



Carers NSW and Carers Victoria joint submission to the Senate Standing Committee on the delivery of outcomes under the National Disability Strategy 2010–2020 to build inclusive and accessible communities

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AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

1. Introduction

Carers NSW and Carers Victoria wish to thank the Senate Standing Committee on Community Affairs for the opportunity to make a joint submission on the delivery of outcomes under the National Disability Strategy 2010–2020 to build inclusive and accessible communities. 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, 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.

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2. Background

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. The person receiving care may be a parent, child, spouse/partner, grandparent, other relative or friend. Caring for a person with disability often involves advocating for the 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 and both functional and cognitive impairment. Furthermore, more than one in three carers have a disability themselves.¹

Inclusive and accessible communities are integral to people in care relationships. The National Disability Strategy is a positive initiative; however, progress since its introduction has not changed the fact we as a society still have a long way to go before we achieve genuinely inclusive policy and practice consistently implemented nationwide.

3. Housing

3.1 Universal housing design

Housing is a human right, therefore carers and people with disability have a right to safe, secure, appropriate, accessible and affordable housing. Carers are affected in very direct ways by the housing options available to the person with disability, as the majority (80 per cent) live with the person they share a care relationship with (where the person has a severe or profound limitation).²

Article 25 of the Universal Declaration of Human Rights states: 'Everyone has the right to a standard of living adequate for the health and wellbeing of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control'.³

Additionally, Article 19(a) of the Convention on the Rights of Persons with Disabilities provides that '...persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement'. Article 19(b) further provides that '...persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community'.⁴

A centrepiece of outcome one 'inclusive and accessible communities' in the 2010–2020 National Disability Strategy was a targeted 'universal design standard' in all new housing by 2020.⁵ The silver level Liveable Housing Design Guidelines are understood to be the housing universal design standard. These guidelines promote inclusion by making homes easier to access, navigate and live in and cheaper to modify if and/or when circumstances change.⁶ Carers Victoria and Carers NSW are therefore pleased the Council of Australian Governments (COAG) has agreed that new publicly funded housing stock will incorporate these standards.⁷

However, in the for-profit building sector, the uptake of these standards is underpinned by an assumption that '...both the building industry and the wider community will automatically think in terms of universal and livable design principles and how they can benefit individuals and families throughout their lives'.⁸ This assumption is further entrenched by national voluntary accreditation system which is estimated to achieve less than 5 per cent of the 2020 target.⁹

The planning and design of universal housing design standards has been well considered and has the potential to increase the pool of accessible housing options for people in care relationships, especially in the public and community housing sectors. However, for targets to become achievable, governments should amend the requirements in the National Construction Code to include universal design standards for all new and extensively renovated housing, in order to ensure necessary uptake in the for-profit building sector.

3.2 Impact of slow uptake of universal housing design targets

3.2.1 Injury risk to carers

Housing which does not meet universal design standards risks injury to carers, with back injury a common complaint among carers providing care in unsuitable home environments. A study by Heywood noted, '...many carers were finding the physical strain and risk to their backs was unsustainable, and there was a common fear that without help, admission to residential care would be unavoidable [for the care recipient]'.¹⁰ Unsuitable housing has also been linked to interrupted sleep and increased stress for carers.¹¹

3.2.2 Continued reliance on major home modifications

A further impact is continued reliance on major home modifications to enable accessibility for people in care relationships. Home modifications are almost always retro-fitted to the carer's home and before the introduction of the NDIS the cost was covered by carers, unless they were eligible for state subsidies.¹² As Sauger's research found, '...in addition to receiving a low income, people with

disabilities and family carers also had to pay themselves for some of the cost of disability equipment and physical adaptations as available grants only covered partial costs'.¹³

The NDIS will be responsible for the reasonable and necessary costs of home modifications of eligible people with disability in private housing (owner occupier and private rental),¹⁴ which should relieve former cost burdens for many carers. However, what is considered reasonable and necessary for the participant, may not take into account the needs of the carer. The needs of the entire household should be considered, especially where the person living with the disability is not the primary user of all home facilities.¹⁵

Since the home can be a quasi-workplace for carers, there should also be provision of private space for the carer to take time out when required.¹⁶ If such principles are not taken into account or prioritised by astute planners, carers may be at a disadvantage following modifications or be forced to pay for other modifications that sustain their caring role.

An additional issue is that few existing houses in the private rental market have been built to universal design standards and there is no incentive for landlords of rental properties to approve home modifications that may take time, be inconvenient or aesthetically unappealing.^{17,18} Morden found '...most landlords will not agree to modification, even at no cost to them, and would most likely just choose an applicant who is able and willing to move into the property without the need for modification. Discrimination is a prerogative of the landlord as they are not bound by social responsibility and social justice principles in dealing with clients'.¹⁹

Failure to adhere to universal design standards will inevitably shift the costs for modifications to the NDIS and carers. A small upfront investment in new builds is more desirable than major modifications in homes that don't have inherent capabilities of easy and cost-effective adaptations.²⁰ In the long term, a more accessible housing stock will also greatly reduce the cost of home modifications to the NDIS, increasing its overall fiscal sustainability.

Recommendation 1: Carers NSW and Carers Victoria recommend the amendment of National Construction Code requirements to include universal design standards for all new and extensively renovated housing.

4. Transport services and infrastructure

Inaccessible public transport and whole of journey infrastructure continues to be a significant barrier to the economic and social participation of people with disability, directly impacting on many carers.

4.1 Public transport

National statistics show around one in five people with disability avoid using public transport as a result of their disability.²¹ The majority of people with disability who experience difficulties utilising public transport state that physical features are the main barrier, with steps when getting in and out of vehicles or carriages were the most frequently reported barrier (12 per cent).²²

The second review of the *Disability Standards for Accessible Public Transport 2002* found that while compliance targets for trains were generally met, 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

4.2 Whole-of-journey infrastructure

The second most commonly reported barrier for people with disability experiencing difficulties with public transport is getting to stops or stations (9 per cent).²⁴ 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.²⁵

Progress has been made towards reducing physical barriers and improving whole-of-journey accessibility via the *Commonwealth Disability (Access to Premises – Buildings) Standards 2010*. The Victorian Government has also developed an online resource to complement these standards.²⁶

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.²⁷

For example, a 2013 report found that 97 per cent of local governments in NSW are 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.²⁸

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.'²⁹ One local council in Victoria, the City of Yarra, is an exemplar of comprehensive policies regarding accessible footpaths.

At present, Carers NSW and Carers Victoria await the draft consultation report, *The Whole Journey: A guide for thinking beyond compliance to create accessible public transport journeys*, developed by the Department of Infrastructure and Regional Development, which has the potential to address these issues. The Department states the aim of this guide is to 'think beyond compliance' towards 'accessibility needs'.³⁰ However, Carers NSW and Carers Victoria believe minimum standards are also required to ensure accountability across all jurisdictions for accessible public transport and infrastructure.

Recommendation 2: Carers NSW and Carers Victoria recommend local governments are financially assisted to enhance the accessibility of whole-of-journey infrastructure in local communities.

Recommendation 3: Carers NSW and Carers Victoria recommend greater accountability measures to ensure local governments are making amendments to enhance disability access in local communities.

4.3 Impact of inaccessible public transport and whole of journey infrastructure

With limited access to public transport services, people with disability rely heavily on transport by carers, community transport and taxis. According to the ABS, approximately 22 per cent of people with disability across Australia require assistance for their transport needs,³¹ with 85 per cent

reporting informal carers were the main providers of their transport needs. Many required such assistance on a weekly (42 per cent) or daily (19 per cent) basis.³²

4.3.1 Increased financial costs to carers

Carers often incur significant costs associated with transport, including vehicle purchase and modification; maintenance and repair; and petrol and parking. Research indicates households with a person with disability tend to have higher transport costs.³³ Given at least one third of carers live in low income households (defined as households within the lowest two quintiles of equivalised household income),³⁴ many cannot absorb these costs without experiencing significant economic hardship.

Carers' incomes are 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.³⁵ According to the Australian Council of Social Services, this group of carers is typically on or below the poverty line.³⁶

The National Companion Card Scheme aims to alleviate some of these 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 some NDIS participants may be ineligible for a Companion Card, which is unusual given unpaid carers are not direct beneficiaries of NDIS plans. It also appears this is not the case in other states and territories.

Carers Victoria is not aware of similar issues occurring in the Victorian roll-out of the NDIS, but supports Carers NSW in highlighting the vital importance of the Companion Card for the ongoing social participation and transport needs of people with disability and their carers to ensure the integrity of the Scheme is maintained. 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.³⁷

Recommendation 4: Carers NSW and Carers Victoria recommend clear and nationally consistent information about Companion Card eligibility in the context of the NDIS rollout.

4.3.2 Opportunity costs for carers

The time involved in transporting someone to a medical appointment, to work or participate in the community can represent an opportunity cost for carers, especially with regard to carers' workforce participation³⁸ and social participation.³⁹ 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.⁴⁰ With regard to social participation, 175,000 primary carers did not participate in leisure activities away from home in the last year.⁴¹

4.3.3 Community transport

For many people with disability and their carers, community transport provides a valuable point-to-point transport service staffed with qualified personnel. Prior to the NDIS, people in care relationships were able to access this service at a low cost. However, the shift from block funding to individualised packages under the NDIS has placed this service in jeopardy. Providers receiving funding per NDIS

participant may reduce overall funding, making it difficult for them to cover fleet purchase and upkeep, and to adequately subsidise fares.

By contrast, the Commonwealth Home Support Program (CHSP) continues to subsidise carers accompanying a person who is over 65 years of age. Carers NSW and Carers Victoria are concerned about the additional out-of-pocket expenses incurred by carers who do not qualify for community transport subsidies when accompanying an NDIS participant. Furthermore, we see high priced transport costs as a potential barrier to the economic and social participation of people with disability and their carers.

Recommendation 5: Carers NSW and Carers Victoria recommend the Committee considers the impact of consumer directed funding on community transport providers and the out-of-pocket expenses incurred by carers as a potential barrier to inclusion.

5. Online communication and information systems

5.1 Internet Access and affordability

People with disability often experience a range of inhibiting factors to internet use. Moreover, particular disabilities such as visual impairment, impairment of fine motor skills and cognitive impairment may constrain a person's ability to use the internet.⁴²

The National Disability Strategy states the ongoing roll-out of the National Broadband Network (NBN) will provide people with disability and their carers with increased access to a range of government services, as well as access to other opportunities. With the continuing roll-out of the NBN across Australia, Carers Victoria and Carers NSW emphasise that affordability issues continue to constrain access to such technology. For example, a recent survey of low income households found that approximately 65 per cent of respondents who were receiving the Carer Payment experienced difficulty affording telecommunications technologies. This was higher than those receiving the Disability Support Pension or the Age Pension.⁴³

While income support recipients may receive the Telephone Allowance (as part of the Pension Supplement), research indicates less than half of respondents believed the Telephone Allowance was sufficient to cover their telecommunications costs.⁴⁴ The Telephone Allowance may assist with the ongoing costs of an internet or mobile subscription; however this allowance may not be sufficient for outright purchases of computers or enabling devices/digital technologies. Despite access to broadband via the NBN, cost factors may prevent people having complete 'accessibility' without the devices to use these technologies, thus impacting on participation in a range of areas.⁴⁵

Recommendation 6: Carers NSW and Carers Victoria recommend the Committee considers the impact of telecommunication as a potential barrier to the participation and inclusion of people with disability and carers.

5.2 Website Accessibility

Carers NSW and Carers Victoria would like to commend the NSW and Victorian Governments on implementing Web Accessibility Guidelines for government websites. However, many non-government websites still do not meet the most basic accessibility requirements.

Most Australian Government services, including the National Disability Insurance Scheme (NDIS), My Aged Care, Medicare and Centrelink, are now delivered via online platforms. This has also resulted in a decline in face-to-face service delivery models, which directly impacts people in care relationships accessing essential government services.

As outlined by Carers Australia, digital exclusion is a growing concern for carers.⁴⁶ The Australian Digital Inclusion Index⁴⁷ illustrates people of a low socio-economic status, older people, Indigenous people 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.⁴⁸ 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.⁴⁹

Recommendation 7: Carers NSW and Carers Victoria recommend the Committee consider the importance of engaging the private and non-government sector to ensure web accessibility enabling all people to access the information they require.

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