MS AUSTRALIA MS

Submission to the ACT Legislative Assembly Standing Committee on Health, Ageing and Social Services enquiry into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS) in the ACT

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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 ACT Legislative Assembly Standing Committee on Health, Ageing and Social Services enquiry into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS) in the ACT.

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 the ACT.

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.

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

Terms of reference

The submission is based on the experiences of the MS organisation providing services in the ACT to people living with multiple sclerosis (MS) and other neurological conditions. We have focused on those terms of reference that refer to gaps or duplicate roles and responsibilities; the availability of services; the implementation of local area coordination and unique factors relating to the provision of disability services affected by the implementation of the NDIS in the ACT.

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

Inconsistencies and errors

1. There is inconsistency in funded supports across participant plans. It seems that those who are unable to express themselves clearly or who are unable to advocate for themselves end up with poorer funded supports in their plans. This inconsistency makes the provision of advice to potential participants particularly difficult.
2. Errors in plans are caused by the Agency not taking all the information provided by the participant into consideration. Often these are simple mistakes which could be easily avoided, e.g. confusion or errors in whether a participant's plan is set up as self-managed, NDIA-managed or managed by a Plan Management Agency (PMA), the inclusion of incorrect assistive technology (AT) supports in a plan. Support Coordinator hours are often exhausted following up on mistakes made by the NDIA.
3. The hours for Support Coordination included in participant's plans are often inconsistent and inadequate given the complexity and progressive nature of clients living with multiple sclerosis or motor neurone disease. This means that hours are often quickly used up. This, combined with a lack of success in seeking an early review of the plan by the NDIA, means that the provider has to deliver "unfunded work".

Rejection of plan reviews and gaps

4. Requests for early reviews of plans are either rejected or not expedited in a timely way by the Agency (e.g. a Support Coordinator will call the Agency to see where a review is up to and be told that it is still "in progress").
5. Requests to include major home modifications in a plan are either rejected or are deemed to be 'in progress' for in excess of 12 months. Often supporting information has to be submitted to the Agency repeatedly, is lost, not uploaded correctly, or attached to another client's file. If the supporting information is not acted upon before the annual review takes place, the Support Coordinator will resubmit the

material during the review process to ensure the new plan has the support – despite this effort, the Agency will then still request new reports and quotes.

6. Expired plans and plan gaps are still occurring and often the new plan is not backdated to fill the gap.

Inconsistent and poor communication

7. Communication in general from the Agency to participants and Support Coordinators is patchy and inconsistent.
8. Where a plan escalation is necessary there is never any follow up by the Agency to the participant nor to the Support Coordinator, despite assurances from the Agency of 24-48 hours for "priority follow up". The health and safety implications of these delays are raised with the Agency but there seems to be no way of prioritising these 'escalations' within the Agency.
9. Local Area Coordinator (LAC) time is limited to a one-hour face-to-face meeting to implement a plan with the participant. The participant is expected to contact the LAC to request implementation of their plan.

Agency staff expertise

10. The longer term NDIA staff do have an understanding of multiple sclerosis as a complex, progressive, degenerative neurological condition, but the system renders them almost 'impotent' to assist participants. For example, the process and response time for organising coordination of care or the acquisition of assistive technology is so protracted, any Agency staff awareness of the needs of people living with multiple sclerosis is negated by the system. Feros Care staff (providing Local Area Coordination services in the ACT) undertook specialist MS training from the MS organisation in February, which we hope will make some difference.
11. We understand that Agency staff in the ACT are recruited through local recruitment agencies and are only being offered 3 to 6 month work contracts, which is unlikely to lead to the development of a cohort of staff that are able to build the knowledge and experience necessary to understand the needs of people living with chronic neurological conditions such as multiple sclerosis.

Case studies

These challenges 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:

Lost Support Coordination following LAC review; planning to submit a request for an internal review of a Reviewable Decision.

Sue is a 50 year old woman diagnosed with relapsing remitting multiple sclerosis (RRMS) in 1997.

Sue lives alone, since her adult children left home; her partner who is supportive when he is not working away from Canberra.

Sue has recently reduced her work hours due to ongoing health concerns and the need to balance work hours with medical appointments. Sue not only has MS, but a range of other health-related concerns which are impacting on her daily function, and which have resulted in a recent reduction in work hours. Her health has deteriorated significantly causing a tremendous amount of stress both physically and emotionally.

As stated in her Outcomes Report, despite Sue being an independent, competent individual, her ongoing concerns with her health and the progressive nature of her MS, significantly impact on her ability to manage her plan by herself and liaise with providers, whilst endeavouring to hold down her job. Sue has limited informal supports. Despite this, Sue was not deemed eligible for Support Coordination.

On appealing the NDIA to re-consider this outcome, Sue was informed that Coordination of Support (COS) is usually time limited to support participants to establish, engage and connect to supports. If these supports are stable then there is no ongoing role for COS and the LAC partner has the role to link to any new supports required after each plan review.

Sue will continue to appeal this outcome as she is reliant on her Support Coordinator for support with the timely and efficient implementation and ongoing maintenance of her plan.

Case study 2:
Multiple plan errors; incorrect advice given by NDIA staff; need for Support Coordinator to provide unfunded support

Barry is a 55 year old man diagnosed with motor neurone disease (MND) in 2016.

His Support Coordinator, on two separate occasions, was informed by NDIA staff, that he had funding in his plan for an assistive technology (AT) budget in *addition* to the sum of $6,600 for FlexEquip which could be used for other equipment items.

FlexEquip is a service of the Motor Neurone Disease Association of NSW (MND NSW), a registered NDIS provider, which assists adults with rapidly progressive neurological conditions to obtain AT to meet short to medium term needs.

His AT funds were withdrawn and it is now apparent that the budget information provided by the Agency was incorrect and his FlexEquip budget has been drawn down on, leaving him without funds for the hire equipment he desperately needs.

There have been a number of issues since his Plan approval, with a Change of Circumstances form submitted on 3 August 2017 to address the need for additional funding for equipment. This still remains pending with the NDIA for action. MND NSW are now providing equipment to Barry in "good faith".

His Support Coordinator has had multiple contacts with the NDIA who acknowledged an error had occurred, that the matter would be escalated and the SC would receive a return call within 48 hours; this was on the 29 November 2017. The SC is still waiting for the call.

Senior staff from the MS organisation engaged in advocacy with NDIA on this matter in December 2017. As a result Barry's plan was amended in January 2018 in relation to the FlexEquip, which has allowed the issue to be resolved. This however was the only aspect of the plan considered, despite a Change of Circumstances request being submitted in August 2017; as this client lives this with MND, time is of the essence! Neither Barry nor his Support Coordinator were contacted.

The Support Coordinator has used considerable hours, needing to rectify errors and with poor communication from the Agency, trying to support a participant who has MND.

In addition, Barry's family have experienced considerable struggles to receive reimbursement from the NDIA for low risk equipment. His Support Coordination budget is now exhausted. Once again, our senior staff are attempting to advocate with the Agency for additional hours, as the plan is not due for review until May 2018.

The NDIA have advised that a considerable Support Coordination budget was allocated. Barry and his wife are legal guardians to his neurologically impaired adult sister, and combined with his MND diagnosis this adds considerable stress and anxiety to his day-to-day life.

Unfortunately as an organisation we find ourselves in a position where we need to continue to provide unfunded assistance to participants, even though this is not sustainable and could have been avoided if the change of circumstances form was actioned by the Agency.

Case study 3:
Lack of appropriate Support Coordination hours allocated in multiple plans; ongoing need to 'fight for funding' despite significant psychosocial factors.

Jenny is a 62 year old women diagnosed with MS in 2015.

During an unscheduled review meeting in October 2016, it was verbally acknowledged by her Planner, that Jenny's needs were complex and that ongoing assistance from her current Support Coordinator would be needed in her future plan. However, when Jenny received her new plan, Support Coordination was limited to 10 hours. An Internal Review of this decision was requested but rejected in Nov 2016.

Her Support Coordinator had attempted to set clear expectations with Jenny re available hours, but she continued to contact seeking assistance. Once the 10 hours were exhausted, her SC had to significantly reduce contact with Jenny, which was extremely distressing for both her and the SC.

During this period Jenny became highly frustrated and following a presentation to the SC's office, a decision was made to accompany Jenny to the NDIA office to verbally appeal the decision and seek additional funding for Support Coordination.

Jenny and her SC engaged with an effective Agency worker who acknowledged the inadequacy of the system and made changes to Jenny's plan to include SC. A new plan was issued in May 2017. Despite what was considered at the time to be a reasonable allocation of support hours, this has been utilized, due to Jenny's progressive condition and social factors. Her SC is now again attempting to engage the Agency to either appoint a LAC or review the plan and add additional funding,

Case study 4

Impact of inadequate support coordination hours on family stability

Fran is a 60+ year old woman living with multiple sclerosis.

Fran lives in ACT housing accommodation with her young granddaughter. She has limited familial support and few friends. As her condition continues to rob Fran of her independence, she relies more and more on funded supports (cleaning, gardening, AT, allied health, transport, meal preparation/shopping, social and community engagement and Support Coordination), provided in her NDIS Plan.

Although Fran received a reasonable amount of Support Coordination hours in her current Plan, Fran relies heavily on her SC for: connection with appropriate service providers and ongoing liaison with these providers; resolving multiple issues of conflict between Support Workers/Providers. Fran also relies on her SC to ensure that funded budgets are not exceeded, and that she is included in decisions related to budgeting and the types of services that would assist her.

At the suggestion of the NDIA, efforts to secure Support Worker assistance to undertake a number of these "liaison and organisational" roles performed by the Support Coordinator have proved futile, due to the transient nature of these employees. Ongoing attempts to build Fran's 'capacity and enhance her independence' have met with limited success, due to the progressive nature of her multiple sclerosis. Fran has recently stated, "I can't do things myself. In particular, my mental dexterity and memory are not good enough to organise myself!"

Fran is Legal Guardian for her granddaughter. Her granddaughter's biological mother is an ice addict who suffers psychotic episodes, and is unable to care for her daughter. Fran has cared for her granddaughter since she was an infant, and she has stated that without Support Coordination to keep her "organized and in working order" she would be unable to maintain this care for her granddaughter. Without the adequate provision of SC hours in her plan, Fran believes that she would find it increasingly difficult to keep her granddaughter out of "an institution".

Case study 5:

Errors with essential home modifications leading to safety concerns

Chris had major home modifications included in her first NDIS plan with all recommendations submitted to the NDIS in March 2017. These recommendations were escalated a number of times with the agency, as the client's safety was beginning to be impacted in her current bathroom.

Multiple call-back requests were made by both Chris and her Support Coordinator to inquire about the progress of the home modification request. No calls were ever returned to Chris nor her SC.

All documents were resubmitted to the agency September 2017, as the support coordinator was informed that some pieces were missing from Chris's file. These documents remained "in progress" until Chris's annual scheduled review in January 2018.

Approximately one week before the scheduled review, the Support Coordinator emailed the Local Area Coordinator (LAC) completing the review, all of the documents pertaining to Chris's required home modifications. These documents were acknowledged as received by the LAC and provided to the NDIA delegate. During the face-to-face review, the documents were again provided in hard copy to the LAC, who assured Chris that the funding requested would be reviewed and included in the new plan as readily available.

Upon approval of the new plan, it was clear that the home modifications information provided by the LAC was not reviewed adequately by the NDIA worker. Chris's new plan included a budget for an external ramp – no reports were ever submitted for this modification (the reports submitted pertained to bathroom and kitchen modifications). The line item in Chris's plan was strictly for an external ramp modification, therefore Chris has been unable to organise the bathroom modifications as required.

Upon following up by the SC with the Agency, it was clear that an error was made in building the plan, as Chris was informed by the Agency to appeal the decision. Since doing so, no further progress has been made and Chris is still unable to safely attend to personal care or use her bathroom.

Case study 6:

Lack of ability by NDIA to provide crisis intervention; unfunded support provided to guarantee participant's safety

Cathy is a 41-year-old woman, living alone in government housing with a diagnosis of secondary progressive MS (SPMS) and schizophrenia, combined with hoarding behaviours.

Cathy is also supporting her son and nephew financially and with accommodation when requested. Her only other family (her sister) does not provide any informal support and has suggested that Cathy should be permanently placed into an aged care nursing home facility.

A Support Coordinator (SC) has been working with Cathy to establish funded, mainstream and community connections and implement much needed supports. Due to Cathy's mental health concerns, all formal supports would frequently break down and Cathy would require interventions to get services up and running again.

In May 2017, Cathy was admitted to a mental health facility, displaying aggressive behaviour and confusion. Cathy was released shortly after and her SC spent considerable time ensuring the home was safe to come back to and arranging implementation of further in-home and community services.

Not long after being released, Cathy ceased all services and began to spiral into a psychosis. At this point, an urgent request was made to the NDIS to have Cathy's plan reviewed immediately, to ensure her safety within the home and community. The request was labelled by the Agency as being urgent as Cathy's immediate safety was in danger.

Less than a week after being released from the mental health care facility, Cathy experienced a fall whilst unattended within her home. She was readmitted to the hospital, where she was again assessed as being mentally incapable of being released back to her home. Due to the lack of hospital capacity, Cathy was required to be released to an unsafe home environment. At this stage, all support coordination funding had been exhausted at the previous crisis point and the SC was required to complete over 20 hours of unfunded, non-billable works to ensure Cathy's safety upon being released from the hospital. Multiple escalations were made to the NDIA in regards to the request for review, with no follow up provided by the Agency.

Cathy was living in an unsafe environment, with no informal supports or community/mainstream connections for over six months. During this time, her SC provided unfunded 'case management' to Cathy and made multiple complaints with the NDIA, both over the phone, in writing and in person at the local office.

Cathy's mental health care team also made multiple escalations to the Agency and provided extensive documentation that outlined the priority and safety concerns – all with zero response or follow up from the NDIA.

In October of 2017, Cathy was contacted by her LAC service for her annual plan review meeting. When the SC followed up with the LAC service, the SC was informed that they had no record of Cathy's request for an urgent review and that Cathy simply 'fell into their normal workflow' for the review.

The SC stressed the complexities of Cathy's situation and the need to have an experienced NDIS planner attend the meeting. Unfortunately, none of this information was taken on board by the Agency, and the response from the NDIS was that Cathy would need to attend the annual meeting with LAC service as there was no capacity within the Agency to complete the unscheduled review with an NDIS planner.

As expected, Cathy's support coordination funding was slashed and she did not receive the necessary supports to maintain living independently and safely within her own home. Cathy requires extensive, ongoing support coordination to maintain her services and supports and to ensure a hospital admission is not imminent. With few hours left of the current support coordination, a change of circumstances has been submitted to the Agency for this aspect of Cathy's plan to be considered and amended. It is concerning that Cathy will have no support should a crisis arise whilst the change of circumstances is "in process".

Submission from Dr Vanessa Fanning

We understand that Dr Vanessa Fanning, a member of the MS community in the ACT, has also made a submission to this enquiry and we commend it to you. Vanessa's submission provides a very detailed account of how the very unfair application of the rules around the implementation of the NDIS in the ACT in 2014 has had dire consequences for an individual living with a non-age related neurological disability.

Her submission clearly shows how the original intention of the NDIS has not been met.

It is worth noting that Vanessa is now attempting to deal with having her disability needs met through the My Aged Care system, which is in no way equivalent to the NDIS. The financial commitment required from the individual (contributions for assistive technology, full price and no choice for therapists) is but one example of where the disability needs of those aged over 65 are not being met.

Recommendations

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

1. Ensure consistency in funded support across participant plans, further ensuring participants, LACs and SCs all have a clear, shared understanding of the elements and implications of a participant's plan.
2. Ensure all supporting information provided by a participant is properly recorded and taken into consideration when determining or reviewing a plan to avoid, or at least minimise, errors in plans.
3. Ensure 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. Ensure 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 Motor Neurone Disease and Primary Progressive MS.
5. Ensure plans have contingency funding built in to minimise or preferably avoid the need to frequently review plans for participants living with progressive neurological conditions.
6. Implement systems to ensure supporting documentation is secure and filed accurately.
7. Dramatically improve communications systems to ensure participants and SC's are kept properly informed, especially when a plan escalation is necessary.
8. Seek ways to improve Agency staff knowledge of the needs of people with complex, progressive, degenerative neurological conditions such as multiple sclerosis.

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.