MULTIPLE SCLEROSIS AUSTRALIA

Submission to the NDIS consultation on Planning policy for personalised budgets and plan flexibility

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Introduction

MS Australia (MSA) is pleased to provide a submission to the NDIS consultation on Planning policy for personalised budgets and plan flexibility.

The focus of the comments provided in this submission are on key areas that will impact on people affected by multiple sclerosis (MS) and other neurological conditions for which our state organisations provide services and support. The comments have been provided by representatives of our state organisations who assist people to navigate the NDIS and in some instances, directly from people living with MS. MSA's role is to work on behalf of all of our 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 MS 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.

Consultation questions

1. **How should a participant's plan be set out so it's easier to understand? How can we make it easy for participants to understand how their funding can be spent?**

- Provide clear, easy to understand guidance material e.g. provide clear definitions of "core" and "capital" and other terminology used in the planning material or avoid the use of terms such as "core", "capacity" and "capital" altogether and use simple English. The use of jargon such as "Improved Daily Living", "Health and Wellbeing" and "Improved Life Choices" is confusing. Plans would be easier to read and better understood if the descriptors were in more familiar terms, e.g. Allied Health and Therapies, Exercise and Health Supports and Financial Management
- Another similar suggestion is to rename the title "Plan Manager" to "NDIS Financial Manager/Bookkeeper"
- Provide a clear description of categories, describe clearly where flexibility is allowed between categories, and include more information about what participants can and cannot do with their funding. This would help alleviate incorrect information being given by planners or providers. Against each category heading include how the funding is managed instead of at the start of the plan

- Provide a point of contact at the NDIA to obtain more information or to ask a question
- Reduce the number of pages in the Plan – it is too long!
- Avoid cutting and pasting information from previous plans
- Include more visual representation of funding allocations
- Use standardised, consistent and transparent language (e.g. the word 'flexibility' is used in plans, despite some elements not being flexible)
- Greater consistency with the layout and terminology used across participant's plans, so that support persons and health professionals can more easily interpret the plan to provide support to the participant.

2. **How can we support participants to prepare for a planning meeting? What might be needed to support participant decision-making?**

- Make sure participant is clear on all the supporting documentation needed for the meeting e.g. medical reports, allied health reports, and ensure sufficient time is given for the participant to prepare for the planning meeting
- Make sure participant knows what will occur during the meeting, what will be discussed, what are the expected outcomes, what are the next steps and timeline
- Make sure participant knows how long the meeting will take – fatigue is common symptom experienced by most people with MS and can affect concentration
- Ensure the participant is aware that they can take someone to the meeting who is familiar with their situation to support them
- Make sure the participant knows their rights as far as choice of providers is concerned.
- Clearer assessment around actual support needs
- Planners need to read the 9-month reports and place greater value on the 9-month reports completed by Support Coordinators
- Assist participants to understand the limitations and utilisations of plans (what will and will not be funded). Explain clearly the boundaries and reasoning behind what is considered 'reasonable & necessary' with reference to a participant's disability
- Improvements in contacting participants in a timely manner prior to plan end date
- Support participants to have choice over the method and location of the planning meeting ie. At home, in the community, via phone. Many participants fid the phone meetings challenging to convey their needs.

3. **Which supports should always be in the fixed budget? What principles should apply in determining when supports should be included in the fixed budget?**

- If "Choice and Control" is considered, no supports should be excluded
- People with MS need help with thermal regulation, so air-conditioners should be mandated in all plans of people with MS under the capital/assistive technology/home modifications categories
- All people with MS require allied health supports such as physiotherapy, OT assessments, myotherapy, massage, podiatry
- A minimum level of travel should be included to enable travel to work, family, community and visits to allied health appointments
- For people with cognitive impairment some allocation for Support Coordination should be mandated

- Support Coordination should be fixed and stated, however remain flexible to use Core Supports for Support Coordination
- Plan Management should be fixed and stated
- Given the changing and progressive nature of MS support coordination should always be funded and included in a participant's plan, to ensure they are supported to have their needs met as their condition progresses
- This needs to be tailored to the individual participant and their capacity to understand and manage their funding if it is truly flexible ie. Ensuing participants do not overspend on AT or therapy and have limited funds available for daily supports. Some participants do not have the cognitive capacity to make these decisions – who will be providing this support to them?
- Medium to high risk AT/HM over $1500 needs to be fixed to ensure appropriate clinical input to ensure safe use and effectiveness for that person. A lot of funding is currently being wasted by participants purchasing inappropriate AT without relevant clinical input.

4. **How can we assure participants that their plan budgets are at the right level? (e.g. panels of the Independent Advisory Council that meet every six-months to review learnings and suggest improvements)**

- Making case studies and precedent from other successful plans available to participants and Support Coordinators
- NDIA monitor plan usage at quarterly intervals and identify if plan is tracking according to allocated budgets
- More focus on 9-month reports and participant impact statements
- All participants should receive Support Coordination (at varied levels as currently funded) for first 3 years of being an NDIS participant. After that, assess at annual reviews or ability to request this support over the phone through the NDIA
- The reports and quotes provided by providers (Allied Health and Supports) should be taken seriously and considered as required rather than a disputable document
- Ensure that the participant has a reasonable plan and budgets before assuring them of the fact, and provide the client a straightforward avenue to dispute their plan funding if it is not at the right level

5. **What new tools and resources should we provide to support people using their plan and new plan flexibilities?**

- Providing clear, easy to understand guidance material
- Check that there is clear understanding by the participant of where to go for help
- Make case studies and examples of effective plan use and flexibility available to participants and Support Coordinators
- Better support participants to understand the Participant portal
- Higher level of personalised support to help participants navigate their funding decisions
- Provide an online "calculator" for budget calculating (to predict expenditure) – a tool that is readily available and accessible for all abilities
- Support Coordination provided to all participants for a minimum of 3 years
- Better training and education to NDIA call centre operators to ensure accurate and consistent information is being provided

- Ensure participants have a consistent and reliable contact person (LAC) who is able to support he participant to use their plan
- Improved regulation and review of the support coordination role to ensure they are providing consistent and reliable support to participants

6. **What do we need to consider for children aged 7 and above in the new planning process?**

- Make sure information is clear for family members and carers of young participants.
- Give greater consideration to daily life and parental information including informal supports
- Explore the "day in the life" of each child and focus on the child's profile.
- Increased funding for Support Coordination
- Less assumption that parental responsibility includes NDIS plan management
- Provide greater funding for Core Supports.

7. **What ideas do you have for how people can use their plan more innovatively?**

- Encourage participants to suggest ideas
- Provide examples, de-identified case studies and fact sheets of what are considered to be successful "innovative" plans to participants and Support Coordinators
- Provide increased assistance for participants to understand the types of supports that can be purchased
- Provide access to a portal where participants can see and track their MS-aligned funding
- Take a greater look at individual needs and fill the basic needs at a minimum (this does not always occur). Therapies and mandatory supports for people with MS are often underfunded; these need to be addressed before any innovation can be truly realised)
- Create, true person-centred goals
- Provide clearer guidance around what does or does not meet 'reasonable and necessary criteria using examples
- Increased awareness and education for participants that a support that may meet R&N for one individual may not mean it is R&N for everybody else
- Faster and more consistent response times to participant queries regarding what they can use their plan for – better education and training for NDIS phone operators
- What is the purpose of a 'draft' plan if changes are unable to be made to the draft plan?
- What is the purpose of having NDIS goals if the funding amount is set prior to goals being made? Why are funding amounts no longer linked to or relevant to NDIS goals? It is concerning participants will have to limit their goals to the funding available based off the IA.

8. **How best to handle the timing of the release of funds into plans and rollover of un-used funds?**

- Ensure participants understand the implications of the timing of release of funds and rollover of unused funds

- Ensure participants understand rules regarding accessing funding retrospectively and obtaining reimbursement of costs
- Suggest quarterly or bi-annual release of funds and introduce ability to release funding on MyGov web-site, allow the Support Coordinator or Nominee to trigger release of funds. Use a button and comment box on My Gov web-site, with an acknowledgement tick of the understanding that funding is coming from overall funding and does not mean additional funds will be available overall in the plan. NDIA staff could then monitor these requests and approve or follow-up
- Release of funds needs to be flexible to account for fluctuation in capacity or rapid worsening of condition ie. People with MS may need a greater level of daily support funding in the warmer months released to compensate for thermoregulation issues, but may need increased therapy funding in the cooler months as they have greater capacity to leave the home and attend/participant in appointments
- Who will determine the most appropriate interval for the individual participant? IAs will likely not have enough time to accurately assess for and determine capacity for this.

9. How should check-ins be undertaken? Under what circumstances is a check-in needed? Who should be involved in a check-in?

- Check-ins should be at the request of the participant
- Who is involved should also be at the request of the participant – may involve family members and carers for all or part of the check-in, only if participant requests
- Normally expect check-ins to take place before a plan ends, but people with more complex needs or a change in circumstances may need more frequently
- LACs should be more involved with participants’ plans and should be present during check-ins.
- Method to be determined by the individual participant and their supports.

10. How often should we check-in with participants in different circumstances?

- Normally expect check-ins to take place at least annually before a plan ends, but people with more complex needs or a change in circumstances (worsening of symptoms) may need more regular check-ins, e.g. people with comorbidities, people living and managing on their own without family/carer support
- A person with a complex plan, support needs, condition or supports in place should be no less than quarterly; check-in should include funding, condition changes and service quality
- To be determined by the individual participant and their supports
- More frequent check ins for participants in the first 3 years of their plan
- Active check ins to prompt participants in areas they may need assistance in but may not have self-identified
- Check in needs to remind participants of the 3 month period for light touch review and when this is approaching.

11. How can the NDIS ensure positive relationships between participants and planners?

- Planners being well prepared before the planning meeting, e.g. understanding of the participant’s background, understanding of MS (especially invisible symptoms) and

what to expect from a participant with MS, by accessing the MS snapshot and video on the NDIS intranet
- Ensuring the participant is clear about what will take place during the planning meeting, what are the next steps, where to go for more information, how to provide additional information following the meeting
- Ensure that planners are clear on the regulations around participant decisions and that they should not personally influence provider decisions. If participants feel they are pressured into making a decision, trust will be broken
- Provide opportunities for more face-to-face interaction with planners
- Planner remains as participant's planner for duration of plan, where practicably possible
- Planner contact details provided to the participant
- Less checklist/box ticking, more education provided on disability and interpersonal skills
- Greater communication, reduction in financial/budgetary KPI (less focus on cost saving, greater focus on satisfaction and effectiveness in plans)
- Greater understanding of the importance and benefit of the therapeutic relationship participants have with their existing service providers.

12. How can we best support participants to transition to this new planning model?

- Providing clear, easy to understand guidance material
- Providing a point of contact to obtain information or ask a question
- Greater roll out communication (emails, physical letters/notifications to participants and their nominees), webinars, in-person events and a dedicated team to pass the information on via NDIA call centres
- More consistent and accurate information being provided via call centre. Increased training and education for these operators as NDIS has far too many inconsistencies.

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.