

**MULTIPLE SCLEROSIS AUSTRALIA**

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# NDIS Review of Support Coordination

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**Chief Executive Officer**

### **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 NDIS Review of Support Coordination.

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, including Support Coordination, 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.

## This submission

This submission has been informed by information provided by our state member organisations and their clients and seeks to address the questions posed in the Discussion Paper.

## Introduction

MS Australia on behalf of its state member organisations strongly supports the inclusion of Support Coordination in NDIS Plans. Participants not allocated sufficient Support Coordination Funding in their plan, or no Support Coordination funding at all, have been previously left feeling unsupported, overwhelmed, and unable to utilise their plans and funding to reach their goals or full potential. They have lacked the confidence and knowledge to navigate the service sector, engage providers and reap the benefits of their NDIS plan. This has caused added stress in the lives of those living with a disability, their family, and carers, at times exacerbating their compromised health.

## Inclusion of Support Coordination in Plans

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

Overall, we believe that due to their neurological conditions, many of our state organisations' customers should receive Support Coordination within their Plan. When determining whether a customer should receive Support Coordination, the following factors should be taken into account:

- a. Does the participant have higher or more complex needs? E.g. housing issues, education, etc
- b. Does the participant have a degenerative condition that may require more assistance in managing their needs?
  - i. Does the participant have cognitive impairment that may affect their ability to implement/manage their NDIS plan?
  - ii. Has the participant experienced a decrease in ability since the previous plan (in the case of renewals)
- c. Does the participant have involvement across multiple service systems?
- d. Recognition that the need for Support Coordination may not be a time-limited support
- e. A participant may have informal supports (family, friends, carers) to assist them with their plan but are they in a position to offer ongoing support and are they in a position to build any type of capacity if they do not have any formal training?
- f. At plan renewal, what level of plan funding was utilised in previous plans and have goals been achieved?
  - i. The NDIA should accept that for some participants, that in the absence of case management support being available under the NDIS, that support coordination services for some may be required for the long term and may not be time-limited support.

### 2. Should the current three-level structure of Support coordination be retained or changed?

Our state organisations support only a limited number of participants with level 1 funding. In these cases, they have found that the support required is more consistent with the type of support required under level 2 funding. It is our view that if a person is only needing level 1 support (i.e. "connection") they could have these needs met by their LAC.

The needs of the participants supported with Level 3 coordination is inconsistent. Some do need this level of support while others on this level do not appear to have any complex needs or goals.

This may be a result of planning where goals and issues that the participant faces are not being correctly identified, for example:

A participant received level 2 support however when a home visit was conducted, it was discovered that the home was inaccessible due to clutter and hoarding and that the complexity of their situation would have been better suited to level 3 funding.

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

In the case of Local Area Coordinators – our state organisation’s Support Coordinators interact with LACs when they are no longer able to provide satisfactory services and to ensure that they can be supported by the LAC to find a suitable replacement.

We also feel that LACs should follow up with participants to ensure that a Support Coordinator has been engaged so that supports can commence as soon as possible. This may also improve the level of plan utilisation.

### **4. How should Support Coordination interact with and complement existing mainstream services?**

The Support Coordinator should be aware of all mainstream supports available to the participant and work to ensure that there is a seamless interaction between the two. More education would be required to ensure that all Support Coordinators have an appropriate level of understanding.

Our state organisations have received feedback from participants that one of the hurdles when using mainstream services was that the client is expected to make a co-contribution for the services whereas, under the NDIA funding, they do not. This was in the case of accessing Counselling services through a Health Care plan.

### **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?**

- a. Earlier engagement with Support Coordination. Our state organisations have had instances where participants only engage with their services once the Plan is well underway. This situation could be improved by the LACs undertaking better follow up of those participants with Support Coordination in plans, to ensure that the participant has chosen a provider and they have had a first meeting.
- b. Support Coordinators often need better information about the types of services offered by the various registered service providers. The list available in the NDIS portal does not include enough specific information about the service offerings available.
- c. Our state organisation’s Support Coordinators report that they are not able to view details of the amount of funding that has been used by a service provider for a participant. The only way for them to check this, is to contact the client and sometimes visit the client to have them check the participant portal. This is time-consuming especially when it requires a home visit. Support Coordinators feel that they would be much better able to manage spending if they could view this information. This is also frustrating as Plan Managers do have access to this information.

## **Role of support coordination**

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

We feel that the responsibilities of the Support Coordination role are well defined in the latest NDIS price guide. This is important as it has been our experience that when our state organisation's Support Coordinators meet new participants, their understanding about the role of the support coordinator is not well understood by them.

This lack of clarity has also been echoed by staff within the Agency, so more work needs to be done to further clarify the functions of the role.

We feel that a support coordinator should not:

- a. provide advocacy for unfunded supports such as justice department issues
- b. be expected to be an emergency service
- c. be recommending service providers

**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?**

We believe that more targeted goals result in better outcomes for participants. We feel that it is also easier to measure success for specific goals rather than when general goals are included. We have found this particularly true for those with specific goals around housing requirements.

Our state organisations have seen examples of two different plans for different time-periods where the goals have just been cut and pasted from a previous plan.

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

We believe that as a starting point, there should be greater clarity of role definition for all stakeholders – Agency staff, service providers and most importantly, participants, especially new participants.

## **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?**

Yes, as a minimum we would expect that the person providing Level 2 support should have at least have a tertiary qualification or a Diploma in Community Services or a related field combined with a minimum of at least three years' experience working with people with a disability.

It is agreed that the minimum qualification should be "tertiary qualified" as per existing NDIS guidelines for Level 3 support coordination services.

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

We believe that the effectiveness of Support Coordination should be measured by;

- a. The successful achievement of goals as agreed in the participant's NDIS plan, and
- b. The requirement for fewer hours of support coordination required in subsequent NDIS plans.

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

Current examples of emerging good practice within Support Coordination revolve around the support for customers entering/leaving mainstream medical facilities. This includes increased support to:

- a. Reduce the waiting-time process for people leaving hospital to go into supported accommodation if they are unable to go back to their home;
- b. Improve support and information for people to leave aged care facilities to move into their own homes.

**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?**

No comments.

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

We feel that this would be a good approach but we are unsure of how it would work. The goals would need to be more specific and measurable. It could possibly be paid as a bonus type incentive based on the outcome. However, we also feel it could lead to conflict between the Support Coordinator and the participant as to whether the goal was actually achieved if the decision has some bearing and impact on the participants' plan.

**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 can assist participants to make informed decisions by ensuring they have access to all the information that they need about prospective providers to help them make informed decisions about the most suitable provider. Currently, there is no clear list of services within the participant's area to assist with this decision-making process. While the NDIA has some resources they are at times difficult to navigate and out of date.

In addition, better education as to the role of a Support Coordinator would assist the participant in understanding what they can ask for to obtain the most out of the interaction.

**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?**

Support coordinators can work towards independence during their first meeting with the participant by discussing expectations, goals and working out a “road-map” towards independence.

However, we feel it should be noted that Support Coordination cannot always build a participant’s capacity due to the nature of their disability. With the client group served by our state organisations, people living with chronic, progressive, degenerative neurological conditions, the customers capacity to navigate the NDIS system often deteriorates.

**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?**

We feel that there needs to be a strong distinction as to the ability for a Support Coordinator to act as an advocate for their customers. We feel that advocacy within Support Coordination role should be limited to support with conflict resolution regarding funded NDIS services.

Further, we feel that advocacy regarding non-funded supports such as complex family dynamics, complex rent issues, financial issues, etc. require professional advocacy services and should not be undertaken by Support Coordinators.

## **Conflict of interest**

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

More appropriate when:

- a. The participant has worked with a particular service provider for a long period of time and that provider understands and has expertise with their disability
- b. The participant has complex health needs and would benefit from an overall approach to their wellbeing rather than having multiple providers that inhibit case management
- c. The participant has cognitive or other issues that make interaction with more than one provider confusing for them
- d. There are thin markets for service provision in the given location

Less appropriate when:

- a. When a service provider does not have the expertise to support the participant requirements, for example, when a person with a mental health issue requires more specialist support.
- b. There is not adequate provision made to manage conflict of interest issues

**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?**

No, we do not believe that this is necessary. We feel there are already existing rules that address these issues and penalties in place for non-compliance in current

legislation. Our state organisations have supported many of our clients for many years and we feel that they are best placed to understand and support their needs.

Providing that there are safeguards in place to ensure that conflict of interest issues are addressed, we think that the negative aspects of this action would outweigh any assumed benefits.

This view is also supported by the NDS and we feel that the recommendations from the Tune Report did not support such a measure by suggestions that the NDIA outline circumstances in which it is not appropriate for the providers of support coordination to be the provider of any other funded supports in a participant's plan, to protect participants from the provider's conflicts of interest.

Comments extracted from the Tune Review (Review of the National Disability Insurance Scheme Act 2013, Removing red tape and implementing the NDIS Participant Service Guarantee, David Tune AO PSM, December 2019) specific to support coordination services also support this position:

"7.41 Importantly, support coordination should not be provided independently of other service providers if it is against the wishes of the participant or if that separation would mean the participant could no longer live in their community. Nevertheless, first principles would suggest that it is reasonable to expect that in most cases the provider of support coordination is not the provider of any other funded supports in a participant's plan."

"7.42 It should also be noted that support coordination, like any other NDIS support, is subject to the provider registration and practice standards rules enforced by the NDIS Quality and Safeguards Commission unless the participant is self-managing and using an unregistered support coordination provider. The NDIS Quality and Safeguards Commission's requirements include ensuring participants receive transparent and factual advice about the support options available in their community and that providers have respect for the participant's rights to freedom of expression, self-determination and decision-making."

"7.43 Legislative amendments should not restrict, in any way, participants from having choice and control over their NDIS supports. On this basis, the legislation should not require support coordination to be independent of other service provision, but rather mitigate the risk of participants being exposed to inappropriate conflicts of interests. This could be achieved by requiring the NDIA to actively assess the risk to participants when supporting them through plan implementation. This would not be limited to participants receiving SIL but would be of particular importance for this cohort."

## **18. What impacts would a stricter conflict of interest requirements have on NDIS participants and the NDIS market?**

We believe that stricter conflict of interest requirements would, in many cases, inhibit effective service delivery and customer choice. Not finding the correct balance would result in:

- a. Fewer providers able to offer support coordination which would result in decreased choice and control
- b. Adverse outcomes for participants living in areas where there are thin markets

- c. Lack of a coordinated approach to service delivery for some customers with complex needs.

## General

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

- a. The NDIA needs to set out the factors that the NDIA will consider in funding support coordination in a participant's plan (as per recommendations of the Tune Review of the NDIS 2019)
- b. The NDIA needs to outline circumstances in which it is not appropriate for the providers of support coordination to be the provider of any other funded supports in a participant's plan, to protect participants from provider's conflicts of interest (as per recommendations of the Tune Review of the NDIS 2019)
- c. That the Support Coordinator will only be included in the Plan if the participant meets strict complexity guidelines and is usually only funded temporarily while the participant needs help to engage service providers.
- d. As the support is considered time-limited, there is frequently no opportunity for a long-term relationship to develop; a rapport which may impact the participant's ongoing ability to get the most from their plan.
- e. Support Coordination needs to be automatically inserted into the plan of any potentially vulnerable participant (and "vulnerable" needs a clear definition)
- f. That the NDIA recognise that often the best support coordinators come from the service provider agency because they understand the disability and they know the participant.
- g. The participant would benefit if they had more access to information about service bookings and participant "balance remaining" information. This would be used to monitor the performance of the selected service provider so that they could ensure that funds were being used. It would resemble the information that Plan Managers are currently able to view. It would potentially lead to greater plan utilisation.
- h. Confusion about the role of the support coordinator. Consider a change to the title as it is often confusing for participants. Our state organisations have received feedback from participants that they do not understand the difference between the Plan Manager role and the Support Coordinator role. Many participants seem to think that the Plan Manager should be their first point of contact to implement their plan.
- i. Ongoing flexibility such as Support Coordination funding via Core Supports

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

We believe that the priority actions for the NDIA include;

- a. Better definition of the role of the Support Coordinator
- b. Better education for both customer and service staff about the role
- c. Recognise that it is an essential need to ensure that more participants learn how to implement their plan
- d. Not having NDIA planners limit a participant's choice and control by advising participants that they cannot choose the same provider for support coordination as for their other supports

- e. Continue flexible arrangements around Core/Capacity Building categories to ensure participants can access Support Coordination by using their Core funding on an ongoing basis (see Appendix).

**KEY FACTS ABOUT MS:**

- 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

## Appendix

### Support Coordination Funding via Core Supports

Recently, the NDIA announced that they intend to make Core/Capacity Building categories flexible which will hopefully mean that participants can access Support Coordination by using their Core funding on an ongoing basis. MS Australia strongly encourages the NDIS to continue these flexible arrangements.

The added flexibility of being able to convert core funding into Support Coordination has improved participants overall outcomes, as this has enabled a timely response to their changing needs and ability to seek increased support when they need it, thus prompting choice and control for the consumer.

Previously, NDIS participants that were Agency, Plan or Self-Managed would need to have Support Coordination as a stated (pre-approved) funded support in their NDIS Plan to access assistance with coordinating, understanding, implementing, budgeting and monitoring their NDIS Plan as well as the preparation, review or altering of their plan and its predecessor for the forthcoming year.

With the introduction of Support Coordination being a non-stated item and therefore readily available, NDIS participants can gain supports to navigate their NDIS plan for ongoing or very specific and situational purposes.

Previously, NDIS participants would be suggested to contact their LAC or the NDIA to gain advice or assistance with their Plan which resulted in waiting periods, resulting in this access becoming an associated stressor and subsequently further complicating or delaying a participant's contact to gain assistance with their plan.

### Benefits and outcomes to the consumer

- Participants have gained increased confidence and capability on how to utilise their plan, developing increased understanding on funding categories and how to utilise this to reach their goals.
- Enhanced capacity and confidence to select suitable providers to meet their disability related needs as well as negotiating between providers / understanding the difference between registered/ nonregistered providers.
- Can self-advocate particularly during planning reviews/conversations.
- Consumers feel supported knowing they have someone to refer to and can step in, when they are unwell or feeling too overwhelmed, or experiencing a relapse.
- Assisting to relieve carer stress and burnout, thus enhancing personal relationships.
- Having someone who can assist during transition points: hospital discharge to home or sourcing other accommodation options (SDA).
- Reduced delays in service provision waiting on unscheduled reviews to occur to have Support Coordination Funds included in plans.
- The participant can exercise choice and control by changing Support Coordinator at any time, to find a more suitable or compatible service option, which is not necessarily the case with LAC's and Planners.
- Learning how to manage the complexities of NDIS.

- Understanding how to submit invoices and navigate the portal.
- Choice and control, access to professional support

### **What might happen if the provision of this flexibility were to cease**

- Concern for those participants who cannot advocate for themselves due to their disability, lack of confidence and knowledge.
- Concern for carer burnout, (especially older and ageing carers,) and relationship breakdown for those left without support or guidance at critical life points.
- Concern for participants falling through the gaps, without the right level of monitoring.
- Concern for participants' funding being exploited by providers. Participant can be vulnerable, and Support Coordinators support them to be well informed and educated.
- Pressure on the hospital sector without appropriate facilitation of discharge planning; input that Support Coordinators can provide.
- Risk that participants will be inappropriately housed in Residential Aged Care without the expertise Support Coordinators can offer to navigate housing needs.
- Concern for disability-related needs going unmet, due to the progressive nature of MS; when a relapse occurs.
- Increased pressure on the sector, such as on LACs.
- Participant goals not achieved, underutilisation of plan funding.
- Reduction in participant support, removal of choice and control.

### **The benefit to the NDIS – the economic offset of providing this capacity building to consumers on an ongoing basis**

- Less unscheduled plan reviews.
- Reduce the cost on the NDIS Service Officer Call Centre, as the Support Coordinator can develop a relationship with the LAC or Planner, and work with the independent NDIS team, ie Aged Care Team, AT Team, Participant Transitions team, etc, to help participants achieve their goals.
- Over time, Support Coordination funding is an investment in the participant's and carer's wellbeing, relieving the burden on community health services and hospital system; it can also relieve the NDIA by replacing the Call Centre as a single-point-of-contact for participants who need help with their NDIS plans. The Support Coordinator is the link between the participant and the NDIA.
- Keeping participants out of main-stream medical services.
- It can help participants remain stable and well, requiring less of the medical system and on NDIS funding as their level of disability does not progress. They get timely access to service and supports through the activation of the Support Coordinator.
- Reduce Stress on family when hours running low (causes considerable anxiety).
- Reduction in NDIA / LAC calls, Plan reviews, requests for Plan changes and unrealistic expectations surrounding Planners and LACs able to provide ongoing support to those without Support Coordination.
- Majority of participants have additional funds in Core as a contingency plan, this funding could be utilised instead of additional funding being placed.
- Capacity Building Support's overall purpose is to increase the impact on an NDIS Plan long-term for NDIS participants – Funding this continually for those that require additional or ad-hoc Support Coordination allows for true capacity building and plan impact, reducing the ongoing costs of other components of NDIS plans.

## Case studies

### Case example one:

Being able to continue to support a participant with his SDA application when his original Support Coordination Funding had been exhausted. Without the timely ability to access CORE, the Support Coordinator would not have been able to proceed with extensive input and liaison with the Summer Foundation to progress an SDA application which led to this participant securing an offer. The alternative would have been for our state organisation to provide this assistance without being paid or submit a request for an unscheduled plan review which can be slow.

Without the assistance of a Support Coordinator the process would have been overwhelming for the participant to manage independently and the outcome could have been less than optimal.

Participants and family rely on Support Coordinators to support them with SDA applications, Centrelink rent assistance information, SDA service agreements, setting up SIL and NDIS supports for SDA.

### Case example two:

Support Coordinator was able to access core funding to continue to support a participant whose original plan was not well built and did not meet her deteriorating neurological needs. She was original allocated a small SC budget which was exhausted. The Support Coordinator was able to coach the participant, develop her confidence to self -advocate at a plan review meeting to ensure her subsequent plan would adequately meet her needs.

The Support Coordinator was able to engage appropriate Neurological PT or OT to provide reports so appropriate funds were allocated in her future plan. Without this assistance, the participant did not know who to contact to request a plan review, or the right providers to engage.

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