MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Joint Standing Committee on the NDIS inquiry into transitional arrangements for the NDIS

---

9 August 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

Multiple Sclerosis Australia
ABN 51 008 515 508

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 Joint Standing Committee on the NDIS inquiry into transitional arrangements for the NDIS.

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

Terms of reference

Our submission is framed around the terms of reference (TOR) as set out in your invitation to make a submission to this inquiry.

MSA acknowledges that many people with MS have received NDIS plans that work for them, though it has been reported to us that those with successful plans tend to be participants who are more able to speak up for themselves and negotiate better outcomes. Those who are vulnerable, confused and isolated tend not to fare so well.

MSA is keen to ensure that the NDIS is successfully implemented. The issues raised and examples set out in this submission are provided as constructive suggestions and to highlight areas where improvements to the Scheme need to be made.

Term of Reference (a):
The boundaries and interface of NDIS service provision, and other non-NDIS service provision, with particular reference to health, education and transport services

The interface with the health sector remains unclear and for people with MS in particular, it probably always will. People with progressive neurological conditions such as MS, will often interface with health intermittently as challenges arise and their condition fluctuates or deteriorates. Most people with MS experience periods of relapse and remission, which needs to be recognised and clearer guidelines regarding health services vs NDIS responsibilities are needed. For example, when discharging someone home after a hospital visit following a relapse, the health service should be able to support safe discharge back into the home but we understand that there are now instances where health services are no longer accepting responsibility if the person is an NDIS participant. These processes should provide a seamless pathway of care for the individual rather than participants being subjected to jurisdictional disputes.

Funding the cost of supra-pubic catheters

An example of a jurisdictional dispute between the NDIS and health services is in regard to the funding the cost of supra-pubic catheters.

Changes of supra-pubic catheters (SPC), by registered nurses, under the NDIS using 'Individual Assessment and Support by a Nurse' is no longer being funded in a number of regions across NSW, Victoria and the ACT. Until earlier this year participants in the Hunter and Barwon trial sites had received this funding across multiple plans. The message 'vaguely' being put out by some planners is that this support is to be funded by the relevant health service, however, a number of area health services are pulling out stating that they have had their HACC funding removed and are therefore no longer able to provide this service. This lack of clarity and consistency of message to participants is creating stress and without appropriate and timely catheter changes, places participants at a high risk of requiring hospitalisation due to complications from infections caused by retention of urine, and the triggering of an MS exacerbation due to such an infection increasing core body temperature. At the very least, extra funded supports are needed.

The NDIA, from the limited information they have provided to date, state that they are "in discussions" with Health on the matter. Unfortunately they have been in discussions with Health for quite some time with no outcome. Meanwhile the frustration and potential risks are being experienced by more and more people across the progressive neurological space. The NDIA have stated that the reasoning behind them shifting the responsibility to Health is that the need for a SPC change is not related to 'functional impairment'.

MSA disputes this statement, based on the clinical knowledge gained by our state member organisations over many years. Some people with MS are recommended to have a supra pubic catheter either after using self-catheterisation or as an only option do so because their functional ability to begin or continue self-catheterisation is impaired, that is, their manual dexterity due to symptoms such as spasming and tremor is diminished, their visual acuity is hindered due to their MS or their cognitive state has deteriorated so that self-catheterisation becomes a risk. The fact that the NDIA continue to fund the actual consumables required for SPC changes but not the changes themselves is also confusing to participants.

Advice provided to MSA as a result of a meeting held between the NSW Health Minister, NSW State Health officials and the heads of four NDIS districts at which the topic of funding catheter changes was discussed, indicates that the NSW Health Minister believes continence issues caused by a progressive illness such as MS to be the remit of the NDIA and not Health, as the symptom is linked to the primary disability and involves functional impairment. This may set a precedent for other state Health services.

Funding for wound care

Another example of a jurisdictional dispute between Health and the NDIS is in relation to wound care. Funding for wound care is not covered in NDIS plans, however, we understand that Queensland Health is refusing to provide this service for many NDIS participants. In one example, a participant was discharged from hospital. The hospital refused to provide any wound care once the participant was discharged due to the participant having a NDIS plan. NDIA are in discussions with Queensland Health to address this issue, though the outcome remains unknown.

Bilateral agreements

In terms of the Bilateral agreements, we do not consider they are being met in regards to:

Section 4 - Roles and Responsibilities

The sharing of knowledge and working together to improve and refine the system as set out in this section of the agreements, is not occurring. Our state members have consistently attempted to work with the agency on issues directly relating to individuals and more broadly on the education and development of planners and plans but repeatedly do not get timely or adequate responses. In NSW, in particular it is extremely difficult to have any issue acknowledged, addressed or responded to; NDIA engagement with providers is minimal at best and usually under the Agency's terms.

MSA understands that there has been an improved response by the NDIA in Victoria with Local Area Coordinator providers willing to meet and be provided with information and education on neurological conditions.

Section 5 - Portability and Transition

Problems with transition to the scheme can be considered similarly – there is no smooth transition with minimal service gaps or disruptions. MSA member organisations are repeatedly speaking with participants who have lost services and supports once entering the scheme either through a lack of understanding from the planner or wrong and incomprehensible plans being received with incorrect funding codes. This leaves participants without services and equipment and without any corrections being able to be made in the short term. Lives are disrupted and family breakdown occurs.

The Bilateral Agreements promised to build on the knowledge from the trial sites.

This has not occurred with major inconsistency in planning provision, service responsiveness, variations in plans, understanding and messaging. There is no choice and control for some participants as promised in the Bilateral Agreements, especially those in regional areas where limited services means long waiting lists. Some participants do not how to activate their plans and do not have support coordination built into it. These people are waiting to be supported by the LAC workforce who freely admit they do not have the capacity to meet each participant to set them up on the NDIA portal and explain their plan. MS organisations take frequent phone-calls from people unsure of what to do and despite having developed resources to support people in understanding who their LAC is and what number to contact, this is often not enough information to commence the activation of their plan.

Term of Reference (b):
The consistency of NDIS plans and delivery of NDIS and other services for people with disabilities across Australia

On-going issues with NDIS plans can be summarised as follows:

- Lack of consistency of plans across all regions e.g. variation in hours and levels of support
- Lack of consistency in how planning meetings are held, or even if people are told they are having a planning meeting. The majority are phoned based and people do not understand that this is their planning meeting.
- LAC delivery of service is inconsistent across regions and providers
- Lack of consistency of knowledge by planners of scheme or disability; planners seem to have little or no understanding of neurological conditions
- Inconsistent messages to participants, different message every time someone phones, different messages across regions, different messages at different forums.
- No consistency in what people are being told to do to get their plans started
- No consistency in what is being told at official NDIA forums and what is happening in the roll out

Term of Reference (c):
The rollout of the Information, Linkages and Capacity Building Program

Despite the aims and objectives of the ILC being explained by the NDIA, there still seems to be considerable confusion in the sector as to just exactly how the ILC will work in practice. There is also disappointment and warning signals from some commentators that the planned investment in the ILC is inadequate. There is some hope that as further funding rounds occur, projects commence and their impact is evaluated, that some of the aims of the ILC will start to be achieved, though the lack of overall funding for ILC remains a concern.

Term of Reference (d):
Any other related matters

Time taken to establish plan

The time taken from registration with the NDIA through to planning, completion and activation of a plan be considerably delayed for some participants with the resultant negative impact on the participant's day-to-day life and disability progression.

Co-ordination of support

MSA reiterates the point (as it has in previous submissions) that case coordination is essential for participants with complex needs, especially with disability acquired through neurological conditions

Conclusion

Further specific details and case studies of experiences with the implementation of the NDIS are set out in MSL's submission to the Joint Committee's inquiry into general issues around the implementation and performance of the NDIS (submission number 14).

These experiences can be categorised into three main areas of concern:
1. The Planning process
2. Plan implementation
3. Plan reviews.

Many of the issues raised in this submission were previously canvassed in submissions made to the Productivity Commission's inquiry regarding NDIS costs in July (see attachment 1).

In addition, many of these issues were raised in a Joint Position Paper issued by the Neurological Alliance Australia (NAA) at an event in Canberra in March, also submitted to the Productivity Commission's inquiry (see attachment 2).

MSA is looking forward to seeing the issues set out above addressed and improvements to the NDIS being made in the very near future. The continual reporting on these issues, providing submissions, speaking at senate enquiries, sending individual emails regarding various implementation issues to the NDIA, and continually attending meetings and forums has become a challenge for all.

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.

***