MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Senate Joint Standing Committee on the NDIS enquiry into NDIS Planning

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6 September 2019

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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 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 causes, prevention, improving treatments, 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 positive 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:**
  Who, as MS specialists, are 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, which 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 Senate Joint Standing Committee on the NDIS enquiry into NDIS Planning.

The focus of the comments provided in this submission are on key areas that will impact on people affected by MS and other neurological conditions for which our state organisations provide services and support. 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 (providing services and support in Western Australia)
- MS SA/NT (providing services and support in South Australia and the Northern Territory)
- MS QLD (providing services and support in Queensland)
- MSL (Multiple Sclerosis Limited providing services and support in 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 regardless of age, 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, allied health services, education and information workshops, seminars and webinars, psychology, financial support, supported accommodation, residential and in home respite, peer support co-ordination and employment services.

During 2018, MS Australia and MS Limited made two joint submissions to state government enquiries into the performance and implementation of the NDIS in the ACT and in NSW. Most of the matters raised in these submissions relate to planning issues.

1. 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, 30 March 2018.

2. 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, 6 August 2018.

These two submissions are attached to this submission (Attachments 1 and 2).

Terms of reference

Comments and examples are provided below against most of the terms of reference (ToR) for this Senate Joint Standing Committee on the NDIS enquiry into NDIS Planning, and should be considered in addition to the material provided in the attachments.

a. the experience, expertise and qualifications of planners

Here are some examples of experiences with NDIS planners:

1. A phone planning meeting was organized for a participant that had a speech impairment. The impairment was detailed in the Access Request Form sent to the NDIA and phone planning meeting considered inappropriate in this case. The meeting went ahead as a phone meeting but was difficult for the participant and his wife.

2. A person with a degenerative condition (MND) was asked by an NDIS planner, “What is the emotional impact of your diagnosis on your life?”. A planner with a better knowledge of disability may have been able to ask this type of question in a more sensitive manner. The NDIS participant was extremely upset by the question.

3. NDIS planners do not have an understanding of the effects of fatigue on people with neurological conditions and the impact it has on their lives.

What’s different about MS fatigue? Fatigue in MS is thought to result from different factors, partly caused by MS itself (known as primary fatigue) and partly by other factors (secondary fatigue) that affect people with MS, more than those without the condition. ‘Ordinary’ fatigue can usually be managed by rest and a good night’s sleep, which is quite different to the fatigue experienced in MS. MS fatigue can be physical and/or mental, saps your energy in an instant and stops you from completing tasks. MS fatigue can be debilitating with a longer recovery and can’t be 'worked through'. The overwhelming sense of tiredness of MS fatigue can occur at any time without warning, for no apparent reason or after mild activities such as writing or reading, with an immediate need to rest.

4. A lack of knowledge about the person a planner is meeting with can be evident. An example was a case when the planner was not aware of the person’s diagnosis and asked the person for proof at the planning meeting. This would have already been made available to the NDIA to gain eligibility.

5. Newly appointed LACs often have inadequate knowledge of how the NDIS works and this might point to inadequate training being offered. For example, an NDIS planner during a planning interview said to the participant, “I know that these are stupid questions” which indicates a lack of confidence in NDIS by the planner and undermines participant confidence.

6. Planners not understanding or recognizing the assistive technology, equipment and consumable needs a person with a disability may have, which may be associated with the “invisible symptoms” of MS, such as continence products.

7. Planners not understanding the effects of cognitive impairments. People with cognitive issues should be encouraged to always have a carer or someone who knows them well, present at planning meetings otherwise information about a participant’s needs can be overlooked or not discussed. A person with cognitive issues can present well and underestimate their need for services.

8. It is important that a participant's overall needs are considered. For example, a participant received social support in their plan, but the plan did not include the therapy supports required by the participant so that they could safely access their community. To be able to safely activate the social support, the participant's swallowing and continence issues needed to be discussed and funded. Services such as speech therapy, catheters and continence products were all omitted from their NDIS plan.

9. One NDIS participant has had seven NDIS plans in seven months. Numerous re-writes of the plan were required to receive a correct plan that included all of the services required.

10. Following the introduction of the LAC role in WA, there have been situations during a planning meeting where the participant has been asked for documentation to justify their requests for funding for the services they ask for – this had not happened with NDIS planners before and may be due to lack of experience of the new LAC. This takes up time in the meeting that could better be used in discussing needs of the participant.

b. <u>the ability of planners to understand and address complex needs</u>

1. NDIS planners without knowledge of disabilities are not able to understand the other services (therapies) that a participant must address so that they can access community again – continence products, speech therapy services re swallowing etc.

2. In some cases, NDIS participants that are deemed to be complex, intensive or super intensive by the NDIA, have their planning completed by NDIA staff rather than the LAC. Some participants have not been determined to be intensive and have the LAC involved in planning discussions, only then to have the planning work repeated when it became obvious that the participant's needs were 'intensive'. Other times, if a participant is not deemed intensive/super intensive and is, the planning may be completed by an LAC without sufficient experience and a plan developed that does not meet the needs of the person. How is intensive/super intensive determined by NDIA and can this process be improved?

3. Setting or discussing goals for people with terminal illness can be confronting and perhaps better education for planners could be provided re end of life care as against a person with say stable disability? Find that NDIS plans do not allow for the rapid changes experienced by people at end of life stage in a timely manner and they could then be asked to ask for plan review – change of circumstances – that can take considerable time to complete when for people in this situation, time very limited.

4. Plans for people with rapidly changing conditions or have terminal illness do not always consider that Rental options for equipment might be a better and more cost effective alternative.

c. the ongoing training and professional development of planners

In February 2019, an 'MS Snapshot' was commissioned by the National Disability Insurance Agency (NDIA) and developed by MS Australia (MSA) to assist NDIA staff, such as planners or LACs (Local Area Coordinators), to better understand multiple sclerosis and improve their interactions with people with MS. The 'MS Snapshot' is supported by a video of two people with MS talking about three key themes:

1. My lived experience
2. Use my strengths
3. How to communicate with me

We trust the MS Snapshot and video has been of value to the Agency, though MS Australia has not received any feedback from the Agency as to how this material is being used within the Agency nor its efficacy.

We will continue to test the value of these resources to people living with MS to see if they have improved their interactions with Agency staff.

The experience with the new LAC role introduced from 1 July 2019 in Western Australia has been mixed, with some planners seeming to have a better knowledge of NDIS than others. This could point to a lack of consistent training before job is commenced.

d. participant involvement in planning processes and the efficacy of introducing draft plans

1. We have not seen any drafts plans issued to date. We have received feedback from participants that draft plans would be beneficial and provide the participant an opportunity to confirm that all of the supports discussed in planning have been included.

2. We have found generally that participants are involved in the planning processes but still think that they benefit from pre-planning options with experienced staff from service provider.

e. the incidence, severity and impact of plan gaps

1. Some services that have been provided to people with disability are not always funded by the NDIA. Services such as massage, for example, have been shown to be beneficial to a number of our clients (people living with MS and other neurological conditions) however this is a service not funded by NDIA.

2. Plans often do not have sufficient funding to allow for the funding of services to the level where they have been previously provided. For example, weekly physiotherapy has been found to be beneficial to a number of clients but is not necessarily determined to be reasonable and necessary by the NDIA. This can result in decreased mobility for the participant.

3. Plan gaps can cause clients to become stressed when they discover that they will not be able to receive the level of services they feel they require. Participants are not able to understand the pricing of services relative to the budgets in their plans. It is often up to

the service provider to advise them that they do not have enough funding to receive all the services they desire.

f. <u>the incidence of appeals to the AAT and possible measures to reduce the number</u>

An improved system to explain to participants what is funded in their plans may help. The number of appeals may be reduced if people have a better understanding of why something is not funded in their plan.

g. <u>the circumstances in which plans could be automatically rolled-over, and the circumstances in which longer plans could be introduced;</u>

Participants that are experiencing a relatively stable level of disability could have their plans automatically rolled over, and could be suitable to have longer plans.

It is important that NDIA staff understand that MS symptoms are varied and unpredictable, depending on which part of the central nervous system is affected and to what degree. No two cases of MS are the same and symptoms, depending on where MS lesions develop on the brain and spinal cord, can manifest in many different ways.

Whilst some participants with MS may experience periods of “stability” with their disease progression, others may not, so a “one size fits all” approach is not appropriate.

h. <u>the adequacy of the planning process for rural and regional participants;</u>

The adequacy of the planning process for rural and regional participants is patchy.

Whilst some participants living in rural and regional areas report good experiences with local NDIA staff, others are less satisfactory. For example, a person living in the Great Southern Region of WA was found to be eligible for the NDIS in October 2018. Our last contact with the person was in May this year and at this stage they had not received any further information from the NDIA as to when arrangements for a planning meeting might be made. The person felt that a home visit for planning was required so that her living situation and needs could be better considered. At this stage they have been waiting for almost seven months for a planning meeting.

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.

ATTACHMENT 1

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

6 August 2018

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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.

ATTACHMENT 2

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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30 March 2018

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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.'[2]

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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[2] 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:

9. 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.
10. 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.
11. 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!
12. 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.
13. 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.
14. Implement systems to ensure supporting documentation is secure and filed accurately.
15. Dramatically improve communications systems to ensure participants and SC's are kept properly informed, especially when a plan escalation is necessary.
16. 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.
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- 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.