MULTIPLE SCLEROSIS AUSTRALIA

Submission to the National Disability Insurance Scheme (NDIS) 2017 Price Controls Review

13 April 2017

Deidre Mackechnie
Chief Executive Officer

MS Australia
Level 19 Northpoint Building,
100 Miller St
NORTH SYDNEY NSW 2060
T: 02 8413 7977
F: 02 8413 7988

www.msaustralia.org.au

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 2017 Price Controls Review.

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

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 multiple sclerosis across the country.

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
- Employment

Our submission is framed around the questions in the discussion paper for providers and as the range and level of services varies from state to state, the submission is largely based on the experiences of MSL providing services in NSW, Victoria, the ACT and Tasmania.

Consultation questions – Approach to setting price limits for attendant care

Question 1 (for providers) – How do you decide what price to charge participants?

Prior to the NDIS, clients made contributions to the cost of services provided to them based upon their income, and the balance of their cost of their care either came from block funding grants and/or funds raised to provide 'mission services'.

Post implementation of the NDIS, pricing quotes have been constructed based on the actual cost of the care.

Question 2 (for providers) – Do you have any comments on the current price limits, eg, are current price limits sufficient to recover the costs of providing attendant care and earn sufficient profit, and do they affect the ability of your organisation to compete in the NDIS market?

The current price limits are insufficient to cover costs and earn sufficient surplus that can be reinvested into facilities, for example, which is necessary to ensure facilities are fit for purpose.

Also, the current price limits will affect the organisation's ability (in NSW, Victoria, ACT and Tasmania) to continue to provide residential services.

Question 3 (for providers) – Do you charge a different price for agency-managed participants, self-managed participants or non-NDIS participants?

No.

Question 4 (for providers) – Do you have any comments on the approach of setting price limits based on the efficient cost of provision?

We believe that there is a place for benchmarking and pursuing efficient costs of provision. The difficulty comes from the individual needs of participants and the lack of transparent instruments that indicate the level of care required. For example, for multiple sclerosis, we understand that the Expanded Disability Status Scale (EDSS) is used by the NDIA but not transparently. Also, this instrument does not account for the cognitive issues experience by the participants, which may involve a higher level of complexity in service provision.

Question 5 (for providers) – What changes are you likely to make in your provision of attendant care (eg, quality and amount of care provided) under the NDIS if the price limit for attendant care was:

- *not changed in the next price guide;*

- *increased in the next price guide; or*
- *decreased in the next price guide?*

Multiple Sclerosis Limited (MSL) is continually considering its ability to provide attendant care. Any additional administrative load will necessarily favour organisations who can utilise economies of scale.

Question 6 (for providers) – Do you have any specific concerns regarding access to sufficient labour to offer attendant care under the NDIS? If so do you feel this is impacting costs (such as wages) and if so how is your organisation responding?

Recruiting for staff in this sector is a costly exercise due to the (appropriate, but significant) regulatory overlay. Wages must be set at levels to encourage participation and retention of workforce.

Question 7 (for participants) – Have you had any difficult in securing a provider that will give you the amount of attendant care services in your plan? If so, please explain the circumstances.

N/A

Consultation questions – Assumptions for estimating prices for attendant care

Question 8 (for providers) – Are the assumptions outlined in this section appropriate for estimating the efficient cost of providing attendant care? If possible, please provide examples of your experience.

The assumption that overhead costs are generally low for attendant care is questionable for all levels of dependency. In MSL's case many of our residents require close to one-to-one care, 24 hours a day. The standards for documentation of care are high given the levels of dependency and this feeds into increases in both supervisory and infrastructure costs.

Question 9 (for providers) – Do you have any comments on the suggested modelling approach, such as, on the appropriateness of the cost categories?

Given the awards that apply in MSL's case are state-based, regional jurisdictional differences should be taken to account.

The base hourly rate assumption, employees "are paid at level 2 pay point 3" disadvantages MSL as most of its employees and managers are on the highest increment points. Implicit in the model is that increased turnover of staff is required to operate efficiently. MSL cares for residents over extended periods of time and the personal relationships that form are valued by our residents. It seems heartless that the model will insist these relationships are discarded to provide secure, but less than optimal, services.

Clarity should be provided regarding the source of the long service assumption and its applicability to this sector.

Consultation questions – Simplification of shared care price controls
Question 10 (for providers and participants) – Should the structure of price controls be changed, and if so, why? Do you have any suggested changes?
Question 11 (for providers) – Do you have any comments on how a change to the structure of price controls would change the services you provide or your business processes?

The proposed fixed ratio for 'shared care' appears to be a 'one size fits all' approach. Our experience is that ratios can change over a day. Morning and late evening activities typically require more resources than during the day. In a 'shared care' environment, this may vary from resident to resident.

The specification that Supported Independent Living (SIL) does not apply to the hours between 9am and 3pm will require us to specifically record and separately raise fees from Core Supports, for care during this period when the participant stays in for the day. The additional administrative burden will be high. Management interaction with clients will reduce as attention to "client related matters" will be replaced by income related matters.

C**onsultation questions – Other updates**

Question 12 (for providers and participants) – Do you have any comments regarding the proposed changes to rules and controls, eg, changes that require further investigation, additional minor adjustments that should be made?

Support	**Issue(s)**	**Options for change**	***Comment***
Community participation supports	Participant transport	Clearer rules around the provision of transport services, and how to claim for these services.	*Agreed*

Short term accommodation	Price limits apply on a flat day rate, which includes all expenses in a 24 hour period with no additional loading.	- Consider whether price controls should be split by levels of need. - Consider whether higher rates should apply for weekend/holiday rates. - Clearer definition of the base level(s) of support expected within the daily rate. - Clarify whether/how providers can claim for additional supports over and above a base level.	- *Single per diem pricing is not appropriate* - *Differing levels of dependency must be recognised* - *Full review of pricing required* - *Careful consideration of how this support is to be included in Plans needs to be undertaken.*
Therapy services	Provider travel	Adjustment/clarification of rules to maximise value for participants	*Participants may require multiple simultaneous services (from the same provider) so the system should allow multiple service bookings.*

Consultation questions – Price banding

Question 13 (for providers and participants) – What do you think would be advantages and disadvantages of using a price banding approach?

The use of price banding should produce a more transparent system of funding for participants. If as proposed, there is a system of base funding that is applicable to all, and an additional funding allowance that is based on transparent criteria relating to, for example, dependency or location, then the variance from the base could be more easily attained. We would support this approach.

Question 14 – Do you think price banding would lead to better outcomes for participants? If so, please give your reasons and explain for which services you think price banding would be useful.

Inevitably the NDIA's decisions for individuals are going to be compared when providers have access to multiple plans. It will be in the participant's interest that determinations on "reasonable and necessary" are transparent and explainable. We believe that acceptance and willing participation is essential to the Scheme's ultimate success and individuals (both providers and participants) will need be to be assured of the underlying fairness of the implementation process.

KEY FACTS:

- Multiple sclerosis (MS) is a 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 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.

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