each year from the formal economy to replace the work done by informal carers, were their services no longer available. If all hours of informal care were replaced with services purchased from formal care providers and provided in the home, the replacement value was estimated to be \$40.9 billion, with informal carers together providing an estimated 1.32 billion hours of care in 2010 (*Access Economics*, p. 20).

Moreover, the *Access Economics* report (2010) emphasised young carers are an often overlooked group in informal caring. It is claimed that young carers are at high risk of long term disadvantage as a result of missed education opportunities and compromised high school performance. The '25-hour rule' which limits recipients of Carer Payment to a maximum of 25 hours per week of study, work and travel, compounds the many difficulties that young carers face in obtaining certain tertiary qualifications.

### **3. Prevailing issues and challenges in informal caring**

Investigating the matter of informal caring at a global level, international literature suggests several prevailing issues and challenges. Arksey and Hirst (2005), for example, observed unpaid carer's access to and the use of primary care services is a key issue in informal caring. Drawing on data from a longitudinal analysis of carers' contact with the GPs, they found men who look after someone in the same household (for more than 20 hours/week) increase their consultation rates

with GPs, whereas women taking on the role of a carer have relatively less contact with GPs. Summarising literature on barriers to health care for carers, Arksey and Hirst identified, amongst others, that barriers related to professional responses, service organisation and delivery, as well as barriers related to lack of information and knowledge prevailed. Brodaty & Green (2002) likewise recognised the importance of GPs in providing support to the carer, particularly in the case of dementia. They suggest GPs and carers should work as partners in the long-term management of dementia thereby reducing adverse health effects.

Moreover, qualitative studies on the Quality of Life (QOL) of people providing unpaid assistance have emerged (McGarry & Arthur, 2001; Golics, Basra, Finlay & Salek, 2013; Rand & Malley, 2013). For example, in interviews with 14 carers selected during one round of annual over-75 health checks carried out in one large general practice in the UK, McGarry & Arthur (2011) found particular challenges in the organisational demands and structure of the caring relationship and highlighted the importance of informal support networks. Furthermore, the recognition of the essence of formal services as well as the constancy of caring and the need for the role of carer to be recognised emerged. Rand and Malley (2013) observed similar themes in their interviews with 31 carers, stressing that the QOL of carers is particularly affected by social care support, access to services, and how individual needs and preferences are considered when making decisions about care. In a review of 158 papers included in the OvidSP Medline database, the general impact of disease on the life of families was examined (Golics et al., 2013), allowing them to draw conclusions for medical care. The authors identified a variety of aspects that impacted the QOL, such as emotional, financial, family relationships, education and work as well as leisure time and social activities.

Exploring the experiences of carers through a grounded research approach, Burton (2008) found redirecting resources to provide support and information at both the onset of caring responsibilities and at times when there is an increase in dependency, would have helped many of these carers come to terms with the change when assuming a caring role. Moreover, Burton's findings suggest the carers' feelings about their role may improve if they feel they understand how to approach professionals, how to get the most appropriate equipment and how to do the caring tasks effectively.

Finally, an article by Simmons (2014) points out that the role of carers is not solely confined to family and friends, but also often searched for within the wider community, such as religious professionals. Simmons, however, observed religious professionals have to deal with increased challenges in the demand for care resulting from the complexity of the last third of life, social changes and church demographics. He argues that *"what can be hoped for from even the most generous congregation is a few – perhaps six – months of supportive care (...), but almost never the kinds of hands-on care that typical hospital discharge policies require, including nursing and toileting."* (p.4).

To date there has been no profiling of the demographic and economic characteristics of carers in the Northern Territory (NT or 'Territory'). In this research brief, we aim to profile residents of the NT who stated in the last Census (2011) that they were providing unpaid assistance. The unique

population dynamics of the Territory, with a youthful population and high proportion of Indigenous residents with relatively low life expectancies and the early onset of chronic illnesses, means that caring in the Territory context is different to that of other States. We compare and contrast characteristics of carers (including age, gender and Indigenous status) between the Territory and the rest of Australia (ROA), as well as across geographic regions within the Territory.

## 4. Methods

Despite the international literature available on this topic, the introduction of this research brief revealed the ABS Survey on Disability, Ageing and Carers in Australia (2014a) is one of the main and few sources when investigating the economic and social contribution of carers in Australia and the NT. For the first time in 2006, however, the Census of Population and Housing included a variable on Core Activity Need for Assistance (ASSNP). This variable was developed in order to measure the number of people with a profound or severe disability. As with the ABS Surveys of Disability, Ageing and Carers, the Census of Population and Housing defines the profound or severe disability population as:

*'those people needing help or assistance in one or more of the three core activity areas of self-care, mobility and communication, because of a long-term health condition (lasting six months or more), a disability (lasting six months or more), or old age' (ABS, 2011a, para. 2).*

While the intent of the questions is the same in both the Survey and the Census, output items differ to reflect the differences in the populations due to the different methodologies in the two collections. The 2006 Census was the first Census to include the variable on unpaid assistance of a person with disability (UNCAREP). This variable *'...records people who in the two weeks prior to Census Night spent time providing unpaid care, help or assistance to family members or others because of a disability, a long term illness or problems related to old age.'* (ABS, 2011b, para. 1). It includes people who are in receipt of a Carer Allowance or Carer Payment, but does not include work done through a voluntary organisation or group.

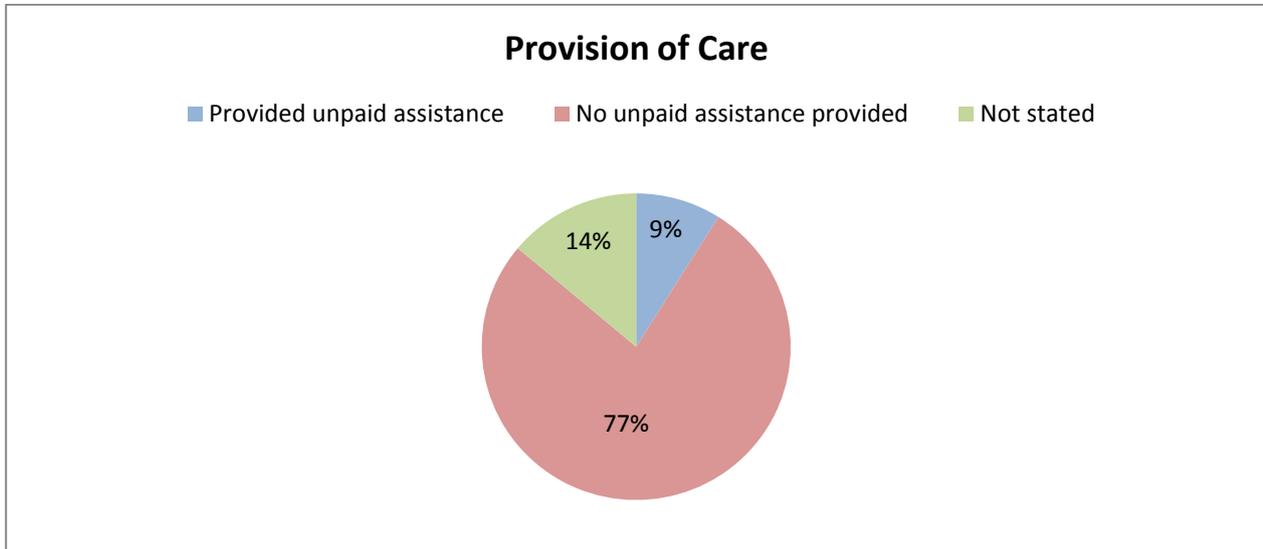
The set of questions for providing unpaid assistance were repeated in the 2011 Census. The inclusion of this variable allows us to profile carers based on geographic areas and to compare and contrast these. In order to create a baseline profile of carers in the Northern Territory on the basis of sex, age, indigenous status or income, for example, we created custom built tables from the 2011 Census of Population and Housing using ABS Table Builder software. The results are outlined in the next section.

## 5. Results

The 2011 Census revealed the total number of people providing unpaid assistance in the Northern Territory was 14,566, or 9% of the population 15 years or older (Figure 3), while 77% did not provide unpaid assistance and 14% did not respond to the question. Within the ROA, around 11%

identified as carers, with 81% not providing unpaid assistance and 8% not answering the corresponding questions.

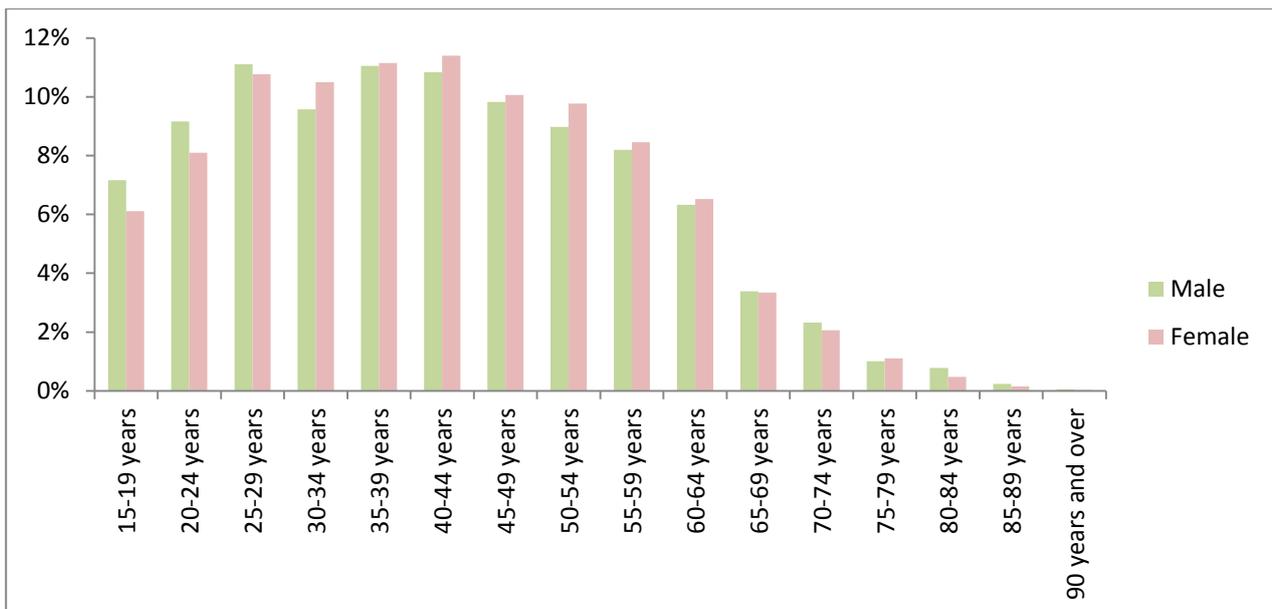
**Figure 3: Percentage of people providing care in the NT, 2011**



Source: Custom data created from ABS TableBuilder

In terms of gender, 59% of responses were female and 41% were male carers. Figure 4 indicates the highest percentage of women providing unpaid assistance was in the 35 to 39 and 40 to 44 years age range (11.1% and 11.4% respectively). The highest percentage of men providing unpaid assistance was in the 25 to 29 and 35 to 39 years age ranges (11.1% for both age groups).

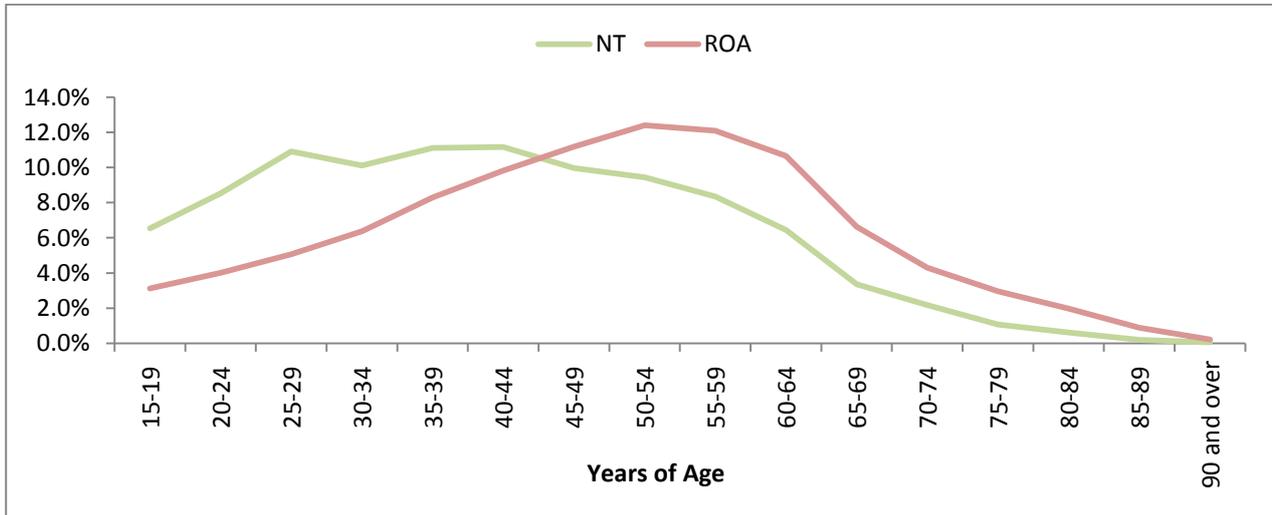
**Figure 4: Age and gender distribution of people providing unpaid assistance in the NT, 2011**



Source: Custom data created from ABS TableBuilder

If we compare these results to the survey of Disability, Ageing and Caring as well as the ROA in the 2011 Census, we find the population providing unpaid assistance in the NT was comparatively younger than the rest of Australians providing unpaid assistance (Figure 5).

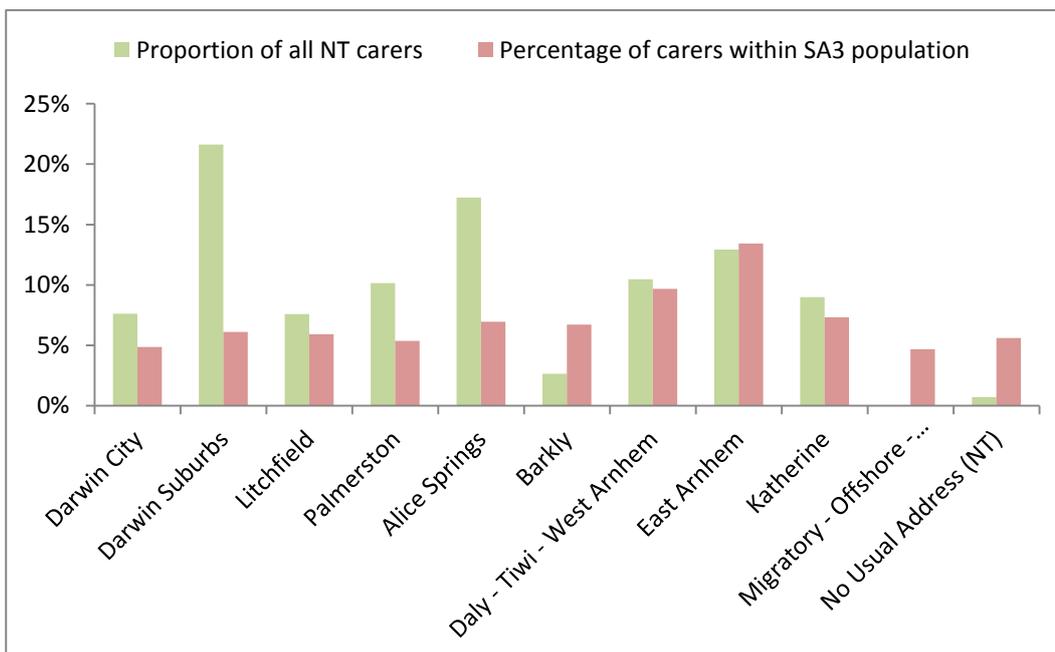
**Figure 5: Age comparison NT and ROA, 2011**



Source: Custom data created from ABS TableBuilder

Examining the geographic location of carers according to Statistical Area Level 3 (SA3) shows the highest proportion of Territory carers resided in the Darwin Suburbs (22%), followed by Alice Springs (17%) and East Arnhem (13%) (Figure 6). For comparison, Figure 6 includes a second series, depicting the percentage of carers of the total population of the SA3. This comparison reveals a slightly different picture as the Darwin Suburbs, for example, have a relatively lower proportion of carers within the population, compared to the overall proportion of NT carers.

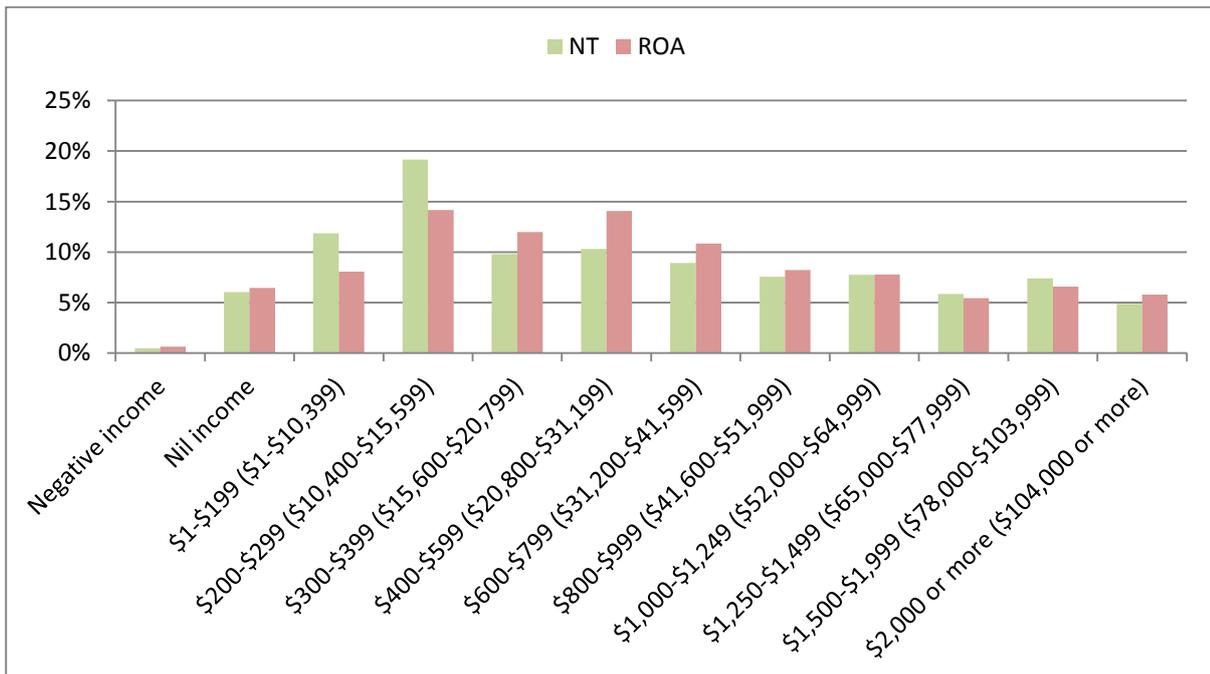
**Figure 6: Geographic location of people providing unpaid assistance with a disability**



Source: Custom data created from ABS TableBuilder

Examining personal income of people providing unpaid assistance, shows 19% of the carers in the NT stated they had a very low income of \$200 to \$299 per week, which equates to \$10,400 to \$15,599 per year (Figure 7). In the ROA, 14% of carers were in the \$200-\$299 per week income range, closely followed by the \$400-\$599 a week (\$10,400 to \$15,599, or \$20,800-\$31,199 a year) income range.

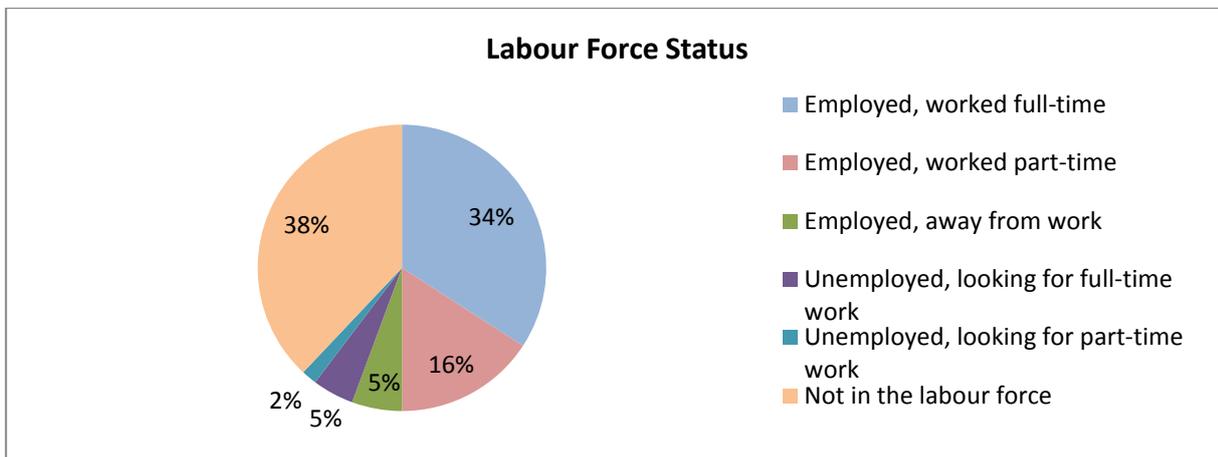
**Figure 7: Total personal income of carers in the NT and the ROA per week (with yearly income in brackets), 2011**



Source: Custom data created from ABS TableBuilder

An often discussed variable in the Survey of Disability, Ageing and Caring is the labour force status of people providing unpaid assistance to people in need of care. The results of the 2011 Census show 38% of the carers in the NT were not in the labour force, compared to 40% in the ROA. 34% were working full time (compared to 32% in the ROA) and 16% were working part time (Figure 8).

**Figure 8: Labour Force Status of carers in the NT, 2011**

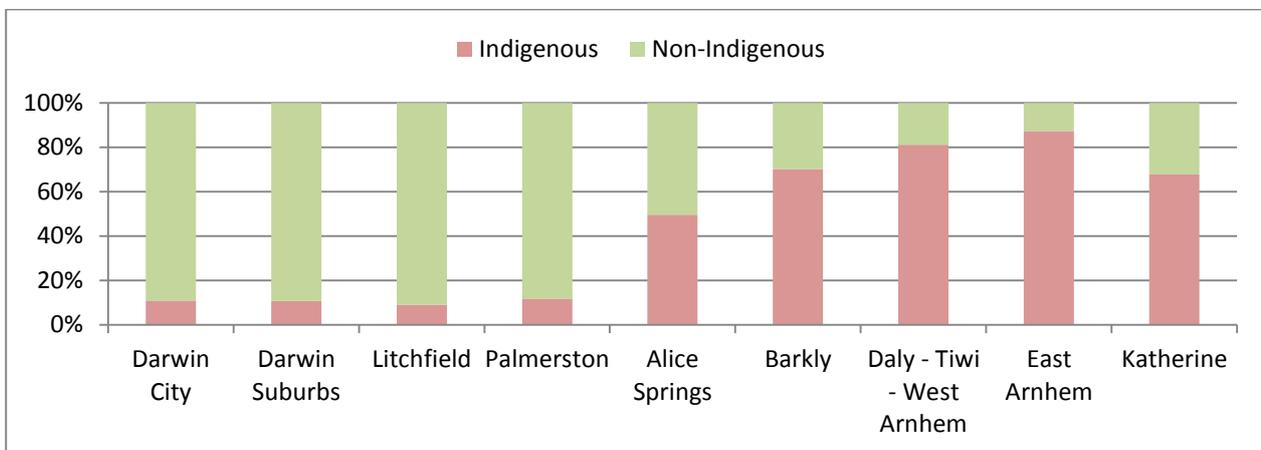


Source: Custom data created from ABS TableBuilder

Concerning Indigenous status, the Census revealed 42% of the people who stated they were providing unpaid assistance in the NT were Indigenous. The statistics for geographic regions in Figure 9 demonstrate there are significant differences in the Indigenous composition of the carer’s cohort within the Territory. For example, almost 90% of carers in the East Arnhem region were Indigenous (compared to 62% of the population being Indigenous), while in Darwin (11%) and Litchfield (9%) only a small proportion of carers were Indigenous.

By comparison, within the ROA 2% of the carers stated they were Indigenous. In total, 11% of the total Indigenous population in the NT provided unpaid assistance compared to 8% of the Indigenous population in the ROA.

**Figure 9: Indigenous status of carers in SA3s, 2011**



Source: Custom data created from ABS TableBuilder

## 6. Discussion and Conclusion

Summarising the results of our baseline profiling , a ‘typical carer’ in the NT can be characterised as female, between 40 to 44 years old, unemployed with an income between \$200-\$299/week, being located in the Darwin suburbs and of non-Indigenous status (Figure 10).

**Figure 10: Profile of a ‘typical’ carer in the NT**



From this profile we gain an initial understanding of carers in the NT. However, our examination of the data at SA3 level indicated significant differences between the regions exist, especially regarding the Indigenous status of carers since, in remote parts of the Territory, Indigenous carers are the majority.

While the proportion of people providing unpaid assistance in the NT (Indigenous and non-Indigenous together) compared to the rest of Australia is generally lower, as the report 'Health and Welfare of Australia's Aboriginal and Torres Strait Islanders' pointed out, a substantially higher proportion of people in the NT did not respond to the questions on caring when compared to the total Australian population. The lower figure for the NT might reflect its low median age, at 31.4 years in 2011 compared to 37 years for Australia as a whole (ABS, 2013). Thus, the numbers and proportion of carers in the Indigenous population and the NT population as a whole is likely to be understated given the larger estimated under-enumeration rate for Indigenous people in the Territory. This is particularly important when comparing regional differences by Indigenous status and it may be the carer profile looks very much different when accounting for the carers who did not respond. Regardless of these issues, it is clear that Indigenous carers provide a vital community role in remote areas of the Territory.

Likewise, given the population in the NT is projected to start ageing dramatically within the coming decades, with the median age increasing from 31.4 years in 2011 to 34.7 years by 2041 (Northern Territory Department of Treasury and Finance, 2014), we argue that the proportion of people required to provide unpaid assistance in the NT is likely to increase substantially. Subsequently, this trend will influence the age of carers and greatly impact health care policies in the NT. Being a territory with many sparsely populated areas, carers will play a crucial role in the health care system and greatly contribute to the wellbeing of residents of remote (Indigenous) communities. Issues such as the aforementioned unpaid carer's access to and use of primary care services will be particularly relevant. Moreover, a described lack of information and knowledge regarding western health issues within the Indigenous community (Opie, 2005) will influence policies and practices and make the reliance on a social support network greater.

On a technical note, it appears the intent of the Census questions on caring have been understood by Territory Census respondents, despite the high number of not stated responses. Intra-regional differences in caring rates by Indigenous status suggest Indigenous people have recognised and recorded their caring roles within extended family networks. We can conclude, although further work is required to ascertain the relative economic contribution of carers in the NT, the profiling in this research brief underlines the significant and increasing contribution carers make to communities across the NT.

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