

**Submission  
No 20**

**ACCESS TO TRANSPORT FOR SENIORS AND  
DISADVANTAGED PEOPLE IN RURAL AND  
REGIONAL NSW**

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**Date Received:** 18 July 2016

18 July 2016

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### **Inquiry into access to transport for seniors and disadvantaged people in rural and regional NSW**

Carers NSW would like to thank the Committee on Community Services for the opportunity to respond to this inquiry. Our submission will briefly address the items within the terms of reference which reflect the transport needs of carers.

A carer is anyone who provides informal care and support to a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or who is frail aged. Whilst there can be rewarding aspects of caring for a loved one, carers also face many challenges.

Carers NSW is the peak non-government organisation for carers in NSW and a member of the National Network of Carers Associations. Carers NSW vision is an Australia that values and supports all carers, and our goals are to work with carers to improve their health, wellbeing, resilience and financial security; and to have caring recognised as a shared responsibility of family, community, and government.

Thank you for accepting our submission. For further information regarding this submission, please contact Freya Saich, [REDACTED]  
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Yours sincerely

Elena Katrakis  
CEO  
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## **Carers NSW submission to the Inquiry into access to transport for seniors and disadvantaged people in rural and regional NSW**

### **Background**

There are approximately 857,200 carers living in NSW, equivalent to around 12 per cent of the population. Nearly 30 per cent of these carers live in rural or regional areas.<sup>i</sup> Carers provide invaluable assistance to the people they care for and make a significant contribution to the Australian economy. Nationally in 2015 carers provided 1.9 billion hours of care, equivalent in value to what would be an estimated \$60.3 billion worth of replacement care.<sup>ii</sup> Transport assistance is one of the key forms of assistance provided by carers, with 83 per cent of people with a reported disability in NSW who needed assistance with transport receiving it from informal carers.<sup>iii</sup>

In rural and regional areas of NSW accessing transport can be a particular challenge. This is due to a plethora of factors, including insufficient and inaccessible public transport infrastructure and a lack of alternative and affordable transport options.<sup>iv</sup> As a result, many carers are dependent on their private vehicle to transport the person or people they care for to and from medical appointments, social engagements, employment, education and community activities. Carers NSW is concerned about the financial and psychosocial toll placed on carers from this inequitable distribution of service provision and dependence on private transport.

This submission addresses the challenges that carers and the people they care for face when seeking to use public transport, Community Transport, Wheelchair Accessible Taxis and the Isolated Patients Travel and Accommodation Assistance Scheme in rural and regional areas of NSW. It also touches on the important role of the Companion Card, and uncertainty about the future provision of funded and subsidised transport for National Disability Insurance Scheme (NDIS) participants.

### **The financial and psychosocial toll of transport disadvantage**

Compared to the general population, carers are more likely to experience economic disadvantage. More than one third of carers in NSW live in low income households<sup>1</sup>, compared to only around one in four non-carers.<sup>v</sup> Carers are also more likely to be out of the labour force (45 per cent) compared to non-carers (33 per cent), and many carers leave the workforce, reduce their hours or limit their career progression in order to care for a loved one.<sup>vi-vii</sup>

This economic disadvantage is exacerbated in rural and regional areas. Hill *et al.* have identified that in non-metropolitan areas, the direct costs of caring, including expenditure on medicines, home modifications and clothing, are higher than for those living in metropolitan areas.<sup>viii</sup> As services tend to be concentrated in major cities, service users living in rural and regional areas travel greater distances and experience higher travel costs than those in

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<sup>1</sup> Low income households are defined as households within the lowest two quintiles of equivalised household income.

metropolitan areas. Consequently, carers in non-metropolitan areas are more likely than those in metropolitan areas to find transport costs to be an added financial burden.<sup>ix</sup>

Due to limited public transport infrastructure, addressed in the next section, there is also considerable reliance on private vehicles in rural areas, leaving many carers with no other option than to drive the person they care for where they need to go.<sup>x</sup> Low income can affect a carer's ability to afford and maintain a car and cover ongoing petrol costs, especially when long-distance travel is required. Additionally, driving the person they care for may limit a carer's availability to participate equitably in employment and education, further entrenching economic disadvantage.<sup>xi</sup>

### **Accessibility of public transport in rural and regional NSW**

Despite efforts to enhance the accessibility of public transport throughout NSW, around one third of people with disability in NSW have difficulty using public transport.<sup>xii</sup> In 2012, only 40 per cent of train stations in rural and regional NSW were completely accessible compared to 68 per cent in metropolitan Sydney.<sup>xiii</sup> Furthermore, in rural and regional areas there is a lack of accessible bus stop infrastructure.<sup>xiv</sup> Consequently, 8 per cent of people with disability, and 20 per cent with a profound or severe core activity limitation had difficulty getting to stops or stations in 2012.<sup>xv</sup>

When public transport is inaccessible, the person being cared for is invariably dependent on the carer to drive them or accompany them. Communities with large Aboriginal populations are particularly likely to lack adequate public transport infrastructure and rely on informal networks for transport.<sup>xvi</sup> This can be problematic given that car ownership is less common in Aboriginal communities.

Inaccessible public transport infrastructure can be compounded by the difficulties people with cognitive impairment often have navigating this infrastructure. Peel *et al.* state, for example, that people with higher cognitive capacity are more likely to be capable of using multiple forms of transport.<sup>xvii</sup> Without being accompanied by an informal carer or paid support worker, or given adequate travel training, people with cognitive impairment are especially likely to rely on support, as demonstrated in the vignette below. With the incidence of dementia set to increase as the population ages, this will place increasing demand on carers to drive the person they care for.

*Linda\* expressed concerns regarding her son Ryan's\* use of public transport. Ryan has an intellectual disability which limits his problem solving capacity and ability to ask for help when required. Linda states that while her son is capable of using public transport if the route is familiar, short and uncomplicated; there is only one route which he can travel independently. For all other transport, he must be driven.*

Carers NSW has been pleased to learn of a flexible route service project to be piloted in rural NSW.<sup>xviii</sup> Carers NSW looks forward to the outcome of this pilot as Peel *et al.* have reported positive outcomes from such flexibility.<sup>xix</sup> We stress that any evaluation of this

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\* For anonymity purposes all names have been replaced with pseudonyms.

project should consider the impact that a flexible route service would have on carers, potentially relieving them of the need to drive or accompany the person they care for.

**Recommendation 1:** Carers NSW recommends that the scale and speed of improvements to rural and regional train stations be increased to ensure these services are accessible to people with disability.

**Recommendation 2:** Local councils in rural and regional areas must take further action to improve the state of curbs, pavements and bus stops to enhance the accessibility of bus services to people with disability and promote independence.

**Recommendation 3:** Innovative approaches such as flexible route services should be considered as viable transport options in rural and regional areas.

## Community Transport

In NSW nearly one in five people with a disability cannot use any form of public transport.<sup>xx</sup> Community Transport is designed to assist people who are unable to utilise public transport due to disability or frailty, as well as their carers. Whilst some carers may be required to accompany the person they care for when using this service, for others, Community Transport creates independence. This allows carers to pursue other activities such as employment rather than transporting the person they care for.

Many carers living in rural areas have expressed difficulties when seeking to use this service. Community Transport providers are simultaneously struggling to cope with increasing demand. In particular, this system does not cater for unexpected trips, as bookings must be made in advance. Such services are also likely to turn people away when they require regular trips.<sup>xxi</sup> As a result of funding arrangements, carers have also stated that some providers will only make trips for medical appointments, leaving transport needs for other activities unmet. Furthermore, due to the inflexibility of this system people are unable to receive Chemotherapy and Dialysis treatment on weekends.

Community Transport has, on average, a higher price per trip compared to public transport, making it an expensive option for people who are already experiencing economic hardship. The running costs in rural and regional areas are also likely to be higher considering the vast distances travelled. The impact of individualised funding within the disability and aged care sectors are also changing the way these services are funded, in many cases reducing providers' flexibility to cover fleet purchase and upkeep and adequately subsidise fares. With ongoing reform in this sector, Carers NSW is concerned about the future costs of Community Transport for carers and those they care for.

Under Ageing, Disability and Home Care (ADHC) funding arrangements carers are able to accompany the care recipient. However, with the NDIS, funding will be redirected from the service provider to the client. As a result, funding previously available to cover a carer's use of Community Transport may soon become unavailable, requiring carers to absorb the costs of their own transport. Whilst Commonwealth Home Support Program (CHSP) funding continues to subsidise carers accompanying a person who is over 65 of age, Carers NSW is concerned about carers who do not qualify for community transport subsidies.

**Recommendation 4:** Carers NSW recommends that Community Transport funding continue to be available to carers to ensure that they are not financially disadvantaged when required to accompany the person they care for.

### Wheelchair Accessible Taxis and the Taxi Transport Subsidy Scheme

Carers NSW welcomes the recent increase of the Taxi Transport Subsidy Scheme (TTSS) payments from \$30 to \$60. This increase will make taxi transport more affordable for people with disability, older people and their carers, as the previous rate was outdated and grossly inadequate, leaving many individuals significantly out of pocket to cover basic travel requirements. An adequately subsidised scheme could facilitate independence and reduce reliance on carers' transport assistance.

However, Carers NSW is concerned that people living in rural and regional areas will not fully benefit from this increase. Currently, there are insufficient Wheelchair Accessible Taxis (WATs) to service rural and regional areas, limiting the usefulness of a subsidy for people with particular physical accessibility requirements. The lack of WATS reduces the choice people have when seeking to travel. Moreover, taxi fares are often prohibitive in rural and regional areas considering the vast distances required to travel. Even with a subsidy, this can make taxi transport simply unaffordable.

Carers NSW is pleased that regulatory changes could enable Community Transport Providers to register their vehicles as WATS allowing passengers to access the TTSS. Carers NSW believes these regulations will contribute to enhanced service provision and reduce financial disadvantage in rural and regional areas.

**Recommendation 5:** Carers NSW recommends that the TTSS scheme be reflective of the higher than average distances travelled in rural and regional areas.

### Companion Card

The Companion Card reduces travel costs for carers who need to accompany the person they care for on public transport. Carers can travel free with the person they care for if eligible. However, Carers NSW is concerned about the future of the Companion Card with the ongoing roll-out of the NDIS.

The NDIS provides differing levels of transport funding assistance to eligible people with a disability. However, such funding is entirely directed towards the person with a disability and not their carer. NDIS participants are also no longer eligible for an additional Mobility Allowance. Transport funding in NDIS plans has been found in many cases to be inadequate to meet participants' transport needs, especially in regional areas, requiring participants and carers to make up the costs or fill the gap with private transport.

Carers NSW has been advised that some NDIS participants may be ineligible for a Companion Card, however it is unclear to Carers NSW why NDIS participants should be excluded, especially as unpaid carers are not direct beneficiaries of NDIS plans. It also appears that this is not the case in other states. Carers NSW is concerned what this will be once the NDIS is fully rolled out across NSW. As with a number of other services and entitlements in NSW, it is unclear whether all current users will be eligible for equivalent support under the NDIS.

**Recommendation 6:** Carers NSW recommends that the relationship between the Companion Card and the NDIS in NSW be clarified, and that funding transition in NSW does not disadvantage carers currently able to benefit from the Companion Card.

### Isolated Patients Travel and Accommodation Assistance Scheme

Despite people in rural and regional areas having generally poorer health than those in major cities, healthcare is not distributed according to need.<sup>xxii</sup> Healthcare services are disproportionately located in major cities and at least 85 per cent of medical specialists are located in major cities.<sup>xxiii</sup> As a result, accessing specialist care often requires costly, long-distance travel.

The Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) contributes to the cost of travel and accommodation of a person with a disability and their carer in these situations. To be eligible, people must live more than 100 kilometres from the nearest specialist or the total of their trips exceed 200 kilometres.<sup>xxiv</sup> A co-payment of \$30 per return journey is generally required, capped at \$120 annually from September 2015. The co-payment can, however, be waived if a person holds a pension or health care card.<sup>xxv</sup>

Feedback from carers indicates that IPTAAS neither covers the real costs of having to travel to large centres for care, nor adequately compensates carers for the costs of being away from one's own work, family and community responsibilities.

**Recommendation 7:** IPTAAS subsidies should increase annually to match the rise in the cost of living.

### Access to Respite Services

Approximately 40 per cent of primary carers care for more than 40 hours a week.<sup>xxvi</sup> Respite is an integral opportunity for many carers to take a break from their caring responsibilities in order to address their own emotional wellbeing. Respite has been shown to increase a carer's ability to cope with the demands of everyday life. Simultaneously, a lack of respite is associated with the relinquishment of care to residential facilities.<sup>xxvii-xxviii</sup>



Like healthcare services, respite services are located disproportionately in major cities or in regional centres. One carer has expressed to Carers NSW that the nearest respite service is over 100 kilometres from her place of residence. Unless transport arrangements can be made with services, carers are required to absorb the costs of transporting the person they care to access respite services. Accessing respite services should be made affordable for carers living in rural and regional areas to enhance their overall emotional wellbeing.

**Recommendation 8:** Carers NSW recommends that the costs of accessing respite services be addressed within the Integrated Care Support System to ensure equitable access throughout NSW.

## Conclusion

Carers living in rural and regional NSW currently experience significant transport disadvantage. Carers NSW believes that any future changes to transport provision should consider the financial and psychosocial toll that insufficient service provision has on carers and their ability to sustain their caring role.

<sup>i</sup> Australian Bureau of Statistics (2014) *Disability, Ageing and Carers, Summary 2012*, Catalogue no. 4430.0, Canberra.

<sup>ii</sup> Deloitte Access Economics (2015) *The economic value of informal care in Australia in 2015*, Carers Australia, 2015.

<sup>iii</sup> ABS (2014)

<sup>iv</sup> Rosier, K. and McDonald, M. (2011) *The relationship between transport and disadvantage in Australia*, Communities and Families Clearinghouse Australia Resource Sheet, Melbourne.

<sup>v</sup> ABS (2014)

<sup>vi</sup> Ibid.

<sup>vii</sup> Liang, P., Liddle, J., Fleming, J. and Gustafsson, L. (2016) 'Family members' narratives of lifespan: Mapping changes before and after a brain injury causing driving disruption', *Australian Occupational Therapy Journal*, vol. 63, no. 3, pp. 164-174.

<sup>viii</sup> Hill, T. Thomson, C. and Cass, B. (2008) *The costs of caring and the living standards of carers*, Social Policy Research Paper No. 43, Social Policy Research Centre, University of New South Wales.

<sup>ix</sup> Carers NSW (2014) *Carers Survey: Main Report*, Sydney.

<sup>x</sup> Peel, N., Westmoreland, J. and Steinberg, M. (2002) 'Transport safety for older people: A study of their experiences, perceptions and management needs', *Injury Control and Safety Promotion*, vol. 9, no.1, pp. 19-24.

<sup>xi</sup> Dew, A., Bulkeley, K., Veitch, C., Bundy, A., Gallego, G., Lincoln, M., Brentnall, J. and Griffiths, S. (2013) 'Addressing the barriers to accessing therapy services in rural and remote areas', *Disability and Rehabilitation*, vol. 35, no. 18, pp. 1564-1570.

<sup>xii</sup> ABS (2014)

<sup>xiii</sup> Transport for NSW 2012, *Disability Action Plan 2012-2017*, NSW Government, Sydney.

<sup>xiv</sup> Ibid.

<sup>xv</sup> ABS (2014)

<sup>xvi</sup> Aboriginal Disability Network of NSW (2007), *Telling it Like it Is. A report on community consultations with Aboriginal people with disability and their associates throughout NSW, 2004-2005*, Strawberry Hills.

<sup>xvii</sup> Peel et al. (2002)

<sup>xviii</sup> Transport for NSW Budget Briefing, June 2016.



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<sup>xix</sup> Peel et al. (2002)

<sup>xx</sup> ABS (2014)

<sup>xxi</sup> Anderson, M., Luxford, Y. and Turner, L. (2011) 'Rural Volunteer Community Transport Drivers: The Need for Greater Participation in the Policy Process', *Journal of Economic and Social Policy*, vol. 14, no. 3, pp. 1-17.

<sup>xxii</sup> Australian Institute of Health and Welfare (2008), *Rural, regional and remote health Indicators of health system performance*, Rural Health Series, Number 10, Canberra.

<sup>xxiii</sup> Australian Bureau of Statistics (2013) *Doctors and Nurses*, Catalogue no. 4102.0 - Australian Social Trends, Canberra.

<sup>xxiv</sup> EnableNSW (2016) *Isolated Patients Travel and Accommodation Assistance Scheme: Information for Patients*, Department of Health, NSW Government, accessed 8 July 2016, <http://www.enable.health.nsw.gov.au/home/iptaas>.

<sup>xxv</sup> Ibid.

<sup>xxvi</sup> ABS (2014)

<sup>xxvii</sup> Nankervis, K., Rosewarne, A. and Vassos, M. (2011) 'Why do families relinquish care? An investigation of the factors that lead to relinquishment into out-of-home respite care', *Journal of Intellectual Disability Research*, vol. 55, no. 4, pp. 422–433.

<sup>xxviii</sup> Welsh, R., Dyer, S., Evans, D. and Fereday, J., (2014) 'Identifying benefits and barriers to respite for carers of children with complex health needs: A qualitative study', *Contemporary Nurse*, vol. 48, no. 1, pp. 98–108.