MS AUSTRALIA MS

Submission to the NSW Parliamentary enquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

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Introduction

MS Australia (the national peak body for people living with multiple sclerosis in Australia) and MS (the entity which is the pre-eminent source of information, advice and services for people living with multiple sclerosis in the ACT, NSW, Victoria and Tasmania) are pleased to provide a joint submission to the NSW Parliamentary inquiry into the Implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales.

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

Multiple Sclerosis (MS) is a debilitating disease of the central nervous system that affects more than 23,000 people throughout Australia. It is the most common chronic neurological condition affecting young adults. The average age of diagnosis is between 20 and 40, and 75% of people diagnosed are women.

MS varies significantly from person to person. For some people, it is a disease that fluctuates in severity with periods of unpredictable relapse and remission. For others, it is a progressive decline over time. For all, it is life changing.

Symptoms can include debilitating fatigue, severe pain, walking difficulties, partial blindness or thinking and memory problems.

There is no known cause or cure.

An Economic Impact study of MS conducted by A. Palmer in 2011 stated that, 'the typical course of MS is initially relapsing-remitting, with symptoms partially or completely disappearing during remissions. However, after about 10 years, the majority of people enter a secondary progressive phase and disability gradually accumulates. For a smaller group, the disease course is primary progressive, with ongoing worsening of the initial presentation. Many of these people with MS develop other chronic conditions in the course of the disease.'[1]

We are 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 in NSW.

Many of the broader issues raised in this submission have been previously canvassed in in a Joint Position Paper issued by the Neurological Alliance Australia (NAA) at an event in Canberra in March 2017, in a submission to the Productivity Commission's inquiry regarding NDIS costs in July 2017, and in a submission to the Joint Standing Committee on the NDIS inquiry into transitional arrangements for the NDIS in August 2017. All of these submissions are publically available on MSA's web-site and we commend them to you https:/www.msaustralia.org.au/about-msa/submissions. These issues have also been raised by representatives of our organisations at hearings conducted by the Joint Standing Committee on the NDIS in NSW and Victoria.

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[1] Palmer A., *Economic Impact of MS in 2010 Australian MS Longitudinal Study, September 2011*, page 7.

Terms of reference

This submission is based on the experiences of the MS organisation providing services in NSW to people living with multiple sclerosis (MS) and other neurological conditions. We have focused on those terms of reference that refer to (a) the implementation of the NDIS and its success or otherwise in providing choice and control for people with disability; (b) the experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans; (e) the provision of support services for people with disability regardless of whether they are eligible or ineligible to participate in the NDIS; (g) workforce issues impacting on the delivery of disability services; (h) challenges facing disability services providers and their sustainability (i) incidents where inadequate disability supports results in greater strain on other community services, such as justice and health services; and (j) policies regulation or oversight mechanisms that could improve the provision and accessibility of disability services across NSW.

Major challenges

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.

The application and administration of the scheme has not been friendly nor consistent and has challenged and frustrated many participants, families, and the MS workforce. Negative experiences range from planning through to application and review process, with adverse practices and processes hindering the successful introduction and acceptance of the scheme.

The major challenges of the implementation of the NDIS in NSW are summarised as follows:

1. Difficulties with the planning process; lack of understanding of progressive neurological conditions by NDIA staff
2. Difficulties with plan approval and plan implementation; poor communication with Support Co-ordinators and participants by Local Area Co-ordinators (LACs)
3. Difficulties with the planning review process; high volume of plans needing review; poor communication by NDIA staff regarding complaints and appeals

These challenges are set out in more detail below.

1. Difficulties with the planning process; lack of understanding of progressive neurological conditions by NDIA staff

MS has received considerable feedback from participants, their carers and other members of a participant's support network regarding the planning process and MS staff have supported a number of participants in their planning meetings with LACs. The overwhelming theme of the feedback relates to the apparent lack of understanding of the impact of disability within most of the LAC workforce, the absence of any specific understanding of multiple sclerosis or other progressive neurological conditions, the lack of experience in conducting planning assessments and the nature of these assessments.

Whilst we are aware of a number of LACs who have sound skills and knowledge when it comes to disability and sometimes progressive neurological conditions, it is not the norm. Conditions such as multiple sclerosis are characterised by many hidden symptoms which are often not being explored during the planning assessment. Standing out amongst these often hidden symptoms such as fatigue, continence and heat intolerance, is the changes that multiple sclerosis can have on a person's cognition.

Cognitive changes or deficits are difficult to identify when given ample time and exposure to someone with these symptoms. But when assessments do not explore such a possibility, assessors are not skilled or given scope to drill down and discover the extent of these symptoms, then the likelihood that they are given due attention is unlikely. MS can and does affect a person's ability to pay attention, retain short term memory, process information at normal speed and undertake executive functioning tasks such as planning, problem solving and flexibility of thought or insight. Not realising that these deficits could be affecting the answers being provided is, we believe, a major contributor to plans being developed which do not provide the necessary supports which can combat or help manage cognitive change.

Whilst we are very pleased to have recently been invited by the NDIA to provide material for a "Fact Sheet for Multiple Sclerosis", we have not yet been advised as to how this material will be used or if, and how, the Fact Sheet will be promulgated throughout the Agency.

We believe that Support Coordination should be mandatory in plans for people with a progressive neurological condition such as MS so that a plan can be implemented appropriately, in a timely fashion and without the potential risk that funds will be used inappropriately. Allied health support is also integral to managing some of the visible and hidden symptoms of MS and other neurological conditions. Funding is essential to allow people to continue treatment by trained professionals such as a physiotherapist or exercise physiologist, to manage pain, maintain mobility, reduce fatigue, reduce falls and improve a person's ability to remain in, or re-enter, the workforce. Often the need for these supports is not understood by planners and LACs.

Some examples experienced by MS and persons affected by MS in regards to the planning process are listed below:

- Planners speaking with family members rather than the participant, resulting in a plan that does not match the participant's goals and needs.
- When asking for support coordination to be considered for inclusion in a plan, being told that they 'sound' like they could manage everything themselves.
- Applicants being told they are not eligible for support coordination before the assessment has even begun.
- Planners having no understanding of neurological disability and how it can impact a person's functionality – one planner questioning if MS was a permanent disability.
- Planners following a list of 'scripted' questions, without considering the overall context of what they were asking e.g. asking people severely physically compromised with no movement in arms and/or legs if they can brush their teeth or hang out their washing.

- Applicants being told there is no such thing as “exercise support” in NDIS plans.
- Applicants being told that they can use core support funds to have a support worker give them exercise if they want it.
- Applicant being told that they seem to be able to move around the home ok so would not be eligible for a mobility aid to enable community access.

We were very pleased that, as a result of significant lobbying and advocacy from the sector, the NDIA’s process of conducting planning meetings by telephone has ceased.

2. Difficulties with plan approval and plan implementation; poor communication with Support Co-ordinators and participants by Local Area Co-ordinators (LACs)

The NDIA announced early on that written plans sent out to participants are often incorrect and that they should not be seen as an accurate record of the supports in a person’s plan. In addition, supports identified in the participants ‘myplace’ portal are also often incorrect. This leaves participants unsure of what exactly they are funded for. The language used in some plans is laced with poorly understood jargon and/or just copied and pasted from one plan to the next.

Those participants who have not received funded support coordination are often told that they will receive ‘support connection’ from the LAC who was involved in their planning process. Unfortunately, the nature of the support connection delivered by the Local Coordinator agencies to allow a person to activate a plan, engage providers, develop service agreements, budget their funds and deal with issues is sparse, inadequate and often ineffectual.

Support connection from agencies sometimes seems to entail giving someone a printed handout on what the ‘mygov’ system is, what the ‘myplace’ portal is, definitions of a support agreement and a list of recommended providers which the participant can contact to seek supports or, slightly better, providing a single face-to-face meeting.

LACs have told participants that they do not have the time to provide support due to other commitments in planning and plan reviews but that “they are available if there is a problem”. Unfortunately, LACs can be difficult to contact, sometimes leave the position and are not replaced or report that they still have no time available to support a person.

Other LACs have told participants to ring the MS organisation to provide this assistance, which we do, but this assistance is unfunded. Staff at MS spend a considerable amount of time chasing LACs to implore them to provide the ‘support connection’ services they are contracted to provide. MS staff are assisting participants to submit plan reviews because LACs do not have time or no LAC is currently allocated.

Coordinators of Support in the MS organisation provide considerable support to NDIS participants whose plans were inadequate or who have had reviews delayed which has seen their funds exhausted. In addition, our NDIS Advisors, speak to people on a weekly basis who have their access to the scheme denied or who need assistance with submitting reviews - all of this support is unfunded. We also field calls from participants who call up with no idea what to do with an NDIS plan they have had for months, do not know who their LAC is or have tried contacting them and received no reply. We also spend considerable time trying to track down LACs or if they have left the role, which is common, advocating for a replacement to be allocated or a plan to be reviewed to include support coordination.

Feedback from participants with MS in NSW indicates that many did not know how to implement their plan, did not have sufficient support from their LAC to implement their plan, did not know who their LAC was, or did not receive calls back from the LAC.

These problems result in participants and their carers being highly stressed, anxious and frustrated.

Examples of plan implementation issues include:

- Plans missing basic support that was previously funded under the NSW Ageing, Disability and Home Care program.
- Plans without funds for equipment, including mobility aids and continence equipment, and services such as domestic assistance, yard maintenance, transport funds
- 80% of those plans where the MS organisation provides support coordination are returned for review because of inadequate funding not matching previous state funded supports
- Support needs not understood by LAC resulting in absent or minimal funding for reasonable and necessary supports and/or funds allocated against incorrect support categories
- Participants not knowing who their LAC providing support connection is or haven’t heard from them for weeks sometimes months.
- Participants with MS have been incorrectly classified as ‘general disability’ rather than having a progressive neurological condition and LACs deem they do not have the ability to change this.
- Participant with significant cognitive deficits cared for by mother who does not speak English, received no support coordination and has received no support from local area coordinator. Provider of personal care is billing participants plan for support coordination from core supports, lessening available funds for personal care and community participation. Mother unable to advocate for daughter and does not wish to ‘rock the boat’ and lose funding. LAC believes arrangement is reasonable as she cannot offer support due to workload yet will not submit a review to seek funded support coordination.
- Participant with significant cognitive deficits received no support coordination. Family culturally and linguistically diverse. Care provider having undue influence on participant and makes decisions regarding spending of plan funds. LAC, due to lack of time due to workload, deemed it reasonable for the paid service provider worker to have access to participant’s bank details to enable plan activation.
- LACs not understanding the support categories and line items available. Participants told that exercise physiology and personal training are not available funded supports.

3. Difficulties with the planning review process; high volume of plans needing review; poor communication by NDIA staff regarding complaints and appeals

The number of people which the MS organisation is aware of that have submitted, or are planning to submit a plan review, is substantial.

Of those participants which MS is providing support coordination to, over 80% have required a review due to errors in plans, underfunding of supports previously provided under the State model or unmet needs that were not understood or addressed at plan design.

The process for submitting and waiting for a response from the NDIA is just another cause of stress for those people that are most vulnerable. The fact that a total plan reset is required to change a single item in a plan or to amend an error by the Agency is causing a strain on the resources within the Agency which is then transferring to participants and the MS support staff involved.

Once reviewed, changes to those support areas which were not included in the plan review leads to reductions in funding for core supports. These reductions then lead to yet another review and the cycle begins anew.

A major concern is the lack of communication from the NDIA to participants regarding the progress of a review. Complaints will see a response from the NDIA that the issue has been escalated but not to where and how the matter will be resolved. Staff at the NDIA will often state that they are understaffed and can do no more than escalate the issue. Again, MS is approached by increasing numbers of people seeking assistance in formulating and submitting plan reviews or appeals, something which again is unfunded and we understand should be delivered by LACs.

We are encouraged by the NDIA’s introduction of a ‘participant pathway’, currently being trialled in Victoria, which we hope will address some of the concerns outlined above. The NDIS advise that this will allow amendments to plans without a total rebuild, and that plans will not be activated until signed off by the participant, hopefully reducing the number of reviews in the first three months, though we are concerned that this may prolong the time before a participant receives a workable plan, if the education of planners and LACs remains constant. The Agency has already indicated that they do not have the resources or the systems to roll out the full participant pathway as planned (e.g. a planner and a LAC involved in all planning meetings, participants provided with their LAC’s direct phone number), however we remain cautiously optimistic for the pathway’s national implementation.

Case studies

The challenges set out above are further illustrated by the following case studies. (These case studies have been de-identified; the names used are not the participant’s real names.)

Case Study 1:
Significant delays in implementing home modifications; lack of communication by NDIA planner; led to participant's deterioration; home modifications still not finalised!

Participant in Western Sydney

Chris commenced with the NDIS in January 2017. Chris's primary disability was directly related to MS. Chris is in a manual wheelchair in own home that is carpeted and currently has a bath in the bathroom. The initial Plan supported every aspect of Chris's life including an extensive budget for home modifications to replace the flooring in the home and modify the bathroom so CD can shower.

Chris engaged an occupational therapist (OT) to start the process of the Home Modifications. The OT had to source a recognised NDIA OT who has a specific skill for assessing home modifications. This process took six months before plans were drawn up and builders were involved.

The builder's plans and quotes for home modifications were sent to the NDIA for approval. The main goal in Chris's plan was to access the bathroom and shower at home, but after nine months nothing had changed and Chris's condition was deteriorating.

There was no news from the NDIA regarding the home modifications until Chris and his Support Co-Ordinator (SC) attended a planning meeting with the NDIA, by phone, in December 2017.

The issue of the lack of progress on home modifications was raised at the meeting, as Chris by this stage was extremely distressed and upset. The Planner assured Chris that she (the Planner) would approve the home modifications, as the Planner could see all of the details had been placed on the NDIA system. Chris was relieved and somewhat placated by the words of the Planner and felt it was only a matter of weeks until work on the home modifications would commence.

By the end of January 2018, Chris had not heard any news from the NDIA regarding the home modifications nor a start date. The SC followed up and spoke to a Planner at the NDIA regarding the home modifications querying as to why there had been a hold up; the Planner was not sure and explained a senior delegate would get back to Chris.

A Planner then followed up within a few days and explained that due to changes at the NDIA, builders needed to be registered with the NDIS to roll out home modifications. The Planner explained that the participant would need to source new builders to again get plans and quotes together.

At the beginning of February 2018, Chris asked the OT to set the process of getting new building plans and quotes together in motion as Chris was again extremely depressed due to the rule changes, lack of communication from the NDIA and still nearly 18 months later no access to his own shower.

NDIS-approved builders provided plans and quotes for the work required and all details were submitted to the NDIA again in May 2018.

Currently, Chris is still awaiting an NDIA delegate to approve the home modifications.

Case study 2:
Jurisdictional dispute between NDIA and Department of Health regarding nursing support for management of super pubic catheter; currently before the NSW AAT

Participant in the Hunter

Participant AB commenced in the NDIS in April 2014 in the Hunter trial site. His primary disability for entrance to the Scheme was directly related to his MS.

From 2014, AB had three consecutive plans that supported all aspects of his life including the necessity for super pubic catheter care by a registered nurse (RN).
In February 2017, at a plan review meeting, the NDIA planner stated that the Agency would not cover the cost of RN support in AB's new plan, but would continue to fund his equipment, i.e. the super pubic catheter (SPC) itself.

AB has an SPC due directly to the impact MS has had on his body and the use of the SPC needs to be supported and overseen by an RN. The support took the form of an initial assessment (approximately 4 hours), then 1 hour each month across 12 months – a total cost of around $1700.00.

The Agency stated that the RN support related to "health" and so should be funded by the Department of Health. AB was able to present evidence from pre-eminent neurologists that the SPC and its RN supports related directly to AB's disability and as such was the responsibility of the Agency.

Since this initial rejection of RN support by the Agency, AB's family have lodged requests for multiple reviews with the Agency and been rejected each time. They sought intervention and support from their State MP. As a result of this lobbying the then NSW Health Minister stepped in and organised a nurse from the John Hunter Hospital to continue this support for AB. The Health Minister was able to identify that if this support was not in place, AB could have catastrophic outcomes as a result of infections.

This case was referred to the NSW Administrative Appeals Tribunal (AAT) however, after the initial conference all parties including legal counsel for the Agency agreed that, in accordance with the evidence provided by AB, that this was a clear case for RN support to be included in AB's plan. The need for RN support relates directly to AB's primary disability - if AB did not have MS, AB would be able to toilet himself – and is not a Department of Health responsibility.

The family were asked to submit letters from nursing providers to the AAT, outlining the support required and another hearing of the AAT is set for the end of August 2018.

This significant issue that remains unresolved over the last two years continues to be extremely stressful and emotional for AB and family. Ultimately they are asking for no more than a specific support that relates directly to AB's primary disability.

The family are hopeful that this situation will be resolved very soon and included in all future NDIA Plans for AB.

The MS organisations hope that this precedent will pave the way for this same RN support for SPCs to be included in participant plans nationally.

Case study 3:
Dissatisfaction with planning meeting, significant and unnecessary delay in providing essential communication device, participant experiencing extreme anxiety and frustration.

Participant in Lake Macquarie

In December 2017, Sue, her husband and a Support Co-ordinator (SC) attended a plan review meeting with an NDIS planner.

During the 2-hour meeting, it was felt that the planner was extremely dismissive of Sue and her MS-related disability, even more dismissive of her husband and any input from the SC.

For example, a discussion was held regarding a request from Sue's husband to provide a cup holder on Sue's wheelchair. The planner responded with the question, "why would a cup holder be needed, when SC is unable to use her arms or hands?". Sue's husband was quick to explain that Sue enjoys other drinks besides the water in her "Camelback" water holder and that the simple use of a cup holder and straw would allow her to feel somewhat "normal" in social settings. The planner did not respond.

Once Sue's plan commenced, an allocation for a communication device was built into the plan, pending a trial and quote. The device was approved relatively quickly, however the funds were not released by the planner for another six months following numerous emails and phone calls.

The device was then ordered by the NDIA from the manufacturer without any details attached, such as Sue's name, address or NDIS number. It was only after several complaints from Sue and her SC that the device was located. Once the manufacturer was made aware of who the device was for, the process for delivery was relatively quick.

The NDIA planner was copied into all relevant correspondence and not once did she reply or at the very least apologise for the long delay, which could have easily been avoided.

Sue has been unable to participate in her community safely without this device and the six months of anxiety and anger that she experienced could have easily been avoided if some understanding of SC's disability being brought about by MS was understood.

The SC and other allied health involvement provided by MS have continued to provide the ongoing assistance required to implement the device and other aspects of Sue's plan, despite the delay causing the hours in the Core Budget Daily and Support Co-ordination aspect of Sue's plan being exhausted.

Recommendations

MS Australia and MS recommend that the NDIA in NSW take action to ensure that:

1. The NDIA Fact Sheet on Multiple Sclerosis will be promulgated throughout the Agency so that people with MS can have the expectation that this Fact Sheet will be read by Agency staff prior to their initial meeting and that the Agency seek other ways to improve Agency staff knowledge of the needs of people with complex, progressive, degenerative neurological conditions such as multiple sclerosis.
2. Support Coordination be mandatory in plans for people with a progressive neurological condition such as MS so that a plan can be implemented appropriately, in a timely fashion and without the potential risk that funds will be used inappropriately.
3. Support Coordination hours are consistent and adequate to address the complexity of a participant's needs. There is an urgent requirement to eliminate the need for unfunded SC – this is not sustainable!
4. There is improved communication from Agency staff to participants especially from the LACs who can be difficult to contact, sometimes leave the position and are not replaced or report that they still have no time available to support a person.
5. Requests for plan reviews are addressed in a timely fashion, especially those that include equipment requests for participants faced with rapidly progressive neurological conditions such as Primary Progressive MS and improve communication from the NDIA to participants regarding the progress of a review.
6. Plans have contingency funding built in to minimise or preferably avoid the need to frequently review plans.
7. A dramatically improved communications system is implemented to ensure participants and SCs are kept properly informed, especially when a plan escalation is necessary.
8. That the level of unfunded support provided to applicants through the pre-planning phase and to participants during the planning, review and appeals phases provided by the MS service organisation is recognised and acknowledged and that discussion commence on how this level of ongoing support can be properly funded in the future.

KEY FACTS:

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 25,600 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.