



**Carers NSW and Carers Victoria joint submission to the
Department of Infrastructure and Regional Development
on the 'Whole Journey' guide**

1 June 2017

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

About Carers NSW and Carers Victoria

Carers NSW and Carers Victoria are the peak non-government organisations for carers in their respective states, and are members of the National Network of Carers Associations. Our 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.

For further information, please contact:

- Freya Saich, Policy and Development Officer, Carers NSW, on (02) 9280 4744 or at freyas@carersnsw.org.au
- Rachel Vanstone, Policy Advisor (Disability and Housing), Carers Victoria, on (03) 9396 9528 or at Rachel.Vanstone@carersvictoria.org.au

© Carers NSW and Carers Victoria 2017.

This work is copyright. Apart from any use as permitted under the *Copyright Act 1968*, all other rights are reserved.

Websites: www.carersvictoria.org.au and www.carersnsw.org.au

Contents

Recommendations	4
1. Introduction.....	5
2. Accessible transport and carers.....	5
3. Stakeholder engagement and collaboration	6
4. Minimum standards.....	6
5. National Disability Insurance Scheme (NDIS)	7
6. Ticketing.....	9
7. Driver training.....	9
8. Amenities.....	9
9. Website Accessibility.....	10

Recommendations

Recommendation 1: Carers NSW and Carers Victoria recommend that the guide outline the cost of inadequate whole-of-journey infrastructure on carers and states the implications for carers.

Recommendation 2: Carers NSW and Carers Victoria recommend that the guide include practical information on where to go to receive expert advice for particular transport users, including carers, people with cognitive disability, older people and organisations with companion service experience.

Recommendation 3: Carers NSW and Carers Victoria recommend that the guide include minimum standards for whole-of-journey accessibility to ensure local governments enhance disability access in local communities.

Recommendation 4: Carers NSW and Carers Victoria recommend that the guide clearly reiterate the ongoing responsibilities of local, state and federal governments to ensure Transport Standards compliance targets are met in an NDIS environment.

Recommendation 5: Carers NSW and Carers Victoria recommend that the guide specify the importance of carer awareness training for public transport staff, particularly in regards to their use of the Companion Card.

Recommendation 6: Carers NSW and Carers Victoria recommend that the guide state the importance of public transport staff having a knowledge of disability beyond physical disabilities.

Recommendation 7: Carers NSW and Carers Victoria recommend that the guide clearly explain the importance of 24-hour access to accessible bathroom facilities and suggestions on how access may be provided in a way which limits security or vandalism issues.

Recommendation 8: Carers NSW and Carers Victoria recommend that the guide emphasise the importance of space for personal care assistance when new bathroom facilities are built.

Recommendation 9: Carers NSW and Carers Victoria recommend that the guide promote the notification of the Department of Social Services regarding accessible bathroom facilities for inclusion in the National Public Toilet Map.

Recommendation 10: Carers NSW and Carers Victoria recommend that the guide highlight the fundamental importance of website accessibility as a basic step before accessible tools are developed.

Recommendation 11: Carers NSW and Carers Victoria recommend that the guide provides further information on practical aids in addition to websites and apps.

1. Introduction

Carers NSW and Carers Victoria wish to thank the Department of Infrastructure and Regional Development for the opportunity to make a joint submission on 'The whole journey: a guide for thinking beyond compliance to create accessible public transport journeys'. Our submission will focus on the experiences of people in care relationships.

Carers NSW and Carers Victoria are the peak non-government organisations for carers in their respective states and are members of the National Network of Carers Associations. Our vision is an Australia that values and supports all carers; 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.

For further information, please contact either:

- Freya Saich, Policy and Development Officer, Carers NSW, on (02) 9280 4744 or at freyas@carersnsw.org.au
- Rachel Vanstone, Policy Advisor (Disability and Housing), Carers Victoria, on (03) 9396 9528 or at Rachel.Vanstone@carersvictoria.org.au.

2. Accessible transport and carers

There are approximately 2.7 million carers across Australia providing unpaid 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. The person receiving care may be a parent, child, spouse/partner, grandparent, other relative or friend. Caring for a person often involves advocating for their health, safety, wellbeing, dignity and inclusion to help them meet their potential and lead a life of purpose and meaning; however, this often comes at a personal cost to the carer.

Caring can have negative effects on a carer's own financial situation, retirement security, physical and mental health and wellbeing, housing arrangements, social networks and career trajectory. The impact is particularly pronounced for carers of people who have complex chronic health conditions or both functional and cognitive impairment. Furthermore, more than one in three carers report having a disability themselves.¹

Accessible public transport journeys are fundamental to people in care relationships; however, significant development and investment is necessary for Australia to have a genuinely accessible whole of journey public transport system.

Transport assistance is one of the key forms of assistance provided by carers. Approximately 15 per cent of all people with a reported disability across Australia are unable to use public transport.² Consequently, 22 per cent of people with disability across Australia require assistance for their transport needs.³ Approximately 85 per cent of such transport assistance is provided by informal carers.⁴ Furthermore, many people require transport assistance on a weekly (42 per cent) or daily (19 per cent) basis.⁵ Much of this assistance involves the use of private vehicles belonging to carers. Even when public transport is accessible, carers are often required to accompany the person they care for. Therefore, it is paramount that carers are also considered as consumers of whole-of-journey transport.

Carers often incur significant costs associated with transport, including public transport costs, vehicle purchase and modification, maintenance and repair, fuel and parking. Research indicates households with a person with disability tend to have higher transport costs.⁶ Given at least one third of carers live in low income households (defined as households within the lowest two quintiles of equivalised household income),⁷ many cannot absorb these additional transport costs without experiencing significant economic hardship.

The time involved in transporting someone to a medical appointment, to work or to participate in the community can represent an opportunity cost for carers, especially with regard to carers' workforce participation⁸ and social participation.⁹ The workforce participation rate for primary carers is only 56.3 per cent; whereas the workforce participation rate for Australians who are not carers is 80.3 per cent.¹⁰ With regard to social participation, 175,000 primary carers did not participate in leisure activities away from home in the last year.¹¹

Carers' incomes are also 42 per cent lower than Australians who are not in a care relationship, which equates to a weekly median income of \$520. This median takes into account the salaries of the 56 per cent of primary carers who participate in the workforce. Carers who do not engage in paid work are also more likely than non-carers to have a government pension or allowance as their primary source of income.¹² According to the Australian Council of Social Services, this group of carers is typically on or below the poverty line.¹³

Given the impact of transport assistance on the finances and time of carers, Carers NSW and Carers Victoria are disappointed at the distinct lack of reference to carers throughout this guide.

Recommendation 1: Carers NSW and Carers Victoria recommend that the guide outline the cost of inadequate whole-of-journey infrastructure on carers and states the implications for carers.

3. Stakeholder engagement and collaboration

The guide acknowledges the extensive number of stakeholders involved in 'planning, designing, procuring/purchasing, contrasting, certifying, operating and maintaining and redeveloping public transport systems and their surrounds' but does little to provide practical assistance to stakeholders on who they should consult with when undertaking such activities.

The example on page 38 found 'early and regular consultation with disability groups resulted in positive accessibility outcomes for all users, with the interchange featuring walking strips and electronic braille information stands for blind and vision-impaired people, step-free ground-level access and signage heights and types designed with all users in mind'.

In developing the guide, the consultation sought was based on organisations representing people with physical and sensory disability. It is important that advice is also sought from advocacy organisations for people with cognitive disability, older people, carers and companion services (e.g. Travellers Aid Australia).

Recommendation 2: Carers NSW and Carers Victoria recommend that the guide include practical information on where to go to receive expert advice for particular transport users, including carers, people with cognitive disability, older people and organisations with companion service experience.

4. Minimum standards

Guide users are encouraged to 'think beyond compliance' towards 'people's accessibility needs' (page 6). However, Carers NSW and Carers Victoria believe this to be an insufficient approach. Minimum standards are essential to ensure accountability across all jurisdictions for accessible whole

journey public transport and infrastructure, and the transport standards should be extended to include whole-of journey infrastructure.

National data shows around one in five people with disability avoid using public transport as a result of their disability.¹⁴ The majority of people with disability who experience difficulties utilising public transport state physical features are the main barrier, with steps when getting in and out of vehicles or carriages being the most frequently reported barrier (12 per cent).¹⁵ The second most commonly reported barrier for people with disability experiencing difficulties with public transport is getting to stops or stations (9 per cent).¹⁶ Often this is attributed to inaccessible infrastructure such as bus stops, footpaths and inconsistent kerb heights. Such barriers prevent whole-of-journey accessibility, particularly in rural and regional areas.¹⁷

The Australian Government has noted significant diversity amongst local governments in their ability to provide accessible infrastructure, often due to financial capacity to achieve these outcomes.

While having the best intentions to ensure accessibility for people with disability, especially through providing accessible bus stops, [local governments] bear a large part of the burden of providing infrastructure with little or no financial assistance.¹⁸

For example, a 2013 report found 97 per cent of local governments in NSW undertake planning according to the inclusive and accessible communities 'outcome area' under the National Disability Strategy. However, only 57 per cent were planning for accessible footpaths/roads and 37 per cent were designing or auditing bus stops for accessibility compliance.¹⁹

Furthermore, there is inconsistency in the standards required in the implementation of accessible infrastructure. For example, the Australian Human Rights Commission states there is 'no mandatory minimum technical compliance standard under the DDA [Disability Discrimination Act] that can be referred to in relation to footpaths'.²⁰ Indeed, the existing legislation regarding the minimum width of a footpath of 1000mm only applies to specific buildings under the *Commonwealth Disability (Access to premises – buildings) Standards 2010*. Public footpaths are not subject to the same legislation meaning there is no minimum standard for local governments to adhere to, ultimately limiting accountability to achieve fully accessible whole-of-journey transport.

Some progress has been made towards reducing physical barriers and improving whole-of-journey accessibility via the *Commonwealth Disability (Access to Premises – Buildings) Standards 2010* and the Victorian Government has also developed an online resource to complement these standards.²¹ Despite these efforts, significant progress is required to ensure complete whole-of-journey accessibility.

Recommendation 3: Carers NSW and Carers Victoria recommend that the guide include minimum standards for whole-of-journey accessibility to ensure local governments enhance disability access in local communities.

5. National Disability Insurance Scheme (NDIS)

The guide mentions the NDIS (page 3) in the context of it being a support program. Carers NSW and Carers Victoria believe this needs to be supplemented with further information that accessible community infrastructure – including whole-of-journey public transport – is not within the remit of the NDIS and still remains the responsibility of local, state and federal governments.

Specifically, the NDIS (Supports for Participants) Rule 7.20(d) states the NDIS will not be responsible for 'the improvement of community infrastructure, i.e. accessibility of the built and natural environment, where this is managed through other planning and regulatory systems and though building modifications and reasonable adjustment where required'.

Further, Rule 7.22 states:

The NDIS will not be responsible for: ensuring that public transport options are accessible to a person with disability, including through the funding or concession to people with disability to use public transport; or compliance of transport providers and operators with laws dealing with discrimination on the basis of disability, including the Disability Standards for Accessible Public Transport 2002; or transport infrastructure, including road and footpath infrastructure where this is part of a universal service obligation or reasonable adjustment (including managing disability parking and related initiatives).

Finally, the transport allowance payable under the NDIS is a relatively small per annum payment (see table one) and is only available to participants who cannot use public transport without substantial difficulty due to their disability. This transport allowance for NDIS participants is simply a replacement of the level of subsidy provided by the Mobility Allowance payable by Centrelink.

Table 1: NDIS transport supports

Level 1	The NDIS will provide up to \$1,574.40 per year (\$30 per week) for participants who are not working, studying or attending day programs but are seeking to enhance their community access i.e. volunteering in the community.
Level 2	The NDIS will provide up to \$2,472 per year (\$47 per week) for participants who are currently working or studying part-time (up to 15 hours a week) participating in day programs and for other social recreational or leisure activities.
Level 3	The NDIS will provide up to \$3,416 per year (\$65 per week) for participants who are currently working, looking for work or studying at least 15 hours a week and are unable to use public transport because of their disability.

Carers NSW and Carers Victoria are concerned that governments responsible for whole-of-journey community infrastructure will retreat from disability accessibility under the false premise that the NDIS will meet the gap; this may include the defunding of transport and community infrastructure programs and initiatives in the NDIS environment.

For example, the National Companion Card Scheme aims to alleviate financial costs by enabling carers accompanying cardholders to travel free on public transport services. However, it is unclear whether the Scheme will remain in place as the NDIS rolls out. Carers NSW has been advised that some NDIS participants may be ineligible for a Companion Card, which is concerning given unpaid carers are not direct beneficiaries of NDIS plans. Carers Victoria also acknowledges the safety net provided to Victorian carers with the Victorian Government's 'we care' Victorian Carer Card, does include limited free public transport travel for carers.²²

In Victoria, a review is currently underway into the Multi-Purpose Taxi Program (MPTP). The MPTP provides a 50 per cent subsidy to taxi fares up to a maximum of \$60. This review is considering excluding NDIS participants from the MPTP. Given the often inadequate amount of transport assistance provided to NDIS participants, removal of the MPTP will mean that participants will have to pay more for their transport journeys in real terms. As a result, NDIS participants will either face being financially disadvantaged for the same amount of trips, or unable to maintain the same level of community access.

In comparison, in NSW all people who meet the eligibility criteria for the Taxi Transport Subsidy Scheme (TTSS), regardless of whether they are an NDIS participant, are able to receive this subsidy. The TTSS is similar to the MPTP, subsidising 50 percent of the cost of a taxi journey up to a maximum of \$60. Carers NSW has been advised that NSW and the ACT are among the few states or

territories who have committed to enabling NDIS participants to continue to receive taxi subsidies, assisting people with the financial burden of transport costs.

These examples demonstrate that people in care relationships with NDIS participants may indeed be financially worse off in an NDIS environment, potentially impacting upon their ongoing social and economic participation.

Recommendation 4: Carers NSW and Carers Victoria recommend that the guide clearly reiterate the ongoing responsibilities of local, state and federal governments to ensure Transport Standards compliance targets are met in an NDIS environment.

6. Ticketing

The guide acknowledges that some people may prefer to continue to use paper ticketing. However, it is also important that the guide recognises people using a Companion Card require the support of a carer to travel. The Companion Card enables the person providing attendant care to have free use of public transport and entry into participating venues. Staff must have an understanding of the use of such cards, particularly when this card does not operate in the same way as an Opal or *myki* card.

Recommendation 5: Carers NSW and Carers Victoria recommend that the guide specify the importance of carer awareness training for public transport staff, particularly in regards to their use of the Companion Card.

7. Driver training

The guide states that ‘drivers should be appropriately trained to enable them to assist people with accessibility requirements to use public transport’ (page 32). However, it is important for drivers to have a broader understanding of disability and ageing beyond physical traits, in order to appropriately assist customers with vision, hearing, or mobility impairments, mental illness, cognitive impairment e.g. dementia and intellectual disability. Public transport is one of the key areas where people with disabilities experience discrimination and educating drivers can be one solution to eliminating the discrimination that people with disability and their carers experience.

Recommendation 6: Carers NSW and Carers Victoria recommend that the guide state the importance of public transport staff having a knowledge of disability beyond physical disabilities.

8. Amenities

Carers Victoria and Carers NSW look forward to this year’s third review of the Transport Standards and would like to be consulted as a part of the review. The second review of the *Disability Standards for Accessible Public Transport 2002* found that while compliance targets for trains were generally met, however in many instances the arrangements required staff or carers to directly assist passengers. The report also raised the issue of accessible toilets at stations being locked outside business hours and having insufficient room for carers to assist.²³

Section 3.8.6 of the 'whole journey' guide specifically deals with bathroom facilities. However, it fails to highlight the point that accessible toilets become inaccessible if locked and new builds should include space for personal care assistance for people who require it.

Recommendation 7: Carers NSW and Carers Victoria recommend that the guide clearly explain the importance of 24-hour access to accessible bathroom facilities and suggestions on how access may be provided in a way which limits security or vandalism issues.

Recommendation 8: Carers NSW and Carers Victoria recommend that the guide emphasise the importance of space for personal care assistance when new bathroom facilities are built.

Recommendation 9: Carers NSW and Carers Victoria recommend that the guide promote the notification of the Department of Social Services regarding accessible bathroom facilities for inclusion in the National Public Toilet Map.

9. Website Accessibility

The guide encourages users to provide information in a range of formats, including websites (page 16). While NSW and Victorian Governments have implemented Web Content Accessibility Guidelines (WCAG) for government websites, many non-government websites still do not meet the most basic accessibility requirements (page 17). The guide mentions journey planning tools should meet WCAG, but omits that the website needs to be accessible in the first instance.

As outlined by Carers Australia, digital exclusion is a growing concern for carers.²⁴ The Australian Digital Inclusion Index²⁵ illustrates people of a low socio-economic status, older people, Indigenous people, people from culturally and linguistically diverse communities, and people with disability have levels of digital exclusion significantly above the national average. Surveys undertaken by state and territory carer associations reinforce the broad findings of this report in relation to carers.

The Tasmanian Council of the Ageing's recent research project found that only 40 per cent of the over 600 people surveyed used websites to access information. This decreased with age, with only 12 per cent of 60–74 year olds and 6 per cent of 75–84 olds using websites. Problems cited by survey participants included: limited access to the internet, lack of familiarity, and problems with online instructions and forms. Such evidence needs due consideration in future planning of service delivery.²⁶ A 2015 Carers South Australia survey found that only 21 per cent of respondents used websites specifically designed for carers and 77 per cent of carers in a relationship with an older person had not used My Aged Care.²⁷

Recommendation 10: Carers NSW and Carers Victoria recommend that the guide highlight the fundamental importance of website accessibility as a basic step before accessible tools are developed.

Recommendation 11: Carers NSW and Carers Victoria recommend that the guide provides further information on practical aids in addition to websites and apps.

-
- ¹ Australian Bureau of Statistics, (2017), *Disability, Ageing and Carers, Australia: Summary of Findings*, catalogue number 4430.0, Table 33.1.
- ² Australian Bureau of Statistics, (2016), *Disability, Ageing and Carers, Australia: Summary of Findings*, catalogue number 4430.0, Table 22.3.
- ³ Australian Bureau of Statistics, (2016), *Disability, Ageing and Carers, Australia: Summary of Findings*, catalogue number 4430.0, Table 14.3.
- ⁴ Australian Bureau of Statistics, (2016), *Disability, Ageing and Carers, Australia: Summary of Findings*, catalogue number 4430.0, Table 15.3.
- ⁵ Australian Bureau of Statistics, (2016), *Disability, Ageing and Carers, Australia: Summary of Findings*, catalogue number 4430.0, Table 15.3.
- ⁶ Hill, T. Thomson, C. and Cass, B. (2011), *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; Bourke-Taylor, H., Cotter, C., and Stephan, R. (2014), 'Young children with cerebral palsy: families self-reported equipment needs and out-of-pocket expenditure', *Child Care Health and Development*, vol. 40 no. 5, pp. 654-662.
- ⁷ Australian Bureau of Statistics, (2016), *Disability, Ageing and Carers, Australia: Summary of Findings*, 4430.0.
- ⁸ Arksey, H. and Glendinning, C. (2008), 'Combining Work and Care: Carers' Decision-making in the Context of Competing Policy Pressures', *Social Policy and Administration*, vol. 42, no. 1, pp. 1–18.
- ⁹ 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.
- ¹⁰ Australian Bureau of Statistics, (2016), *Disability, Ageing and Carers, Australia: Summary of Findings*, catalogue number 4430.0, Table 36.1
- ¹¹ Australia Bureau of Statistics, (2016), *Disability, Ageing and Carers, Australia: Summary of Findings*, catalogue number 4430.0, Table 46.1
- ¹² Australian Bureau of Statistics, (2016), *Disability, Ageing and Carers, Australia: Summary of Findings*, catalogue number. 4430.0, Table 36.3.
- ¹³ ACOSS, (2016), *Poverty in Australia*, Social Policy Research Centre, p.25.
- ¹⁴ Australian Bureau of Statistics, (2016), *Disability, Ageing and Carers, Australia: Summary of Findings*, catalogue number 4430.0, Table 22.3.
- ¹⁵ Australian Bureau of Statistics, (2016), *Disability, Ageing and Carers, Australia: Summary of Findings*, catalogue number 4430.0, Table 22.3.
- ¹⁶ Australian Bureau of Statistics, (2016), *Disability, Ageing and Carers, Australia: Summary of Findings*, catalogue number 4430.0, Table 22.3.
- ¹⁷ Transport for NSW (2012), *Disability Action Plan 2012-2017*, NSW Government, Sydney.
- ¹⁸ Australian Government (2015), *Review of the Disability Standards for Accessible Public Transport 2002*.
- ¹⁹ Paterson, K., Milne, C., Ellison, A., Jeyapalan, M., Wilkinson, J., Thaler, O., Johansson, K. (2013), *Disability planning across Local Government in NSW, report commissioned by Local Government NSW and Family and Community Services NSW*, available online at: http://www.lgnsw.org.au/files/imce-uploads/90/Final%20Report_Disability%20planning%20across%20LG%20in%20NSW_For%20distribution_date%20fix.pdf, viewed 21 February 2017.
- ²⁰ Australian Human Rights Commission (2017), *Frequently Asked Questions: Access to premises*, available online at: <https://www.humanrights.gov.au/frequently-asked-questions-access-premises#footpath>, viewed 28 February 2017.
- ²¹ Department of Social Services, (2014), *Progress Report to the Council of Australian Governments on the National Disability Strategy 2010-2020*, p 90.
- ²² Victoria State Government (2017) *Victorian Government Carer Card Program*, available online at: <http://carercard.vic.gov.au/>, viewed 1 March 2017.
- ²³ Australian Government (2015), *Review of the Disability Standards for Accessible Public Transport 2002*, p.27.
- ²⁴ Carers Australia, (2016), *Submission to Department of Social Services on delivering an integrated carer support service*.
- ²⁵ Thomas, J., Barraket, J., Ewing, S., MacDonald, T., Mundell, M. and Tucker, J. (2016), *Measuring Australia's Digital Divide: The Australian Digital Inclusion Index 2016*, Swinburne University of Technology, Melbourne, for Telstra, available online at: <http://digitalinclusionindex.org.au/>, viewed 28 February 2017.
- ²⁶ Council of the Ageing Tasmania (2015) *Finding Out – Supporting older people to access the right information at the right time*, available online at: <http://www.cotatas.org.au/wp-content/uploads/2015/08/FINAL-web-version-FINDING-OUT-REPORT-2015.pdf>, viewed 28 February 2017.
- ²⁷ Carers South Australia (2015) *Our Carers Our World*, Carers SA Carers Survey 2015, available online at: <http://carers-sa.asn.au/Assets/Files/Carers%20SA%20Carers%20Survey%202015%20Summary%20Oct%202015.pdf>, viewed 1 March 2017.