

## **MULTIPLE SCLEROSIS AUSTRALIA**

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# **Submission to the National Disability Insurance Scheme proposal for a Quality and Safeguarding Framework**

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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 the disease, 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 this disease.
- **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, in conjunction with its state member organisations, is pleased to provide a submission to the National Disability Insurance Scheme proposal for a Quality and Safeguarding framework.

The focus of the comments, suggestions and recommendations provided in this submission is on key areas that will impact on people affected by MS.

Our submission is framed around the 8 specific topics listed on the NDIS Quality and Safeguarding website on which feedback is sought, and we have addressed many of the questions posed in the consultation paper.

It is important when addressing the issue of regulatory control, to differentiate the aspects of vulnerability relevant to this discussion. Increasing freedom of choice inherently increases vulnerability, and this should not be underestimated. Regulation must recognise the different life narratives and processes of disability. In relation to MS, specialist involvement is imperative to understanding the disease process, the different forms of disability, and therefore the support options which must be determined by a person's social context, their care plans and prognosis/trajectory of disease. For some people with MS, it is more appropriate to emphasise participant risk and the capacity of an individual to assess, comprehend and self-manage risk, such as: cognition and insight, physical functionality, level of social (informal) and family involvement. It is recognised nonetheless that the coupling of participant risk with provider risk is a good way to safeguard the most vulnerable clients.

### 1. NDIS quality and safeguarding

- What are the most important features of an NDIS information system for participants?
- How can the information system be designed to ensure accessibility
- What would the benefits and risks of enabling participants to share information, for example, through online forums, consumer ratings of providers and other means

The most important features of an NDIS information system is that it be accurate, timely (according to the various stages of disease progression), supportive of those newly diagnosed and provide information to enable early interventions to take place.

Accessibility should be ensured through a variety of communication mechanisms and MSA is supportive of the mechanisms set out in the consultation paper on pages 13 and 14.

Consumers of services and 'communities of interest' will develop their own systems to share information brought about by the explosion of online platforms and social media in recent years. The development of a "TripAdvisor" style of online forum enabling consumer ratings could be seen as inevitable, though this type of assessment system would be more effective and greatly enhanced though the addition of active sampling and objective third party assessments. The development and publishing of printed directories of services is probably best avoided to minimise cost and the difficulty of maintaining currency.

### 2. Building participants' capacity

- Are there additional ways of building natural safeguards that the NDIS should be considering?
- What can be done to support people with a limited number of family and friends?
- What kind of support would providers need to deliver high-quality supports?

The diverse group of people with MS include those with limited natural supports; loss of employment and withdrawal from the community may have occurred over some time and often by design. For this group, service providers can facilitate access to a range of in-home and out-of-home supports that can assist with building confidence to re-engage and develop new networks. This may take some time and some may be reject such attempts; personal choice and desire and motivation may limit opportunities and outcomes.

More care must be taken by NDIS planners to be able to identify people experiencing invisible symptoms such as difficulties with cognition, including processing and memory. This can make people very

vulnerable. A solution is to have tools available to help people identify what they value in a provider and the type of carers they need.

Providers require sufficient funding and the opportunity to tailor individualised flexible responses through a range of options to support the individuals. Networks can be developed and nurtured through access to supports to participate in group activity programs and outings and/or through out-of-home respite options for example.

Quality is achieved through adequate funding levels to support organisations to train staff, develop programs and evaluate their delivery through consumer feedback and self and external assessment.

### **3. Monitoring and oversight**

- Should there be an independent oversight body for the NDIS?
- What functions and powers should an oversight body have?

MSA supports oversight through a single overriding body with a legislative base, led by a senior practitioner that is independent of government and specifically independent of the NDIA. This body should have a focus on practice-based assessment related to legislation regardless of provider status, should monitor and report every incident and provide active oversight to ensure it is not only punitive but positive as well.

### **4. NDIA provider registration**

- Considering the options described (in the NDIA provider registrations section of the consultation paper) which option would provide the best assurance for:
  - Providers?
  - Participants?
- Should the approach to registration depend on the nature of the service?
- How can the right balance be reached between providing assurance and letting people make their own choices?

MSA supports the introduction of one set of regulations that apply to all providers. This will help to ensure the highest level of protection is provided to participants and must be supported by the availability of comprehensive and effective advocacy. We do, however recognise that participant's service decisions will be price sensitive and participants may not appreciate, or be able to afford, the costs of services from providers that have high levels of quality assurance built into their pricing.

Whilst MSA supports the highest level of registration "Option 4: Mandated participation in an external quality assurance system for certain providers of supports" and understands the value of external quality assurance systems especially to meet community expectations, we recognise that there are significant preparation costs as well as audit costs for providers and it is not clear how this level of quality assurance can be funded.

MSA does support the opportunity for participants to maximise their opportunities for choice of providers, however it may be necessary to make some limitations to ensure that services have risk assessment strategies and the risk to participants is minimised, especially in the case of matters surrounding a provider's 'duty of care' such as WHS and fire safety requirements and the provision of training for manual handling where the risk of injury and resultant workers compensation claims is greatest.

### **5. Systems for handling complaints**

- How important is it to have an NDIS complaints system that is independent from providers of supports?
- Should an NDIS complaints system apply only to disability-related supported funded by the NDIS, to all funded supports, or to all disability services regardless of whether they are funded by the NDIS?
- What powers should a complaints body have?

- Should there be community visitor schemes in the NDIS and, if so, what should their role be?

The principle of participants being able to complain to whomever they want, whenever they want is enshrined in the Disability Act and this principle should guide decisions regarding any complaints handling system.

In Victoria, the Victorian Disability Services Commissioner plays an important, independent role that is broader than simply handling complaints, and includes collecting data and making recommendations for systemic improvements.

MSA supports this model and the establishment of the role of an independent Commissioner, outside of the NDIA, who has the necessary strength through legislative powers to be effective. This independent role should not necessarily be focused just on disability, but should encourage cross-sector collaboration, and look for opportunities to bring about systemic change.

The establishment of centralised complaints systems that are available to a range of service jurisdictions is important for people living with multiple sclerosis because they are large users of the multiple service sector, often concurrently. Situations can arise where a person's complaint is related to more than one service or jurisdiction and it is important that the complaint be investigated and responded to as one.

It will also be important to clarify and differentiate the definitions of "complaints" and "serious incidents" and develop a system that gives participants the confidence that their complaints are heard independently without the fear that their services will be disrupted or discontinued.

Complaints in the first instance should be directed to the provider, who is required to have a process in place as part of their contractual requirement. If this is not possible then there are other government funded bodies and advocacy groups who can approach and follow through on their behalf. For example, there is the Office of Health and Disability in WA that provides a link for consumers to lodge complaints and then this Office seeks the response from the provider.

That said, MSA does not support an unnecessarily over regulated system such as Aged Care where providers spend a lot of time and effort responding to reports that are referred directly to the external body rather than using standard complaint management processes which can then be escalated appropriately if the consumer is not satisfied with the outcome. Many of these processes are in place in states through their Disability and Health funding.

MSA views the Community Visitor Schemes as reasonably effective but recommends that a more structured feedback and reporting system be introduced to lead to broader quality improvements.

## **6. Ensuring staff are safe to work with participants**

- Who should make the decision about whether employees are safe to work with people with disability?
- How much information about a person's history is required to ensure they are safe to work with people with disability?
- Of the options described in (this section), which option, or combinations of options, do you prefer?

MSA supports the introduction of a system that can effectively operate across the whole community service sector; one that is not isolated to the disability sector.

These are systems already in place for disability and health funded agencies, and these should be considered as the basis for further improvements to avoid over complication and minimise risk and cost.

It is essential that employee screening is timely and effective, risk-based, and includes relevant processes for renewal and review.

MSA remains concerned about the direct employment of staff by individuals and the safeguards that will be necessary in these situations and for this reason supports the intentions stated under a combination of Option 3: Working with vulnerable people clearances and Option 4: the creation of a banned persons list.

## 7. Safeguards for participants who manage their own plans

- Should people who manage their own plans be able to choose unregistered providers of supports on an 'at your own risk' basis (Option 1) or does the NDIS have a duty of care to ensure that all providers are safe and competent?
- What kind of assistance would be most valuable for people wanting to manage their own supports?

Defining provider risk will be a task requiring considerable thought but considerations with respect to people with MS (and the broader disability community) need to include, for example:

- that specialist/professional services have some kind of minimum requirement (e.g. only qualified Occupational Therapists/Physiotherapists should be making recommendations about appropriate walking aids; capacity assessments should be conducted by neuropsychologists);
- that services with potentially far-reaching consequences for the client should involve greater regulation (e.g. spinal manipulation should be carried out by a physiotherapist as opposed to a massage therapist who has completed a 2 week course);
- that attendant care services staff receive ongoing education and training specific to understanding the characteristics of MS and how to work in partnership with the individual to ensure care and support continues to meet the changing needs of the individual.

Equally, integrated service provision across sectors is imperative for positive outcomes, including appropriate choice and efficiency for the consumer and the cross sector services involved. Specialist provider organisations are the interface across sectors and levels of government. The level of regulation applied needs to reduce fragmentation across service sectors to support a client-centred, well informed and efficient approach.

Accurate information is paramount to people making appropriate choices. We cannot assume that those who seek to manage their plans have the time and mechanisms to sift through supplier information and make effective comparisons.

The capture and reporting of data useful to measuring performance and outcomes, identifying good practice, and alerting to emerging gaps and risks is also important.

Given these considerations and examples, MSA recommends Option 3b: Registration (as set out on page 73 of the consultation paper), for the purposes stated, that it "has the advantage of simplicity", provides the "same level of quality and safeguard protection to all participants" and would ensure that "all providers are on a level playing field in terms of complying with minimum standards in the sector".

## 8. Reducing and eliminating restrictive practices in NDIS funded supports

- Who should decide when restrictive practices can be used?
- What processes or systems might be needed to ensure decisions to use restrictive practices in a behaviour support plan are right for the person concerned?
- Are there safeguards that we should consider that have not been proposed in these options?
- For providers, what kinds of support are you receiving now from state and territory departments that you think would be helpful if it was available under the NDIS?
- Would you support mandatory reporting on the use of restrictive practices?
- If you support mandatory reporting on the use of restrictive practices, what level of reporting do you believe should occur (based on one, or a combination of the options listed in the consultation paper)

Restrictive practices is a broad heading and the definition and use of restrictive practices needs to be clearly understood throughout the health and disability sectors. In practical terms, the reporting of restrictive practices will depend on the nature of the practice and the rationale for its use, and as with any intervention, should be carefully documented including in the Care Plan for the individual which supports the restrictive practice and confirms that the individual or their authorised representative is aware of the rationale and agrees to its use.

MSA understands that in Victoria the work of Authorised Program Officers (APO) in conjunction with the Office of the Senior Practitioner has been of great benefit to their clients and has led to the reduction and elimination of restrictive practices in many cases. Whilst the success of this model depends largely on the

experience of individual APOs, it appears to enjoy broad acceptance and support in the disability community and it would be helpful if this work could be linked to the work of the NDIA Actuary.

MSA supports mandatory reporting Option 3: Providers must report on each occasion where a restrictive practice is used and also recommends that this reporting be independently audited, potentially through a sampling process.

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