NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

Consultation paper: Planning Policy for Personalised Budgets and Plan Flexibility

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 40 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. Together this network represents people living with MND, their carers, family and friends and the health, disability and aged care service providers involved in their care across Australia.

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. **The median survival is 2 to 5 years, although approximately 20% of people may survive for 5 to 10 years**[1,2].

About 1 in 300 people will develop MND over their lifetime, with their risk of developing the disease steadily increasing as they get older[3]. There is no known cause for MND (except in a very small number of genetic cases), no effective treatments and no cure. Progression of MND is usually rapid and relentless creating high levels of disability and a consequent need for a wide range of supports based on the person's changing and progressing needs.

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. These interventions are also critical in helping people to plan ahead and preventing and/or delaying 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. Importantly, people with MND can and do live valued and engaged lives with the right supports, including assistive technologies and a multi-and inter - disciplinary approach, irrespective of disease stage or progression.

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 will be 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.

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[1] Kiernan MC, Vucic S, Cheah BC, et al. Amyotrophic lateral sclerosis. Lancet 2011;377:942-955.

[2] Brown RH, Al-Chalabi A. Amyotrophic Lateral Sclerosis. N Engl J Med 2017;377:162-172.

[3] Martin S, Al Khleifat A and Al-Chalabi A. What causes amyotrophic lateral sclerosis? [version 1; peer review: 3 approved]. F1000Research 2017, 6(F1000 Faculty Rev):371

MND AND BUDGET FLEXIBILITY

It is crucial to recognise that MND is a rapidly progressing, life limiting condition resulting in complex and changing disability needs which require a rapid and responsive approach from diagnosis onwards. It is essential that independent assessments, budget development and planning are undertaken by people with an understanding of the person and the progressive nature of MND. Whilst plan and budget flexibility are to be welcomed the proposed planning policy related to plan development, check-ins, plan variations and plan reassessment will be difficult to implement for people with complex and progressing conditions that result in rapidly changing disability needs such as motor neurone disease.

MND Australia, in partnership with our members, has engaged proactively and successfully with the NDIA since the introduction of the NDIS to support an effective planning process and plan implementation for people living with MND. This led to the development of the first disability/disease specific MND practice guide for planners and an understanding that it was not appropriate for local area coordinators (LAC's) to undertake planning for people with MND.

Most people with MND are now allocated to a planner, and in some areas to a specialist planner, with experience of progressive neurological conditions. At the local level MND Associations have provided training, information and support to planners involved in working with people living with MND thereby assisting the process and helping planners to understand the complex and individual nature of MND. There is widespread recognition by the NDIA that long term plans are not tenable for this cohort.

The proposed planning process for new and existing NDIS participants in conjunction with the introduction of independent assessments will not support an effective planning process for people living with rapidly progressing neurological conditions such as motor neurone disease.

Whilst we welcome the premise of personalised budgets and plan flexibility, the proposed planning process raises many concerns for those with rapidly progressing neurological conditions. It is particularly concerning that the consultation paper does not reference progressing disability and refers only once to reduction in functional capacity related to a degenerative condition. The planning process outlined indicates that the budget will be informed by the outcomes of the independent assessment that will measure functional capacity at that point in time based on assessment tools that will not be sensitive to changing and progressing conditions. In our response to the consultation paper on Access and Eligibility Policy with independent assessments we have strongly recommended that people with a disability that is complex and has potential to progress rapidly should be exempt from undertaking an independent assessment in order to access the NDIS.

It is unclear who will undertake the planning conversation and where this will take place. It is very worrying that apart from the planner being able to add in certain fixed items, such as assistive technology, to the budget and allocate funds as fixed or flexible, the budget and plan cannot be changed following its review by the participant, family and allied health care team.

We are also very concerned about the focus on participant's use of community and mainstream supports combined with their NDIS funding to pursue their goals and aspirations and meet their disability related support needs. MND is life limiting, and therefore a palliative approach is required from diagnosis onwards to support the person to achieve the best outcomes and to live as actively as possible until end of life. There must be an understanding that for people with a diagnosis of MND and other degenerative neurological or neuromuscular diseases a coordinated multi and inter-disciplinary approach involving disability, health and palliative care services is required. A coordinated team based approach to care will be required; with the NDIS funding and addressing needs that are related to a person's disability. It is vital that delegates and planners understand this approach, as well as the impact of the NDIS to date on mainstream health, allied health and community services. The significant impact on the participant's carer, family and friends physically, socially and emotionally must also be taken into account when considering the informal supports available.

With a proposed minimum of 3 months between independent assessments it is imperative that plan budgets for people living with rapidly progressing neurological conditions are truly flexible, can be easily amended, including an increase to their budget, through plan reviews or through the check-in process, and have sufficient budget to draw on to address rapid functional decline. Budgets for AT must continue to reflect the need for a timely response and funding for a wide range of AT devices including communication devices and individualised items based on assessments and reports from the participant's treating allied health professionals. The importance of funding for support coordination for participants with MND must not be under estimated and must be included in all plans developed.

The introduction of independent assessments and the proposed planning policy will undo progress made for people living with MND and lead to the need for a multiple assessment process for people with progressing and changing disability needs. This would be an unnecessary and traumatic experience for people with life limiting and progressing conditions.

MND Australia recommends:

1. The Independent Assessment Framework and proposed planning policy be amended to exempt those with rapidly progressing neurological or neurodegenerative conditions

2. Where exemption is not granted then the Planning Policy for Personalised Budgets and Plan Flexibility should be amended to ensure that people living with progressive, degenerative neurological or neurodegenerative conditions are delegated to planners who are specialists with knowledge and experience of working with people living with these conditions and who have authority to work with the participant to amend draft plans and draft budgets to take progression into account.

3. Where exemption is not granted then the Planning Policy for Personalised Budgets and Plan Flexibility should be amended to include a third category in a budget for participants with rapidly changing needs to draw on as function declines to negate the requirement to wait for and undertake repeated independent assessments and to minimise crisis intervention and unnecessary hospital admissions i.e budgets would include flexible, fixed and emergency/top up funds that could be drawn on following a check-in.

4. The NDIA postpone the implementation of the mandatory independent assessments and changes to the planning process until the second pilot on independent assessments is completed, outcomes determined and publicly released, with any revisions to the Policy considered. If people living with a rapidly progressing disability have not been included in a pilot to date then we recommend a further pilot be conducted to include this cohort.

Feedback on the 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?

For people who have recently acquired a disability, or been diagnosed with a condition that causes disability, the language of disability will be particularly foreign to them. Clear, concise and accessible information is therefore vital. A participant's plan should be set out using everyday language that is consistent and that participants can understand.

Visual representations, infographics and case examples will help people to understand how funding can be spent.

The participant should be provided with the outcomes of their independent assessment to assist them to understand how, and on what basis, their plan has been developed

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

It is proposed that planning will focus on how a participant can best use community and mainstream supports combined with their NDIS funding to pursue their goals and aspirations and meet their disability related support needs. The planner will therefore need to fully understand, and have experience in, the impacts of the person's condition. This will be crucial for people living with MND whose pursuit of goals and aspirations and use of mainstream supports will be very different to those with a stable or long standing disability. In addition these will change over time and in many cases change rapidly. The planner must also be cognisant of the significant impact of MND, progressing loss of function and limited life expectancy on the participant's carer, family and friends and take this into account when considering informal supports available.

We have long campaigned for the role of support organisations in supporting people to prepare for planning meetings and assessments to be recognised by the NDIA as a vital service that should be appropriately funded by the government.

The impact of the NDIS to date on access to, and availability of, mainstream health, allied health and community services in the participant's community must be fully understood by the planner. In addition the planner will need to be fully informed regarding the services available in the person's community, likely wait times for those services and understand the impact of delayed access to services for people with a progressive condition. They must also understand the importance of support coordination and the services provided by the MND Association to inform and support participant decision making.

In addition:

- Inform the participant about the purpose of the planning meeting and changes that can and cannot be made to the plan and plan budget
- If a plan is already in place organise a time and date for a planning meeting well ahead of the current plan end date
- Inform participants and their support coordinator of the date and time of the planning meeting to allow time to discuss the draft plan and draft budget or the changes needed to the next plan
- Have a direct contact for the planner - full name and a contact number - the participants can call if they have anything to add or any questions regarding the draft plan
- Fund disease specific organisations involved in supporting people to access the NDIS and in preparing participants for planning meetings.

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?

The MND Australia Deloitte Access Economics Report[4] reveals that in Australia the per-person cost of MND in 2015 was $1.1 million, dwarfing the cost of many other chronic health conditions. The report states that the total cost of MND in Australia in 2015 was $2.37 billion, comprising $430.9 million in economic costs and $1.94 billion in burden of disease costs. In the Report, aids and equipment comprise one of the highest per person costs highlighting their importance. The often rapid rate of progression requires 'fast track' access to a wide range of AT as soon as a need arises. An assistive technology (AT) item may only be required for a short period of time making purchasing items a costly exercise. The report states that aids and equipment cost $31,598 per person in 2015 and confirmed the MND Association equipment loan service as a cost-effective model in providing equipment to maintain independence and communication.

It is imperative that sufficient funding for AT including rental, AT bundles from MND Associations and personalised AT items is included in a participant's fixed budget. Timely home modifications to support the person to remain as independent as possible and engaged with their family and community are vital in supporting the person to live a meaningful and engaged life for the rest of their life. Home modifications must, therefore, be included in a person's initial plan in the fixed budget to support decision making and planning.

AT and home modification assessments and reports from the participant's allied health professional is a key principle in determining the supports included in the fixed budget. There appears to be no mention or recognition of their role within the proposed policy.

In addition:

- Include Assistive Technology repair and maintenance

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[4] Deloitte Access Economics, 2015, Economic Analysis of motor neurone disease in Australia, report for Motor Neurone Disease Australia

- Allow fixed budget to be transferred to Flexible funds according to participant's needs
- Ensure sufficient funding for support coordination and allied health assessments and reports.

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)

Assurance will depend on trust and confidence in the process and the people involved with the participants. Participants must be confident that their plan budget is at a level to meet their needs rather than at a level to meet the needs of the government.

They will need to be assured that the planner has experience of MND, has undergone training on the impacts of MND and has reviewed the MND Practice Guide for Planners. They will need to be assured that their personalised plan budget *'reflects the expected costs of providing reasonable and necessary package of supports for a participant with a similar level of functional capacity, support need and environmental context'* **who has a rapidly progressing condition and takes into account progression and future need**.

In addition it will be important to:

- Discuss the independent assessment outcomes with the participant, carer and support coordinator (if applicable) prior to plan and budget development by the NDIS delegate to ensure the plan budgets are at the right level to meet the participant's reasonable and necessary needs over the next 3 to 6 months (step 2)
- Provide the participant, carer and support coordinator (if applicable) the opportunity to comment and provide feedback on receipt of their draft plan and draft budget (step 3) prior to the planning conversation (step 4)
- Expand the planning conversation (step 4) to enable the planner to make adjustments to the draft plan based on participant review and feedback to take progression of their condition into account prior to finalisation by the delegate (step 5).

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

As outlined in question 1 ensure the provision of clear, concise and accessible information using everyday language that is consistent and that participants can understand. Use visual representations, infographics and case examples will help people to understand how funding can be spent.

Highlight the value of support coordination in supporting people to use their plans and achieve optimal benefit from the new plan flexibilities.

In addition:

- Maintain choice of how the plan is funded – i.e. self-managed/plan managed
- Provide outlines of plan categories on the NDIS website and what services and supports can be included as flexible funds
- Clearly explain the difference between flexible and fixed funds
- Make the websites and portal user friendly
- Ensure the portal includes an effective and user friendly budgeting tool.
- Make it easy for a participant to distribute their plan information to providers
- Use natural common language and easy English when describing services
- Allow flexibility for all services and ensure sufficient flexible funds for support coordination and allied health assessment, review and interventions.

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

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

For people living with progressive, degenerative neurological or neurodegenerative conditions whose needs are changing rapidly we strongly recommend that the NDIS introduces a third category of emergency or top up funds for the person to draw on if their function declines over the next 12 months. A 12 month budget and plan that cannot be amended without an independent assessment will not be suitable for most people with MND. The current MND Practice Guide recommends 6 month plans as a standard for people with MND.

In addition:

- For people living with progressive, degenerative neurological or neurodegenerative conditions whose needs are changing rapidly allow for light touch plan review and adjustments to budgets at check-in meetings without the need for repeated independent assessments
- Ensure access to fixed funds if flexible funds are depleted
- Allow reimbursement for expenses that are not approved to be reviewed retrospectively e.g vehicle or home modifications.

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

It is proposed that the plans will be up to 5 years long and that funds will be released in monthly or quarterly intervals. 5 year plans, or even in most cases 12 month plans, are not appropriate for people with progressing neurological and neurodegenerative conditions.

People living with rapidly progressing and complex conditions are very likely to need urgent access to additional services and supports that will exceed their monthly allocation. It is unlikely they will have built up sufficient unspent funds to rollover to support increasing functional decline. Allowing people to access additional funds in the first month of the plan that is then offset by smaller monthly allocations will not work for this cohort. As already stated the current MND Practice Guide recommends 6 month plans as a standard for people with MND.

Participants will need increased assistance in managing budgets to ensure people don't overspend and find themselves in periods without support particularly given the scheduled funds release approach. This adds greater emphasis to the importance of adequate support coordination.

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

Regular check-ins are only appropriate for participants who live with stable conditions. For a person with MND this process adds yet another level and layer of stress and anxiety and should only be conducted at the request of the participant or in an emergency situation.

If check-ins are required in the case of an emergency or crisis situation before access to additional funds a mechanism must be in place to ensure a timely response or automatic release of additional funds following a check-in phone call or contact. People will need to know who to contact and have their contact details in case of an emergency or crisis.

In addition:

- A participant should be informed who to contact if a check in is needed and be provided with their contact details – they should be allocated to one person who will undertake all their check-ins
- Providers and participants need more information regarding the purpose of check-ins and changes that can be made as a result of these meetings
- Participants should be fully informed about the changes to plans that can and cannot be made as a result of a check-in
- Check-ins should take place at a time and place that suits the participant and be undertaken by people who have been appropriately trained and have knowledge of the person's condition
- Check-in should be conducted with the participant and their supports including support coordinator or other formal supports, social workers, allied health etc.

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

It is proposed that check-ins may lead to a plan variation to move funds from fixed to flexible and vice versa. Funds will only be added to the plan in response to receipt of a specialist assessment for assistive technology or home modification or in an emergency situation.

We strongly recommend that a third category be included in budgets for participants with rapidly changing needs to draw on as function declines i.e budgets would include flexible, fixed and emergency/top up funds. A check-in would then be undertaken to vary the plan to allow the participant to draw on these additional funds without the need for an independent assessment.

As outlined in our response to the consultation paper on Access and Eligibility Policy with independent assessments people with a MND should be exempt from undertaking an independent assessment in order to access the NDIS.

For people living with MND check-ins should occur at the request of the participant in the following circumstances:

- Following receipt of a specialist assessment for assistive technology or home modification
- 1 Month after the plan is released to check on any changes needed to flexible and fixed funding allocation
- When plan variation is required
- 3 to 6 months after the plan is released to review progression and the need to review plan and increase budget.

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

Ensure that people with progressing neurological conditions are delegated to planners who are specialists with knowledge and experience of working with people living with their condition and who have authority to work with the participant to amend draft plans and draft budgets to take progression into account.

Ensure that planners have experience of MND, have undergone training on the impacts of MND and have reviewed the MND Practice Guide for Planners. Planners should also be sensitive to the language that they use in explaining the reasons behind decisions. MND Associations have observed first hand and received feedback from many clients that planners have advised them that they will not live long enough for AT purchases to be deemed value for money.

Ensure that once access to the scheme is confirmed that the participant is provided with clear timeframes regarding receipt of draft plan, planning conversation and final plan and budget.

In addition:

- Provide the participant with their planners direct NDIS contact details

- Maintain consistency in allocated planners so a person with MND is supported by the same planner throughout their participation in the scheme
- Ensure planners are providing accurate and realistic estimates of likely support funding, timing and review process
- Ensure planners are accountable for the advice they provide.

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

Ensure that current participants diagnosed with conditions that result in rapidly changing and complex disability needs are exempted from having to undertake an independent assessment in order to move to their new plan. Where a participant’s current plan is meeting their needs then the plan should be adjusted to transition approved funds to flexible and fixed. Any assessments required should be provided by the participant’s treating allied health care team.

In addition:

- Seek direct feedback from the participants on the proposed changes
- Advise participants of the forthcoming changes to the process in writing via letter or email and on the NDIS website.

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

Carol Birks,
CEO, MND Australia