

MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Senate inquiry into the delivery of outcomes under the National Disability Strategy 2010-2020

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Introduction

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MS Australia is pleased to provide a submission to the Senate Inquiry into the delivery of outcomes under the National Disability Strategy 2010-2020.

The focus of the comments, suggestions and recommendations provided in this submission is on key areas that will impact on people affected by multiple sclerosis (MS), and, in the main, address term of reference (a) the planning, design, management and regulation of (i) the built and natural environment, including commercial premises, housing, public spaces and amenities.

Introduction of the NDIS

The introduction of the NDIS enables an opportunity for many more people to remain at home; the scheme offers a disruption to the traditional business models in the disability housing sector. In theory, it has been designed to give people with disabilities the opportunity to choose where they live and who they live with.

The introduction of the NDIS, especially the Information, Linkages and Capacity Building (ILC) Framework, will hopefully give participants the capability to access good advice and make better decisions about staying in their own homes with the right supports and modifications.

MS Australia agrees with many other commentators that the housing conversation needs to address the issues that encompass the needs of all people that struggle to find, adapt or access appropriate housing options at all stages of their life and throughout the progress of their disability. The issue of available housing options, including the demand for affordable and accessible housing solutions regardless of age, disability, and home ownership status (homeless/owner/tenant), needs to remain a society-wide issue.

Keeping people at home through a preventative and supportive approach will deliver emotional, social and economic outcomes for individuals and families, ensure the sustainability of the NDIS through cost reductions and, in turn, provide benefits to the wider community.

Young people in nursing homes

We know that there are a large number of young people with MS residing in residential aged care facilities. MS Australia continues to lobby hard to prevent young people entering residential aged care facilities permanently, by seeking appropriate interventions at decision points, and to gain reassurances that all young people in residential aged care have been made aware of their NDIS entitlements. Any housing solutions must include options that:

- enable more young people to choose to move out of aged care facilities
- support young people to choose to live at home through the availability of restorative service models
- support young people to access private rentals that could be modified for disability use.

This could be achieved through offering financial incentives for landlords to make, or allow, reasonable home modifications needed to enhance accessibility as their disability progresses. This measure will mitigate the need for people living with disease

progression or disability to seek alternative accommodation options and open the rental market to people living with disability who would like to remain living in the community.

Need for sector integration

Housing issues such as the lack of accessible housing, affordability and the resulting homelessness can be the end product of the lack of integration between a range of sectors. Many people have to negotiate many different hurdles to meet the various eligibility requirements in each sector and often must “start from scratch” each time. This is despite the principles that were set by COAG to implement the NDIS, and agreements in the National Disability Strategy, all of which promise greater integration of all mainstream services and programs. This integration is yet to be realised.

Require minimum access and adaptability standards in the National Construction Code

MS Australia has a well-established position statement on the implementation of Australia’s Liveable Housing Design Guidelines, to require all new and extensively modified housing to meet accessibility and adaptability standards. The implementation of these standards would ensure viable accommodation options for everyone, regardless of age, family needs, disability and disease and resulting disability progression.

Existing building regulations do not require minimum access or universal design features, despite the low cost of including these features during construction as against the much larger cost of retrofitting.

Minimum access requirements and adaptability standards are defined by the Australian Network for Universal Housing Design (ANUHD), who now recommend equivalence to the “gold level” of the Liveable Housing Design Guidelines, which sets standards for parking spaces, doorway widths, adequate space in toilets, bathrooms and kitchens, and reinforced walls to allow for the installation of grab-rails.

The application of these standards would benefit all people with access needs, including older Australians, people with temporary impairments and people with disability. Regulation is required to ensure an equitable system and to allow incentives to be applied for early adopters. Bonus incentives could apply as the higher standard (platinum level) is implemented.

Support for submission from ANUHD and RIA

The Australian Network for Universal Housing Design (ANUHD) and Rights and Inclusion Australia (RIA) have provided a very extensive, detailed submission to this Inquiry regarding the need for improved accessibility requirements in housing in the National Construction Code (NCC). The submission provides an excellent summary of the current state of play regarding the planning, design and management of accessible housing, the failure of the voluntary approach for regulation of minimum access in housing and clearly sets out the impact of the current lack of accountability and responsibility.

MS Australia supports the conclusion to the ANUHD and RIA submission which states that:

‘Inclusive and accessible communities are contingent on a reliable and adequate supply of accessible housing in the neighbourhood. The Strategy can no longer rely on a voluntary approach if it intends to support the National Dialogue’s agreement to the 2020 target.’

Further MS Australia supports the recommendations set out in the ANUHD and RIA submission, that:

- **Regulatory intervention is necessary to meet the Strategy’s outcome 1, Policy Direction 3 and the commitment to achieve the National Dialogue’s 2020 target**
- **The regulatory intervention needed is an amendment of the NCC to include access features as specified in LHA’s Gold Level in all new and extensively modified housing**
- **These changes to the NCC should be complemented by education and training of the housing sector and the broader community.**

Reducing transaction costs

For home owners that have had a major life change due to the diagnosis of a serious illness or acquired disability, and are faced with a challenging decision about their home which may no longer be suitable, reducing transaction costs through incentives such as a stamp duty exemption for the purchase of more appropriate, adaptable housing should be considered.

The protection of personal wealth acquired is important as in many cases, earnings of one, if not both income earners, may have been diminished or ceased to deal with the health and disability challenges faced. It is important that people are able to make appropriate choices about their housing needs when they can and be able to take some control over this part of their lives at an appropriate time. Over time, making more appropriate earlier choices will reduce the pressure on the wider system.

For those in similar circumstances making changes to existing dwellings, incentives such as GST exemptions for architects and draftsmen and exemptions from local government planning application costs should be considered.

Rental market incentives

People with MS living in rental accommodation are particularly disadvantaged as there is limited opportunity or incentive to adapt or modify their homes to address their symptoms (through better heating, cooling and insulation) or to address their functional impairments. Establishing a variety of products to assist transition from the rental market to home ownership should be considered. These could include such initiatives as:

- novated lease arrangements (that allow people to purchase a house using rent payments to build equity, without being penalised for changing their housing arrangement during that period)

- the creation of financial incentives for the rental market to provide a greater range of accessible options
- encouraging landlords to make accessibility modifications.

The need for policy certainty

MS Australia recognises that where a preventative and proactive approach is no longer possible, access to age appropriate specialised, supported accommodation options need to be available; thus reducing the risk of placement in aged care facilities. For innovative housing supply options to emerge, policy certainty for new and existing disability accommodation providers is a key factor.

Policy certainty for *potential* investors

MS Australia supported the statement made by National Disability Services in its submission to the NDIS inquiry into accommodation for people with disabilities and the NDIS in February 2016:

“Establishing housing has a long lead time and more clarity about future regulatory and funding policy is needed now. Only then can developers, planners, housing providers, disability providers, families and banks be positioned to act on opportunities to invest and innovate in housing options that suit people with disability.”

An important element of this certainty is ensuring accommodation pricing (through the Specialist Disability Accommodation Pricing and Payments Framework) is sufficient and recognises the need for a variety of models. It must also determine how the processes for the registration and assessment of the quality of housing, the portability of a participant’s funds and the long-term viability for accommodation providers will work.

Policy certainty for *existing* disability service providers

National Disability Services in its submission to the NDIS inquiry into accommodation for people with disabilities and the NDIS in February 2016 regarding certainty for *existing* providers said:

“A key historic investment model has been disability service providers owning housing stock where people in their houses use their support services. Recently, however there has been a push in many jurisdictions to separate support and ownership in housing to increase choice and control over support options. Despite this, the NDIS should avoid creating inflexible rules around this matter as it could result in a considerable loss of investment in housing stock by service providers”.

This is the case for the MS organisations around Australia who provide a diverse range of housing options, including long-term high support residential accommodation and planned or crisis residential respite options, thus keeping many people at home and reducing the burden felt by the family and service recipient. They also provide extensive, specialist services for people in this accommodation, drawing on many years of experience in delivering high quality, disease specific and holistic supports and services for individuals living with MS and other neurological conditions. Transition

accommodation is also available, for example, at MS Queensland, which provides medium term accommodation for people with MS who are, for example, waiting for alternative accommodation, home modifications or are out of town visitors attending medical appointments or assessments.

MS Australia supports the NDS statement that “the Commonwealth can play a key role in facilitating collaboration between all governments (including local governments), developers, planners, housing providers, disability providers, families and banks. These groups need to come together to fully understand and act on opportunities to invest and innovate in housing for people with disability. There is a need for partnerships to canvas a wide range of approaches for financing such as shared equity and social investment as well as traditional commercial return and government funded options”.

MS Australia supports this approach and agrees that these stakeholders have much to learn from each other given we are not historic partners.

Transport services

The terms of reference for this Inquiry also include (a) the planning, design, management, and regulation of (ii) transport services and infrastructure.

MS Australia has previously made submissions to various inquiries regarding the lack of adequacy of transport services and infrastructure for people with MS with a disability. In short, these submissions have focused on the lack of integration between various forms of transport (tram, trains, buses) and the lack of reliability and high expense of taxi services. We have also voiced our concerns regarding the very slow rate of progress in implementing review findings, particularly regarding the Transport Standards.

In March 2017, the Minister for Infrastructure and Transport announced the publication of “The Whole Journey: A guide for thinking beyond compliance to create accessible public transport journeys”, to ‘promote complete, seamless public transport journeys for users with disabilities’. This is a welcome development.

MS Australia will consult with public transport users in the MS community and respond to this new Guide in due course.

MS demographics

KEY FACTS

- Multiple sclerosis (MS) is a degenerative neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 23,000 people throughout Australia
- It is the most common chronic degenerative neurological condition diagnosed in young adults
- MS is most commonly diagnosed between the ages of 20 and 40
- 75% of people diagnosed are women.
- MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it means a progressive decline over time; with progression of disability over time. For all, it is life changing.
- Symptoms vary between individuals and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and / or thinking and memory problems.
- There is no known cause or cure.