



MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Senate Joint Standing Committee on the NDIS enquiry into Supported Independent Living

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About Multiple Sclerosis Australia

MS Australia (MSA) is the national peak body for people living with multiple sclerosis (MS) in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Research
- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with MS, their carers and the broader MS community.

Our Vision

Is consistent with the vision of the Multiple Sclerosis International Federation – **‘A world without MS’**

Our Mission

MSA will support our members and work towards meeting the needs of people with MS, their families and carers. We will facilitate a national comprehensive representation of the Member organisations through advocacy and communication.

Our Purpose

On behalf of our members and people with MS, our purpose is to develop:

- **Research:**
Supporting ongoing research to pursue further knowledge in causes, prevention, improving treatments, enhancing quality of life and ultimately, to find a cure.
- **Advocacy and Awareness:**
Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about positive change to the lives of people living with MS.
- **Communication and Information:**
Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member organisations and our key stakeholders.
- **Support for our member organisations:**
Who, as MS specialists, are providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, which addresses their changing needs.
- **International Collaboration:**
Representing the MS cause and promoting collaboration with our domestic and international partners.

Introduction

MS Australia (MSA) is pleased to provide a submission to the Senate Joint Standing Committee on the NDIS enquiry into Supported Independent Living.

The focus of the comments provided in this submission are on key areas that will impact on people affected by MS and other neurological conditions for which our state organisations provide services and support. As stated above, MSA's role is to work on behalf of all state and territory based member organisations to provide a voice for people living with MS across the country.

MSA's member organisations are:

- MSWA (providing services and support in Western Australia)
- MS SA/NT (providing services and support in South Australia and the Northern Territory)
- MS QLD (providing services and support in Queensland)
- MSL (Multiple Sclerosis Limited providing services and support in Victoria, NSW, ACT and Tasmania)

Each of these state-based organisations operates independently to provide a range of services to people living with multiple sclerosis regardless of age, and, in some cases, to a broader group of people with other progressive neurological diseases. These services vary from state to state and include: phone information support and advice, on-line resources, MS clinics, specialist MS nursing, physiotherapy, allied health services, education and information workshops, seminars and webinars, psychology, financial support, supported accommodation, residential and in home respite, peer support co-ordination and employment services.

Terms of reference

The terms of reference (ToR) for the Senate Joint Standing Committee on the NDIS enquiry into Supported Independent Living (SIL) are:

- a) the approval process for access to SIL;
- b) the vacancy management process, including its management and costs;
- c) the funding of SIL; and
- d) any related issues.

Set out below are comments against each of the terms of reference.

(a) the approval process for access to SIL

The quoting process (a quoting tool and template is included in the Provider SIL Pack) is complex and takes a significant amount of time for provider staff to understand the process. The NDIA is not particularly helpful with this, unless and until you can find a senior person in the Agency's head office to provide advice, rather than rely on the regional offices of the NDIA. Staff turnover in the Agency has also been a source of great frustration.

In compiling this submission we received comments such as, “The NDIA is essentially unresponsive on any issues and when a contact is made and nurtured, one can guarantee that the official will be removed from their role within a month and we have to seek another contact”.

The process for the review of plans creates a significant time lag between plan re-approval and funding to the SIL provider. MS Queensland, for example, has experienced a delay for one of their SIL sites of 4 months – leaving them with a cashflow shortfall of more than \$1.5M. This is completely unacceptable and unsustainable. This shortfall in funding, and the need for the provider to continue to provide 24/7 support during the lag period, has been experienced by the other state MS organisations.

With shared supports, every time a person’s needs change or tenancy arrangements change, the quoting process starts again. The administrative burden is unsustainable.

(b) the vacancy management process, including its management and costs

The ‘vacancy management process’ has not emerged as an issue as yet. SDA stock is still in demand and some states have waiting lists. The only issues to emerge so far with vacancy is due to unacceptable delays by the NDIA with SDA approvals.

Once the client is identified by the state provider, there are then delays if the SIL has not been developed. The SIL process cannot be completed until the participant is allocated a place – but in reality the provider does not have all the participant’s details until they move in. Vacancies cost the providers in rent income and pooled \$s.

Some states have NDIS participants wanting to move in to SDA, needing to move in to obtain SIL and therefore needing the design of the SDA property. One state is waiting months for approvals (even when they know the substantiating documentation is complete and accurate).

(c) the funding of SIL

The quotes submitted by our providers for SIL are, generally speaking, accepted without change. Our process is thorough and our evidence for SIL need, substantiates our quote.

Delays due to NDIS plan revisions and/or renewals, causes issues and a significant, onerous, administrative burden.

(d) any related issues.

The SDA approval process is still too long. The panel approval process is a big improvement and is on the right path to ensuring consistency of decisions, but unless the provider continually reminds the right people in the NDIA, the decisions are not timely enough to meet the needs of individuals desperately in need of the accommodation and the SIL that goes with their needs.

One of our state organisations received no SDA funding in FY19 despite having nine participants who were eligible. Approaches to the NDIA at Director level have not advanced the issue to date.

KEY FACTS:

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 25,600 people throughout Australia
- It is the most common chronic 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. For all, it is life changing.
- Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems.
- There is no known cause or cure.
