TOWARDS SOLUTIONS FOR ASSISTIVE TECHNOLOGY
MS contribution

INTRODUCTION

Multiple Sclerosis Limited (MS) welcomes the opportunity to contribute to the NDIA assistive technology (AT) discussion paper ‘Towards Solutions for Assistive Technology’.

MS supports the principles underpinning the service direction for AT. How these principles are operationalized still requires some exploration to ensure knowledge and experience built up by clinicians within the sector can be retained to meet the needs of different disability types, be it through a virtual or actual partnership with contracted suppliers.

MS believes to achieve the best AT outcomes for people with multiple sclerosis it is imperative to establish an integrated approach across the various service sectors (health, aged care, and education) and with a well-articulated pathway. Streamlining information and communication across sectors and stakeholders will assist Participants to be active and as independent as possible in navigating their AT solution/s.

Our contributions to the AT discussion will say that a one size fits all approach will not work for people affected by multiple sclerosis. The progress, severity and specific symptoms of multiple sclerosis vary considerably from person to person and cannot be predicted. The hidden symptoms of multiple sclerosis can be some of the most debilitating and impactful on function thus requiring individual tailored solutions.

1. THE ASSESSMENT FRAMEWORK

We support the NDIA AT framework and agree strongly that such tools and guidelines are critical in supporting people to be as independent and active in directing their life. We also value the thought given to the next steps in relation to Participant Empowerment.

We would like to offer the following recommendations as part of the next steps:

• NDIA planners need to increase their understanding of the less visible symptoms of multiple sclerosis and their impact.

• Development of additional tools such as a checklist for NDIA planners to assess Participant experience in using, accessing and making informed/reasoned decisions about their AT requirements. The tool will prompt how to ask questions of the participant who experiences difficulties with memory, thinking and processing and is not obvious within the conversation.

• As part of (next steps) the stocktake to identify availability of and /or gaps in ILC (previously known as Tier 2) for participants, MS believe it is necessary to acknowledge that a significant body of knowledge and experience of AT risks and needs for specific groups exists within organisations such as MS and there needs to be a way for these organisations to be involved in co-design to:

O enhance the capability and capacity of stakeholders in a person centred approach: including participants themselves, suppliers and allied health professionals across the various sectors (health, aged care, education and community)
2. INFORMATION AND SUPPORT RESOURCES

Adopting a generic ‘participant empowerment’ approach to access information and support resources could result in a one size approach for all disabilities and may impede the desired financial efficiency and best outcomes for the scheme.

It is important to value and find a way for organisations who have specialist, evidence-based practice and experience with specific conditions such as multiple sclerosis to share this knowledge and assist in building community and participant tools that support Participants to build capability in identifying functional need and how to actively participate in the choice of equipment, control and self-direction of suppliers capacity.

To support the Participants to navigate the process and for the best outcome for people living with multiple sclerosis who require access to different sectors at the same time, it is imperative to have a well-articulated pathway that is integrated so that:

- Participants only have one process to contend with.
- Participants will be more open to taking steps to make choices as opposed to deferring any choice or decision making to someone else.
- Participant network of supports are joined up by way of shared communication enabling consistent clinical information to be available to the Participant to assist in decision making.
- Participants are able to actively contribute as opposed to being “lost in a maze”, feeling vulnerable and overwhelmed.

3. FURTHER RESPONSES

Below are further responses to other AT questions that we feel are important to achieving the best outcomes for people affected by multiple sclerosis:

**Importance of Participants to be able to access the widest possible range of AT**

It is important to have access to a wide range of assistive technology products as:

- Needs and goals are very individual and varied in people living with multiple sclerosis. The AT solution, must to be able to address the functional need to assist the individual to achieve their goal/s.
- Inherent in finding the right solution is the importance of trialling different brands /suppliers of equipment and to modify if required. If the range is limited, then usefulness maybe compromised.
- If the AT product range is limited, more Participants may look to purchase from non-contract suppliers. This may result in the purchasing process and implementation of AT solutions being slowed down due to the Participant being required to prove their need.

**It is important to understand when, where and why it may be necessary to curtail the range of choice.**

For some people living with multiple sclerosis who experience difficulties with memory, anxiety and/or processing of information, choosing from an exhaustive list can be overwhelming, may increase confusion (particularly without significant guidance) and a product may be chosen without due consideration.

- There is a question about competition: Is it likely that competition will be reduced with the introduction of contract suppliers and a loss of small niche providers impacting on choice?
4. IMPORTANCE OF AT SUPPLIER SELECTION

It is important for any participant to be engaged in selecting a supplier however again it is about understanding the Participant and their capability, experience and situation.

- For one person with multiple sclerosis; the choice could be overwhelming, they may have no interest in the supplier and just want the AT solution they need in order to have their need resolved, and

- Yet for someone else; it could be beneficial, enabling a relationship to be established with the supplier, making the Participant feel empowered to coordinate trials, repairs and troubleshoot issues for themselves.

With the newness of the scheme and shift in customer focus there are outstanding questions to be considered such as:

- Appropriate resources for varying disability types to assist Participant to be aware of the different suppliers, their qualities and offerings. Tools and education to support Participants and family to make supported or independent decisions, online apps or paper checklists to determine what they would value in a contract AT supplier, (customer service, value for money)

- Will supplier contracts have a code of conduct to safeguard Participants, ensure that they receive accurate information and that the equipment prescribed will meet the need/s and prevent suppliers from exerting undue influence or ‘hard sell’ of unsuitable products to Participants?

Limiting AT contract suppliers will not be problematic:

- If suppliers maintain a product range that meets the diversity of needs,

- If supplier can be responsive to low, high and customised equipment requirements,

- If regulations of sale are enforced,

- If supplier standards and product range are regularly reviewed in order to maintain contract supplier status.

5. OWNERSHIP OF ASSISTIVE TECHNOLOGY

The best outcome for people with multiple sclerosis is for AT to be owned by NDIA so that servicing, repairs and re-issue options are the responsibility of NDIA or a third party.

A loan / re-loan / re-issue scheme might advantage Participants living with multiple sclerosis due to the progressive nature and changing needs, which for some people can be frequent.

Although the AT is not necessarily ‘owned’, the equipment would be available to the Participant for as long as is needed and could be periodically assessed for upgrade as new products come through.

The current process of re-issue through SWEP (or other) is limited and cumbersome and will need to be improved for efficiency and for benefit to the Participant and Agency.

This process requires safeguards to ensure suitability and safety of equipment. It may also be beneficial to have a timely advisory and installation service using trained allied health professionals who are part of a contract supplier or contracted from a registered pool.
6. PROVING NEED FOR NON-CONTRACTED AT SOLUTION

Issues for Participant to prove their need when they want a non-contracted AT solution and impact on maximising outcomes for Participants or their choice and control in relation AT:

- For many people living with multiple sclerosis, understanding what proof is required and being able to explain the trigger for this need or their change in circumstance could be overwhelming and challenging.
- It may force Participants to settle on less suitable AT solutions or to give up pursuing any AT solutions in a timely manner, placing them at risk that results in poor outcomes.
- It is important to allow and encourage AT innovation to enable improved quality of life and independence in addition to the routine AT solutions.

CASE STUDY: INNOVATION AND INDEPENDENCE

The positive of customers having capability to take control over their equipment need and purchasing was highlighted recently.

An example of the positive impact of a customer having the ability to decide their equipment needs, and be involved with the purchasing was highlighted recently. Customer L had recently been shown a powered standing wheelchair by a supplier, and was intrigued about the effect that it might have on her pain and spasticity. Previous advice from an MS physiotherapist indicated that standing with the aid of assistants could help reduce her pain, and assist her with controlling her muscle spasms.

However, while she had some paid carer hours available, they were not enough to allow her to stand as frequently as required. Furthermore, the equipment programs would be unlikely to fund the standing wheelchair as her current wheelchair was still functioning and her application would be within the 7-8 year timeframe that is usually required for replacements.

This coupled with a lack of evidence supporting the use of the product in people with multiple sclerosis particularly with her presentation of disease progression, and the potential need for other equipment in the near future resulted in the MS Consultant advising her that it would be a low priority and one that would probably not be feasible.

Despite this information, customer L independently contacted a supplier regarding a home trial. The trial was a success with L reporting that using the standing wheelchair she was able to assist with meal preparation, and was able to hug her daughter for the first time since she had been confined to the wheelchair. She is now considering funding options to acquire the standing wheelchair.

This is an example of a customer who through many years of therapist input has attained a level of knowledge that has given her confidence to independently explore and trial a product based on her needs. She is also aware of the benefits of engaging a therapist to help with equipment or exercise prescription once she is able to obtain funding. L is a good proponent of the NDIS, demonstrating how an individual can take on the task of gaining their AT solutions, and how therapists may have limited innovation for individuals due to rationed funding and constrained process.
4.1 ALLIED HEALTH PROFESSIONALS

MS would like Contract Suppliers to be required to have an allied health professional(s) to complement a customer outcome focused team. We believe this would be of significant benefit for people who have complex or specialist AT requirements for example pressure care issues. We offer the following two examples:

CASE STUDY A

A common concern that often arises with customers is pressure care. An example of this is a person living with multiple sclerosis who had re-occurring pressure areas on her buttocks. There are many factors that influence pressure including moisture, heat, friction, shearing, nutrition and weight.

This individual was in supported accommodation and the staff placed the client on an air cushion. Despite this, the pressure areas remained. This meant that she was required to have bed rest. This was ineffective as she would put the bed head up, to a point where there would still be significant pressure going through her buttock. Upon further review the cushion was over inflated thus not providing even pressure distribution, she wasn’t using the tilt on her wheelchair often enough and has some moisture from incontinence. The interventions employed were about managing these factors and education with the staff, rather than addressing and changing the equipment.

This demonstrates the complex nature of seating, especially with people that are unable to shift their weight. The medical complications and impact to an individual’s independence from incorrect seating can be huge, thus input from health professionals with experience and knowledge in this area is essential.

CASE STUDY B

R is an example of a client who would likely prefer not to be faced with increased choices regarding services and providers, but would choose to have these decisions made for him. The anxiety and stress of dealing with increased choices and decision making would likely contribute to increases in anxiety, depression, fatigue and significant stress.

R is a 45 year old man, who was diagnosed with Primary Progressive MS 4 years ago. He lives alone in a small unit, uses an electric wheelchair for mobility, and receives daily personal assistance and other services and supports as needed. R lives with cognitive and mental health issues, suffers from depression, severe anxiety and concrete thinking.

R’s social anxiety causes significant difficulty with talking to people, asking or answering questions and talking on the phone and all of which can result R, experiencing increased fatigue, isolation and withdrawal. This example highlights the need for the AT supplier to understand the additional challenges that exist for an individual and the need for a direct allied health support.

IN SUMMARY

It is likely that up to 30% of people affected by multiple sclerosis will require adaptive equipment, and a number of these will also require assistance with the process.

Although MS welcomes the development of solutions for AT there remains a number of issues and concerns that require consideration.