

## **MULTIPLE SCLEROSIS AUSTRALIA**

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# **Submission to the National Disability Insurance Scheme inquiry into accommodation for people with disabilities and the NDIS**

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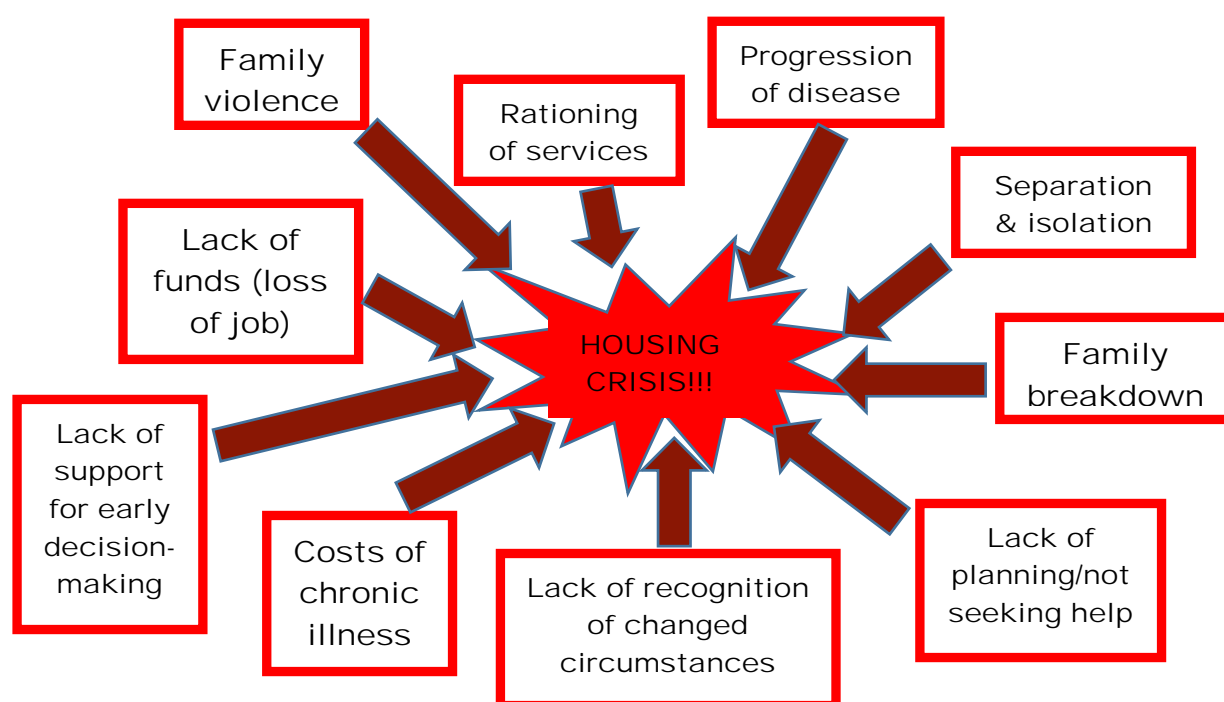
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## Introduction

MS Australia, in conjunction with its state member organisations, is pleased to provide a submission to the National Disability Insurance Scheme inquiry into accommodation for people with disabilities and the NDIS.

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.

The issue of affordable, accessible housing has hit crisis point with many reports from disability organisations estimating levels of unmet demand for housing by people with a disability to be from 45,000 to 100,000 nationally. **We need a better understanding of what has brought about this crisis to find effective solutions.**



## Key recommendations

### MS Australia recommends:

- **A change in focus to equip people with more options to stay at home, through a public education and awareness raising campaign**
- **The creation of the *Time House*; a transition housing concept where decisions for future accommodation and care options can be considered**
- **Improved sector integration through the establishment of a single accommodation gateway for all jurisdictions**

### **Equip people with more options to stay at home**

The housing demand pressures set out in the diagram above speak for themselves.

In Australia, we have reached the current state of accommodation supply shortage due to a combination of a lack of funding and some service providers not adequately adjusting their practice over the years. This has resulted in a lack of alternatives that have not moved very far from institutional-style living arrangements - we have, in some instances, just created smaller, “home-like” institutions.

We need to recognise there is a diversity of need, and that calls for a diversity of solutions. **Not all solutions are those that point to the creation of additional housing stock.**

There is an urgent need to move people away from thinking they need to move away from home; **a change in focus is needed to equip people with more options to stay at home**, or, if a move is considered “essential”, to move someone together with their entire family network.

### **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.**

**A public education and awareness raising campaign is needed** to help people make the right decision, assisted by carers, family and planners, to answer the question – **do I really need to move?** The introduction of the NDIS, especially the Information, Linkages and Capacity Building (ILC) Framework, gives 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 accommodation 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.

### **Early decision-making and incremental adjustments**

Many people with a chronic degenerative condition such as MS struggle at home with the assistance of a carer or a family member, accessing little or no services. With the introduction of the NDIS, services are now becoming available, but these services may come too late in the disease progression and the intrusion into the household is resented and sometimes rejected. It is essential that timely planning occurs, the earliest possible interventions are made and incremental adjustments undertaken, rather than waiting until a dramatic change in circumstances or a crisis develops, making a shift in accommodation inevitable.

### **The need for a preventative and proactive approach**

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. However, it is equally important that where this is no longer possible, access to age appropriate specialised, supported accommodation options are available; thus reducing the risk of placement in aged care facilities.

### **Transition housing – introducing the *Time House* concept**

Many people with chronic degenerative illnesses such as MS need **to access “in between” housing to adjust to new circumstances and to allow time for decisions to be made.**

This need for transition housing often occurs following a hospital visit. If a person with MS cannot immediately return home after hospital because, for example, their home requires modification, they often end up in a nursing home which leads, quite quickly in some cases, to further loss of function and impairment. Once admitted to a nursing home or a residential aged care facility it is then often difficult to maintain restorative care and to meet the cost of returning to an individual’s own home.

The creation of “in between” housing, or a “Time House” would ensure time is allowed for:

- Recovery and restorative care without a decrease in function
- Home modifications to be made
- Enhancement of the various service sectors’ ability to work together to find appropriate supports for the individual
- Maintenance of physical, social, family and community functions
- Decisions for future accommodation and care options to be considered

Aged care sector programs such as the Geriatric Evaluation and Management (GEM) model of care, the proposed Short Term Restorative Care program and the existing Transition Care Programs, offer possible models upon which the Time House concept could be based.

### **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 move out of aged care facilities
- support young people 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.

### **Key decision points**

For someone with a chronic degenerative condition such as MS, the decision to change their accommodation is often made following a stay in hospital. At this point it is essential that a decision is made that takes into account the impact on the individual and their family. This points to the need for new policy and operating guidelines that mandates the sectors involved in the decision-making to work alongside one another.

### **Need for sector integration**

Housing issues such as lack of access and affordability and the resulting homelessness can be the end product of the lack of integration between the community, disability, health and aged care 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.

### **Establish a single accommodation gateway**

One way to achieve integration would be to establish a single accommodation gateway for all jurisdictions and develop a workforce with a ‘can do attitude’ to implement housing solutions for people regardless of the individual situation and context. For example an accommodation “one stop shop” should be trialled to identify if this would minimise the variety of queues and the range of eligibility criteria currently in operation.

### **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 access 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, equal to the “silver level” of the Liveable Housing Design Guidelines, that 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 higher standards (gold and platinum levels) are implemented.

Consequently, MS Australia supports the Australian Network for Universal Housing Design and Rights and Inclusion Australia proposal to review Australian Standard AS 4299 Adaptable housing (1995) to align with the 2010-2020 National Disability Strategy regarding liveable housing design. This review will hopefully align the Standard with current government policy, advance the commitment in the Strategy to an agreed “universal design standard” in all new housing by 2020, eliminate any confusion over current guidelines and reduce overall cost to the 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**

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**

As stated earlier, 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 supports the statement made by National Disability Services in their submission to this enquiry regarding certainty for *potential* investors:

“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**

MS Australia supports the following statements made by National Disability Services in their submission to this enquiry regarding certainty for *existing* providers:

“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 statement in the NDS submission 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.

## 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.

For the purpose of this submission, we have concentrated on the challenges faced by people with multiple sclerosis with physical and or cognitive disabilities within the housing market, regardless of age, and therefore regardless of whether a person with MS will be accessing the NDIS or the aged care system. This is due to **the needs of people with MS for continuity of their housing to enable them to remain with their family in the community and maintain the best possible quality of life.**

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