NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

Feedback: Discussion paper on support coordination

Submitted by:

MND Australia

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Background

MND Australia, its research arm, MND Research Australia, and members, the State MND Associations, form the only national network focused on improving the lives of all Australians living with motor neurone disease (MND) and advancing research to end MND. For over 35 years this national network has helped increase understanding of the disease and advocated for improvements in its treatment and care to ensure people living with MND have the best quality-of-life possible. The six state MND Associations provide direct support and services to people living with MND in all states and territories.

ABOUT MND

MND is the name given to a group of neurological diseases in which motor neurones, the nerve cells that control the movement of voluntary muscles, progressively weaken and die. With no nerves to activate them, the muscles of movement, speech, swallowing and breathing gradually weaken and waste, and paralysis ensues. MND affects each person differently with respect to initial symptoms, rate and pattern of progression, and survival time. **Average life expectancy is 2 to 3 years from diagnosis.**

There is no known cause for MND (except in a very small number of genetic cases), no effective treatments and no cure. There are no remissions and progression of MND is usually rapid and relentless creating high levels of disability and a consequent need for a wide range of progressively changing supports.

THE CHALLENGES

The social and emotional impact of MND is amplified by its complex nature, the speed of its progression and the spiraling series of losses that pose a significant challenge to the person diagnosed, their carer and family as well as the myriad providers involved in meeting the variable, progressing and complex care needs, particularly in regional, rural and remote communities. Timely early intervention and access to expert multidisciplinary care, assistive technology (aids and equipment), specialist planning, assessment and support coordination, including a proactive framework for decision-making, play vital roles in maintaining quality of life and independence. It also helps people to plan ahead to prevent crisis and avoid hospital/residential aged care admissions. Although early intervention will not slow down the disease process in MND, it will strengthen the informal supports available to the person, including supporting the primary carer to maintain their caring role, health and wellbeing.

It is estimated that there are currently 2,000 people living with MND in Australia and around 50% of these people were diagnosed when under the age of 65. All those living with MND under the age of 65 are eligible for the NDIS, however, the range and level of reasonable and necessary supports needed varies greatly. Some of these people will be recently diagnosed and may not need to draw on intensive supports for some months whilst others will be very disabled and require a wide range of assistive technology, services and support on entering the scheme. Approximately 300 to 400 people will be eligible to enter the scheme per annum. Each year the same number will likely die and therefore leave the scheme.

SUPPORT COORDINATION

It is crucial to recognise that MND is a rapidly progressing, life limiting condition resulting in complex and changing needs which requires a rapid and responsive approach from diagnosis onwards. Support coordination is therefore vital throughout the disease trajectory due to complex and progressive decline in functional abilities and importantly, to ensure a person's plan is appropriate and enacted promptly. Support coordination is also a priority for people diagnosed with MND who, in most cases, will have no prior experience of disability and disability support services. It is essential that support coordination is delivered by someone who has an in depth understanding of the disease and who will work at the direction of the participant to ensure a person centered approach.

Submission

Inclusion of Support Coordination:

1.   What factors should be considered when determining if, when and for how long support coordination should be funded in an NDIS participant's plan?

As is currently the case, specific diagnoses should be enough to determine the need for support coordination. Participants with progressive neurological conditions, such as MND, who have constantly changing and increasing requirements for support require funding for support coordination from their first plan onwards to ensure their goals are met. We believe this should be a minimum of 2-3 hours per week increasing in line with care complexity.

It is important to note that capacity building is not generally relevant for someone with progressive neurological conditions and therefore hours of support coordination required generally increase as the disease progresses.

Other factors that need to be considered are the age of the participant, level of family and community support, social situation and cognitive ability. A combination of some or all of these factors will increase complexity and impact the level and amount of support coordination needed.

2.   Should the current three level structure of support coordination be retained or changed?

According to the statistics presented in the discussion paper the need for **Level 1: support connection** is questionable and highlights the need for greater clarity regarding the purpose of the different levels. It could also be argued that support connection is the role of a LAC further negating the need for this level of support coordination.

Most people living with MND are funded at **Level 2: Coordination of Supports**, however, there is a blurring of the requirements of this level of support with **Level 3: Specialist Support Coordination**. Given the progressive and often rapidly changing needs of this cohort there should be some fluidity between Level 2 and 3 and capacity for each to be delivered by the same support coordinator based on the participant's needs at the time. For example, there could be tiers within Level 2, or Level 3 could be replaced with a complexity subsidy for Level 2 support coordination for those who need to expend more support coordination hours to get a plan right for someone with complex disability needs.

In addition, the complexity of NDIA operating processes means that participants need significant support to implement their plans/achieve their goals. Most plans will run out of Level 2 funding early in the plan highlighting the need to ensure this support is better funded.

The structure should also be changed to reflect the need for specialist disease specific knowledge of particular conditions. In order to effectively coordinate the multitude of services required to support someone with MND, it is beneficial for the participant for their

support coordinator to have a thorough understanding of the disease. Specialist Coordinators of Support as provided by the MND Associations are best placed to support people living with MND as outlined below.

3.   How should support coordination interact with other NDIS supports? For example, local area coordinators, community connectors, liaison officers and recovery coaches?

For people living with MND none of these other NDIS supports play a significant part in their support at present. Informal connections will emerge between these supports if needed and, therefore, there is no need for a formal structure if the NDIS is to remain participant focused.

4.   How should support coordination interact with and complement existing mainstream services?

The need to link with supports will always be at the direction of the participant in achieving their plan goals.

Support coordinators are required to have a thorough, up to date working knowledge of mainstream services and be able to identify, liaise with and refer to these services as appropriate to the participant's support needs. However, they are not case managers and their primary role is in identification of providers and referral at the direction of the participant.

More clarity around the responsibilities of the different mainstream services would be helpful, along with mainstream services accepting these responsibilities without pushback.

5.   What can or should be done to address the level of utilisation of support coordination in plans; and is this any different to general issues of utilisation?

Underutilisation in participant plans is directly linked to the quality of the plan issued and the availability of supports. Some plans issued will move to plan review prior to their end date. This provides a false impression in reporting that plans may be underutilised. Most participants with MND will utilise every available part of their plan budget. Our experience is that they frequently require more support than is ever currently funded. Additionally there continues to be inconsistencies between participants in how supports are funded.

Planners, particularly those with experience in MND, understand that the progression of MND is unpredictable and in many cases rapid. Inclusion of adequate support coordination hours is, therefore, vital right from the first plan. Given the difficulty in predicting the rate of progression a person with MND is likely to experience, this is a sensible approach. Insufficient funds prompt an out of cycle plan review request, but plans are not reviewed early based on excess funds.

More generally the underutilisation of plans as presented in the Discussion Paper could be a result of planner and LAC biases in assuming family can and will take on the support

coordination role for a participant. Unlike most disabilities, MND will hit a family 'out of the blue'. These families have no experience of the disability sector and how to access supports etc. This is quite different from the capacity of families who have gathered information, resilience and connections across a very long disability trajectory. More so, carers of people with MND do not have time to wait to build competence to support the person they are caring for.

Understanding the role of a support coordinator

6.   What functions should a support coordinator perform? Are there tasks that a support coordinator should not do?

For participants who have life limiting and progressive conditions like MND, support coordination should be used to ensure that the participant and their family receive the supports and assistive technology that they require, to achieve the objectives of their plan, in a timely manner. They should work, at the direction of the participant, to assist with the changes that occur and any issues that may arise. They should also help the participant navigate the NDIS, its processes and array of forms. A good support coordinator does not replace the participant in the decision making process but rather facilitates a participant's choice and control.

For people with MND and similar complex and progressing conditions, it would be beneficial if the support coordinators could have the remit to liaise more directly with the health services supporting the participant.

7.   Is there evidence that participants with specific plan goals related to education, accommodation and employment would benefit from more targeted support coordination services to achieve these outcomes?

Having a support coordinator that has experience in these areas would of course be beneficial as all are incredibly complex and the support environment for these is still emerging. However, having a support coordinator who understands the person and their condition and a plan that includes appropriate support coordination hours is more important.

A good support coordinator continues to build their competence in the supports noted and it is these skills that differentiate them in the marketplace.

We have experienced a few occasions where two support coordinators with different skills sets have worked collaboratively with the participant and this has been extremely successful – e.g.:

> MND Association Support Coordinator with MND specialist background worked with an ATSI Support Coordinator who was able to engage the local community to support the participant.

8.   How could plan management and support coordination be more closely aligned and what would the potential benefits and risks be?

These roles should remain separate to maintain the support coordinator's independence in assisting the participant to choose and consider services and providers. To combine the two would remove the checks and balances that currently exist to ensure the participant's budget is being properly acquitted.

However, it is important that there is good communication between these two roles to ensure the best outcomes for participants. This includes providing regular updates as to plan utilisation and advice on budget line items.

Quality of support coordination:

9.   Should there be minimum qualification requirements or industry accreditation in place for support coordinators? If so, what might be applicable?

In general minimum qualification should not be required but rather previous work and life experience of working with people with disabilities, a very good understand of NDIS and the ability to build rapport with the participants and their family.

In relation to support coordination for people living with MND (and other complex or rapidly changing conditions) it is important that support coordinators have appropriate qualifications and experience. MND Associations employ support coordinators who are tertiary qualified in allied health, nursing, social work or similar and who have extensive experience in the disability/ageing sectors and a good understanding of the needs of people living with a progressive and terminal condition.

This is supported by a detailed and MND specific induction, orientation and ongoing professional development program ensuring that their knowledge of the impacts of MND and the services and supports available is maintained. These staff also play a role in providing information and education to other services and providers who play a part in the support of the participant living with MND. A Cert 111 or 1V in disability is not a sufficient qualification for someone to work with people with progressive neurological conditions.

10.   How can the effectiveness of support coordination be measured and demonstrated?

Given the choice and control that exists in the NDIS, the effectiveness of support coordination can be measured based on participants retaining the service.

Qualitative measures should also be used such as:

- Participant satisfaction
- Access to community in line with participant wishes
- Maintenance of independence, as appropriate and possible with disease progression
- Plans being "implemented"

Quantitative measures will be less useful due to the lack of uniformity in the needs of participants such as:

- Utilisation of allocation of support coordination – underutilisation could be an indicator of slower than anticipated disease progression, but also potentially poor quality support coordination
- Utilisation of supports funding in the plan – could also reflect the above
- Number of plans over the lifetime of the participant – a good support coordinator will recognise when a plan is inadequate and act quickly to resolve this.

11.   Are there emerging examples of good practice and innovation in support coordination?

The MND Associations' model of support coordination where these services are provided to the MND community is an example of good practice and innovation. MND Association Support Coordinators are experts in the condition and the impacts it brings, and hence the potential supports required. This approach differs from those organisations providing support coordination to a broader audience.

It is important that people living with MND have access to this condition specific support as, given the relative rarity of the condition, generalist services may only come across someone with MND on an infrequent basis. This means they would need to "start from scratch" in understanding MND, the needs of a person living with MND and the manner and speed with which needs change. We know that this delays appropriate supports for the person with MND and exacerbates disability.

12.   Are the levels and relativities in the NDIA price limits across different services including support coordination working effectively in the interests of participants and a sustainable, innovative market?

"You get what you pay for" and in order to attract and keep skilled professionals the NDIA needs to pay higher than the current level 2 rates in the interests of the participants. At present organisations that employ professionals to undertake support coordination need to dip into fundraising dollars to supplement support coordinator salaries as the funding from the NDIA does not cover the salary and on-costs. See previous submission to the Annual NDIS Pricing Review which recommends a pay point between specialist support coordination and coordination of support of $120 to $130 an hour for support coordination for people with complex, rapidly progressing and ongoing support needs.

13.   Should support coordination pricing be determined, at least in part, based on progression of participant goals and outcomes, and how might this work?

In the case of people living with MND, or other progressive neurological conditions, pricing based on goal achievement would be detrimental and counterintuitive. The progression of MND differs from individual to individual and goals for a plan can change quickly. It would only be feasible in the situation where every plan provided exactly met the participants needs

over the plan life. We know this doesn't happen and it would be impossible to achieve for any NDIS participant, MND or not.

In addition, Support Coordinators cannot always control the supports being provided (or not provided) well enough for the goal to be reached. Other factors can also cause goals not to be achieved such illness, family issues, support issues, lack of supports and waiting times, and a participant going away and not using supports for a period.

Building capacity for decision making

14.   How can a support coordinator assist a participant to make informed decisions and choices about their disability supports? What are the challenges?

Support coordinators need to ensure when working with the participant and the family that they don't take over the decision making. The support coordinator needs to provide options to the participant and allow them to make the right decision for themselves.

For MND the expertise in assisting participants to make informed decisions comes with the experience of supporting many others over time with the disease. Support coordinators are able to explain the potential paths of progression and needs that may arise, with empathy and skill, to assist and educate the participant along the way to make decisions based on this information.

Thin markets are a challenge in some areas, particularly regional, rural and remote communities, which sometimes limits choice or results in no choice at all.

15.   How does a support coordinator build a participant's independence rather than reliance? Should support coordination pricing be determined, at least in part, based on building a participant's capacity for decision making to become more independent?

A good support coordinator starts from the premise that they are working for the participant at the participants' direction to provide choice rather than decision.

Pricing should not be determined based on building a participant's capacity for decision making and becoming more independent. Some participants are unable to build capacity but rather need support to maintain capacity for as long as possible. Those with MND tend not to be interested in learning how to independently navigate the NDIS and the complex world of support services given the rapid and terminal nature of their disease. This would be an impossible metric to achieve.

16.   How can a support coordinator assist a participant in need of advocacy without acting outside the parameters of their role? What are the appropriate parameters of the personal advocacy role and the support coordination role?

Support coordinators with a genuine understanding of a participant's current and potential future needs, are best placed to assist those participants to articulate that need to a planner. Many support coordination services currently provide significant unfunded supports prior to

an individual becoming a participant or being in receipt of funding. The role could effectively advocate from point of diagnosis/entry to the scheme to ensure that needs are fully understood and researched. This would improve the quality of initial plans, the timing to access supports once funding is in place and therefore the utilisation of funds. Additionally, a support coordinator is well positioned to advocate for increased funding where a plan is insufficient to meet a participant's needs.

Being an advocate doesn't necessarily mean you are taking choice and control away from participants. It means that you are working WITH the participant for a better outcome on supporting their needs. There is a fine line between supporting and taking over and in the middle is advocacy.

For people living with MND the role of the support coordinator in advocacy is often related to the support coordinator's detailed knowledge of MND as a disease, the impact it has and the application of services and supports under the NDIS for this community. Advocacy in this context often relies on educating providers and services regarding the needs of people with MND and educating NDIS Planners, where their own experience of planning for a person living with MND is limited.

Conflict of interest

17. **In what circumstances is it more or less appropriate for a participant to receive multiple supports from a single provider?**

Where a participant has a condition that requires specialist support such as MND, Spinal Cord Injury, Autism, MS etc providers will tend to specialise and grow to offer the range of services they know are imperative to their client base. Not allowing a single service provider to offer multiple supports would limit an individual's access to specialist supports.

Furthermore, many participants prefer the 'all under one roof' approach as it simplifies the supports for them as well as the billing. Internal communication channels ensure efficient and timely responses and minimise the number of people a participant needs to liaise with. Removing the capacity to access multiple services from a provider restricts choice and control.

In terms of people living with MND, the MND Associations' model of providing support coordination and assistive technology (AT) services is most appropriate for this cohort. The Associations are able to maintain a supply of AT specifically appropriate for this cohort that can be efficiently and effectively delivered and maintained in a timeframe that meets their needs. The MND Associations' AT services and equipment bundles ensure that people living with MND can access as much AT as they require, apart from individualised/specialised items, to meet often rapidly changing needs. This is a service that is unable to be duplicated by other providers. It would also be appropriate when there are thin markets and limited options of providers.

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18.   Should the IAC recommendation for the NDIA to enforce an "independence requirement between intermediary and other funded supports at the participant level" be adopted?

There should not be a blanket rule as there are important exceptions. There is also the danger that this would restrict choice and control and access to specialist services. However, participants need to understand that if they choose to use the same provider for support coordination and supports, issues that arise may be more difficult to solve due to bias.

19.   What impacts would stricter conflict of interest requirements have on NDIS participants and the NDIS market?

That would depend on what the stricter requirements were. If a provider has the capacity to manage conflict of interest, then greater clarity for participants would be a positive outcome. If complete avoidance of conflict of interest is required, this would limit access to appropriate services resulting in participants being forced to access generic service providers which may well offer lesser quality services. For some participants it would mean no access to service delivery.

At this point, whilst the market is relatively immature, there is a danger that stricter requirements would strangle innovation.

General:

20.   What would you identify now as the current critical issues around support coordination?

- ➢ NDIS planners understanding:
  - o the difference between LACs implementing a plan and support coordination which is a materially different role
  - o that not all participants have the capacity, or have family that have capacity, to assist with understanding the plan and finding supports
  - o that some participants need more support coordination hours as time goes on not less, e.g. participant with life limiting disability such as MND as their capacity decreases not increases
  - o support coordination is an important role as it assists the participant to use their plan to the best of their ability and can made a big difference to their lives if supports are correctly in place.

- ➢ Recruitment and retention
  - o challenges faced by service providers due to funding levels creating inconsistency and interrupted supports
  - o stress +++ on many support coordinators to keep up to date leading to high turnover of staff
  - o poorly funded support coordination with no recognition of the actual hours required to support someone properly

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- o needless NDIA processes that chew up a support coordination budget and take away from organisation of supports

- ➤ Lack of guidance from the NDIA
  - o lack of clarity on the role of a support coordinator
  - o challenge of apportioning time to a particular participant
  - o constant changes by the NDIA in relation to support provision and processes that are hard to keep up to date with without spending dedicated time each week to up skill

- ➤ Unfunded NDIS pre planning support

21.   What are the priority actions the NDIA might take to grow an innovative and effective support coordination market in the interests of participants?

- ➤ Fund supports for services provided prior to the first plan
  - o recognise the value of pre-planning
- ➤ Consistency in streaming of people with MND through to specialist senior planners
- ➤ Enable specialised support coordination providers to construct plans i.e. MND Associations creates all plans for people with MND which the agency then approves
- ➤ More detailed Guidelines about the role of support coordination
  - o provide greater clarity to participants and all service providers on the role of a support coordinator
  - o remove similar roles to limit duplication of services and costs.
- ➤ Increased price points for support coordination, so more highly skilled staff can be employed without linking to unachievable constraints such as the need for specialist degrees or professional associations
- ➤ Cultural change within NDIA service delivery teams to work collaboratively as a team with support coordinators and other disability providers to get the best outcomes for participants. They should not to see themselves as gatekeepers with the "power" to dictate but rather, whilst recognising their role as the delegated authority, be more accessible and approachable. This will ultimately lead to better outcomes, less stress and fewer reviews.

MND Australia thanks the National Disability Insurance Agency for the opportunity to respond to this discussion paper on support coordination. We would be pleased to provide further information if required.

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