

MULTIPLE SCLEROSIS AUSTRALIA

Submission to the NDIS Thin Markets Project

20 June 2019

Andrew Giles
Acting Chief Executive Officer

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 targeting prevention, improving treatment, 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 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:**
As MS specialists 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, that 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 NDIS Thin Markets Project.

The focus of the comments provided in this submission are on key areas that will impact on people affected by MS.

Our submission is framed around the questions to guide submissions to this inquiry.

1. What role does your organisation undertake in this sector.

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.

2. Where does your organisation operate and what services does it provide?

MSA's member organisations are:

- MSWA (covering Western Australia)
- MS SA/NT (covering South Australia and the Northern Territory)
- MS QLD (covering Queensland)
- MSL (Multiple Sclerosis Limited covering 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 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, education and information workshops, seminars and webinars, psychology, financial support, accommodation, respite, peer support co-ordination and employment services.

3. Has your organisation recently entered, expanded or ceased service a thin market?

MSL is currently expanding provision of allied health services into Tasmania (Hobart initially).

4. What information does your organisation require to assess the merits of entering a thin market?

Growth potential, certainty of referral source, likely administrative burden, visible consistency in fund allocation for participants.

5. What are the most important factors which impact on your organisation's ability to operate in a thin market, (including barriers you currently face)?

5.1 Ongoing uncertainty in the provision of supports in a given plan due to the rampant inconsistencies continuing in the design of plans and before that the access process to enter the scheme.

Whilst we can readily identify approximate numbers of people in a given area needing to enter the scheme, and have a good understanding of their functional capacity and

probable need for a given support, there is no correlation to the rate of access approval to the scheme. Similarly plan design often poorly mirror actual need. Both of these things make it difficult to model a potential client base and plan for same. Recruiting for and delivering services is reactive.

5.2 The pool of suitable applicants in allied health willing to leave either private practice or the health system and join what to them is an unknown, the NDIS.

The issue in Tasmania is that there is no tertiary training for occupational therapy (OT) or physiotherapy (PT) in Tasmania. Many Tasmanian students attend university in Victoria or further afield and once graduated usually remain on the mainland. Those that do return enter the health service or private practice to deliver NDIS services. Anecdotally we are seeing these people providing allied health services as sole traders, and OT's in particular are burning out early on after start up because of the onerous nature of the payment system, approval processes, accreditation/compliance and the reporting required by the Agency. They are either heading back into the health sector or into a more general private practice or into areas such as employment support services, Workcover rehabilitation, etc. Enticing them to work in an NDIS role is proving impossible.

5.3 Support coordination and the thin market that the NDIS has created, which is a thinning of quality in the marketplace.

Initially during the early phase of the NDIS roll out, as a continuation of what we saw in trial sites, complex participants with MS who had no informal supports, were heavily engaged with the health system, the housing sector or looking to move from residential aged care into the community and were provided with 'specialist support coordination'.

In response, we specifically recruited for support coordinators with tertiary qualifications, usually in allied health, as per the NDIS suitability guide, to cater for this cohort. However, the NDIS are no longer supporting complex MS participants with specialist support coordination (our last referral was 16 months ago). As this support dropped off, we made the decision to employ coordinators in line with the NDIS guidelines for the mid-level coordination as the margins involved in using allied health professionals at a rate which is half of the specialist rate was unsustainable.

Obviously, the numbers of MS participants who live with complex situations due to their disability continue, but we are now left with sourcing coordinators to support them from a very thin market of certificate or diploma level applicants who may, or may not, have the level of experience, soft skills or necessary awareness to support these people in the way that they need. Qualified and experienced coordinators are few and far between. This has seen a high attrition rate for us in our support coordination service as staff not equipped to manage some of these complex issues move on due to the fatigue such relentless coordination creates, exacerbated by failures within the NDIS system such as ongoing reviews, long waiting list for assistive technology approvals and so on.

6. What short-term and long-term approaches do you believe would best address thin market issues for you?

6.1 Address the uncertainty and blockages in the assistive technology (AT) approval processes and reduce the administrative burden. The consensus in allied health circles, particularly among OTs, is that the NDIS is a “nightmare to work with” and allied health skills and knowledge is not valued. Make a role delivering allied health services in the NDIS an attractive option for experienced practitioners because currently it is not.

We do not support a fracturing of allied health supports to allow non degree qualified staff to perform assessments.

6.2 Support organisations to employ new allied health graduates via internships or similar. Encourage and provide incentives for allied health graduates and/or organisations to enter regional and remote areas or areas where there are no local training institutions such as in Tasmania, Western NSW, North East Victoria.

6.3 Address the inadequacies of the level travel allowances for allied health practitioners to support regional and remote participants.

6.4 Address the ‘thin market’ of adequately skilled support coordinators by valuing the potential supports offered by the service and correctly allocating the different levels of support coordination when it is identified as being necessary.

6.5 Release the Support Coordination framework promised 8 months ago. Ensure that the use of specialist support coordination for participants with complex needs is utilised to reduce the burn out of under skilled workers.

6.6 Allow bundling of services where an interdisciplinary approach is evidenced to provide better outcomes for participants. This can be particularly relevant for people in group home settings or similar.

6.7 Support the set up and delivery of digital supports into regional and remote areas.

6.8 We do not recommend a watering down of supports or reallocation of supports to other line items such as support coordination tasks being reallocated to plan management or vice versa, and therapeutic supports being provided by support workers.

Thank you for the opportunity to make a submission on this important issue.

About MS

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord).
- It is the most common chronic neurological condition diagnosed in young adults.
- Over 25,600 people throughout Australia live with MS (and more than 2.3 million worldwide).
- Over 7.6 million Australians know or have a loved one living with MS.
- MS is most commonly diagnosed between the ages of 20 and 40.

- 75% of people diagnosed are women.
- The economic impact of MS on the Australian economy is close to \$2 billion annually.
- MS varies significantly from person to person. For some, 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 single known cause of MS, however studies have found a complex interaction between genetic susceptibility, environmental and lifestyle factors.
- Whilst there is no cure, there are a number of treatment options available, which may help manage symptoms and slow disease progression.

Sources: [MS Australia Key facts and figures about multiple sclerosis](#) and [Understanding MS](#)
