



New Framework Planning and NDIS Supports Consultation

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What is MS?

Multiple Sclerosis (MS) remains one of the most common causes of neurological disability in the young adult population (aged 18–40 years) with over 2.9 million people affected worldwide. More than 37,756 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially disabling neurological condition.

Three times as many women have MS than men. 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. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS can significantly affect quality of life, including through its impacts on pain/mobility, independent living, mental health, relationships and participation in everyday life.

MS Australia is Australia's national multiple sclerosis (MS) not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia represents and collaborates with its state and territory MS Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS

George Pampacos
President

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New Framework Planning and NDIS Supports Consultation

Executive Summary

MS Australia welcomes the opportunity to respond to the Department of Health, Disability and Ageing on the National Disability Insurance Scheme (NDIS) New Framework Planning and NDIS Support consultation.

This submission draws on the expertise of people living with MS and carers and supports clearer, fairer and more accessible NDIS framework planning. MS Australia calls for transparent NDIS plan assessment and budget methods that recognise fluctuating, progressive and degenerative conditions; meaningful consideration of participant and clinical evidence; timely options to correct assessments and vary plans; and practical guidance on support categories. The National Disability Insurance Agency (NDIA) should delay removing replacement supports for six months while an evaluation is undertaken to understand the impact of this measure. Successful implementation will require trained staff, accessible information, real-life examples, open communication and genuine partnership with the disability community.

Lived Experience

This submission draws on the experiences and expertise of MS Australia's [Lived Experience Expert Panel](#) (LEEP) and state and territory [Member Organisations](#). LEEP members are people who live with MS or care for someone with MS and provide expert advice to inform MS Australia's advocacy. Our Member Organisations are registered NDIS providers delivering supports including support coordination, plan management, allied health, accommodation, respite, social support and in-home care. Some also support people with other neurological conditions, including stroke, Parkinson's disease, Huntington's disease, acquired brain injury and motor neurone disease.

MS Australia Recommendations

Support Needs Assessment Rules

- The NDIA provide more detail on the **support needs assessment process** including support given to participants and representatives who cannot clearly articulate their needs, an evidence list including the weight given to each type of evidence, the assessment tools that will be used, the process for obtaining missing information and how the new process will capture fluctuating, progressive and degenerative conditions.
- The NDIA provide more detail on the **support needs assessment report template** including information on how information in current plans will be considered, staff training on interacting with participants, how the template will capture information on fluctuating, progressive and degenerative conditions, how assessors will determine what is a degenerative condition, how informal supports will be assessed, how information provided by participants will be captured, the timeline for a participant to review the report and provide feedback, and provide feedback, partners in the community and how the need for therapy supports will be assessed and recorded.
- MS Australia recommends the **new assessment process** recognises that some participants are retired due to disability and so participation in work or study is not suitable for them.
- The NDIA should consider the following in relation to **replacement assessments**:
 - Replacement assessments should be available when a participant disagrees with the assessment, there are errors or omissions in the report, where a participant with reduced decision making or communication capacity completes the assessment without

appropriate support and/or where vital evidence has been ignored or misinterpreted including reports from health professionals.

- The NDIA should focus on a more open approach to solving assessment disagreements.
- The NDIA should provide more detailed information on the assessment approach for participants whose needs have changed significantly.

Budget Method Rules

- The NDIA provide further information on **budgets** including how they will differ from current budgets, flexible vs fixed budget items, the link between the assessment report and budget calculations, what day to day support can be funded under each category, budget breakdowns, how the budget will factor in costs relating to organising supports and how the budget will address indexing.
- The NDIA produce more **example plans** including ones that feature people with fluctuating, progressive and generative conditions.
- The NDIA provide more detail on the **draft participant plan template** including information on staff training, the supports available under each category, how participants can spend their flexible funding without restrictions and the adjustments section of the template.
- Grouping the definition, rules, examples and restrictions for each support type together to make the **draft participant plan** template easier to understand.

Plan Variation & Reassessment Rules

- The NDIA provide further information on **plan variations and reassessments** including what happens when a plan expires after five years, timeframes including for time sensitive changes and staff training.
- The NDIA establish a clear assessment and planning pathway and timeframes for **participants who have a significant decline in function** over a short period of time.

New Supports Categories

- The NDIA address the **discrepancy in the number of support categories** and the numbering of the categories across the consultation documentation.
- The NDIA can improve the information provided on the **new support categories** by providing more 'real life' examples of how plans can be used including specific examples under each category and more information on what can be funded under low-cost assistive technology and therapy supports, how counselling is funded and consistency on the naming of the disability supports category.
- The NDIA work with the disability community to **improve the NDIS in preparation for the changes** including comprehensive training for NDIA staff, NDIA staff testing the participant experience, more flexibility for people with fluctuating, progressive and degenerative conditions such as MS, a focus on working
- MS Australia recommends that the NDIA consult with **participants who need regular access to specialised therapy supports** to better understand how to reflect the cost of these supports in flexible funding.

- The NDIA should delay **removing replacement supports** for six months while they engage with participants and undertake an evaluation of the impact of removing them.

Consultation Resources

- The NDIA provide **more information** on plan lengths, making minor plan changes, how the changes will improve the NDIS including reducing expenditure and fraud while not harming participants, addressing additional NDIS costs, exploring co-contributions and staff training and support.
- The NDIA can support people with disability to better **understand the new NDIS framework planning** by providing information in more accessible formats including short explanatory videos with captioning and Auslan, documents that are accessible with screen read software, a NDIS staffed hotline and face to face and online information sessions.
- The NDIA can further **support the new changes** with clear, open, honest and regular communication, providing clear and concise facts on the changes and impacts on participants, providing information to help people advocate for themselves and building stronger relationships with the disability community.

Support needs assessment rules

What parts of the support needs assessment process need more explanation?

MS Australia believes the support needs assessment process as currently outlined is clear, however, there is some missing detail that would help participants to better understand the new process:

- What support will be given to participants and their representatives who cannot clearly articulate their needs.
- A clear list of what evidence will be used and what participants will be expected to submit.
- What weight will be given to the information and evidence provided by the participant including reports from health professionals.
- More information on the assessment tools including what is contained in the I-CAN assessment tool and whether people with disability will be able to access the assessment tools ahead of time.
- What the process is when an NDIS delegate determines that information is missing from an assessment report including who is responsible for obtaining the missing information, whether the participant can review or respond to it, the timeframe for resolving the issue, and whether further assessment can occur without disadvantaging the participant.
- How the new process will capture fluctuating, progressive and degenerative conditions.

'I think the process makes sense and I know that I am able to effectively advocate and give an accurate picture of my needs but I am really worried about how some participants and their representatives may understand or navigate this process whether that is due to cognitive understanding, anxieties etc.' - **LEEP Member Hannah**

MS Australia recommends the NDIA provide more detail on the support needs assessment process including support given to participants and representatives who cannot clearly articulate their needs, an evidence list including the weight given to each type of evidence, the assessment

tools that will be used, the process for obtaining missing information and how the new process will capture fluctuating, progressive and degenerative conditions.

What questions and feedback do you have about the draft support needs assessment report template?

MS Australia supports the draft support needs assessment report template and finds it easy to read while also being comprehensive, however, the following information would support participants to better understand the template:

- How information in current plans will be used and if this will be considered as part of the assessment process.
- Information on the training assessment staff have been given in relation to interacting with people with a disability and how to support them to provide the required information. Currently, there is a strong emphasis in the NDIS on using the 'correct language' or terminology which can result in participants missing out on the supports they need.
- As outlined above, how the report will capture information in relation to fluctuating, progressive and degenerative conditions such as MS. This includes the process used and information included for the assessor to determine if a person has a degenerative condition.

'How does fatigue, cognitive load, pain, or fluctuating impairment fit into the report?'
- **LEEP Member Rachel**

- More information on what the NDIS considers informal supports and how this will impact a participant's final plan.
- How the assessor will capture all the information discussed during the session including information provided by the participant and their representatives about their disability, quality of life and support needs.
- The timeframe given to participants to review the assessment report and give feedback before it is finalised.
- More information on partners in the community and who has access to them.
- How the need for therapy supports will be assessed and recorded in a participant's plan. In the example plan provided the person has not been given funds for therapy supports despite it being stated that they need to access them 'Ishaan sees his GP on a regular basis. He sometimes has speech therapy and sees his occupational therapist.'

We also believe the report should recognise the fact that some participants may be retired and not engaging in employment and education:

"I do not work nor do I study full time. Employment and Education - There is nowhere for a person who can be retired because of disability, not age." - **LEEP Member Anne**

MS Australia recommends the NDIA provide more detail on the support needs assessment report template include information on how information in current plans will be considered, staff training on interacting with participants, how the template will capture information on fluctuating, progressive and degenerative conditions, how assessors will determine what is a degenerative condition, how informal supports will be assessed, how information provided by participants will be captured, the timeline for a participant to review the report and provide feedback, partners in the community and how the need for therapy supports will be assessed and recorded.

MS Australia recommends the new assessment process recognises that some participants are retired due to disability and so participation in work or study is not suitable for them.

In what circumstances do you think a replacement assessment should be arranged? Are there additional circumstances that should be considered?

MS Australia strongly supports the new assessment process providing an opportunity for participants to address errors or omissions in the assessment before a plan is developed. A replacement assessment should be arranged when a participant disagrees with the assessment, there are errors or omissions in the report or where vital evidence has been ignored or misinterpreted including reports from medical professionals.

We are also concerned about situations where a participant with reduced decision making or communication capacity has completed an assessment without an advocate, family member or other appropriate support person present and where that absence may have affected the accuracy or completeness of the assessment. In these circumstances they should be able to request a reassessment.

Currently NDIA staff do not give appropriate weight to reports from health professionals and often make decisions that directly contradict the reports. Under the new support needs assessment rules participants need to be able to request a replacement assessment. To avoid participants having to request reassessment, assessors should be required to clearly explain the reasons why they have overlooked evidence and how they came to their final decision.

We encourage the NDIA to make the process of seeking a replacement assessment easy for participants with a focus on a more open approach to solving assessment disagreements. Early and open discussion of assessment outcomes and possible changes would significantly reduce the workload of assessor and delegates and reduce the stress for participants.

We would also like clearer information on how the assessment process will work for people whose needs have changed significantly, and a plan variation is not adequate to meet their needs. This is very important for people living with MS, particularly those living with progressive forms of the condition, as their needs may change significantly over a short period of time.

MS Australia recommends the following in relation to replacement assessments:

- Replacement assessments should be available when a participant disagrees with the assessment, there are errors or omissions in the report, where a participant with reduced decision making or communication capacity completes the assessment without appropriate support and/or where vital evidence has been ignored or misinterpreted including reports from health professionals.
- The NDIA should focus on a more open approach to solving assessment disagreements.
- The NDIA should provide more detail on the assessment approach for participants whose needs have changed significantly.

Budget method rules

What information would help participants understand how a budget is calculated?

The following information would help participants better understand how a budget is calculated:

- How budgets will differ from the way they are done now.
- Which parts of the budget are flexible, and which are fixed.
- Information on the link between assessment report findings and the budget calculation.
- What day to day supports can be funded under the different budget categories.

- Budget breakdowns so participants can understand the factors that make up their budget.
- Information on how budgets will factor in the costs of organising supports including current award wages and minimum engagement times.
- How the budget will address indexing for costs that increase year on year.

We would also like to see the NDIA produce more example plans to better understand how a finished budget looks for a range of participants. This includes plans featuring people with fluctuating, progressive and degenerative conditions.

MS Australia recommends the NDIA provide further information on budgets including how they will differ from current budgets, flexible vs fixed budget items, the link between the assessment report and budget calculations, what day to day support can be funded under each category, budget breakdowns, how the budget will factor in costs relating to organising supports and how the budget will address indexing.

MS Australia recommends NDIA produce more example plans including ones that feature people with fluctuating, progressive and generative conditions.

What questions and feedback do you have about the draft participant plan template?

The following information would help participants better understand the draft participant plan template:

- Information on which NDIA staff will complete the participant plan template and what training they will be given.
- More detail on the supports available under each category including a link to relevant resources on the NDIS website. This could be made available as an appendix to the template.
- More detail on how participants can use the funding allocated to the 'flexible funding without restrictions' category to better support participants in using this funding and reduce fraud.
- More information on the adjustments section of the template. There is a reference on page 3, that states 'Learn more about the adjustments in the Adjustments section of this plan under Your NDIS budget', however, there is no adjustments section in the template.

The information in the template relating to supports is fragmented across the document. Content moves back and forth between flexible, non-flexible and stated supports rather than explaining each support type in full. Grouping the definition, rules, examples and restrictions for each support type together would make the template easier to understand.

MS Australia recommends the NDIA provide more detail on the draft participant plan template including information on staff training, the supports available under each category, how participants can spend their flexible funding without restrictions and the adjustments section of the template.

MS Australia recommends grouping the definition, rules, examples and restrictions for each support type together to make the draft participant plan easier to understand.

Plan variation and reassessment rules

What feedback and questions do you have about plan variations and reassessments?

The following information would help participants better understand plan variations and reassessments:

- Information on what happens when a plan expires after five years, including if participants undertake a whole new assessment or if there is an alternative renewal process.
- The timeframes for plan variations and reassessments including if the new timeframes will be more responsive to sudden changes in a participant's needs.
- Which NDIA staff will undertake plan variations and reassessment and what training they have been given.

'What are the timeframes for plan variations and reassessments? Will there be a triage system for time sensitive concerns or changes to impact of participants with disability, i.e. degenerative/progressive/life-limiting conditions.' - **LEEP Member Julie**

As outlined above we would like further information on how the new framework planning will work for people who have had a significant decline in function including people living with progressive and degenerative conditions such as MS. For some participant this decline in function may happen over a very short period of time, so there needs to be a clearly established pathway and timeframes for managing them.

MS Australia recommends the NDIA provide further information on plan variations and reassessments including what happens when a plan expires after five years, timeframes including for time sensitive changes and staff training.

MS Australia recommends the NDIA establish a clear assessment and planning pathway and timeframes for participants who have a significant decline in function over a short period of time.

New Supports Categories

Are the proposed support categories clear?

The new support categories are clear, and we support the changes to them. However, there is a discrepancy in the number of support categories outlined across the consultation documents. The *New Framework Planning Rules Consultation Paper* lists 18 new support categories and the *NDIS Supports Transitional Rules Consultation Paper* lists 18 new support categories in the main section of the document, however, in *Attachment 1—Mapping of old and new framework supports categories* the support categories are numbered up to 20. The discrepancy appears to be the inclusion of an additional category, 7. *Early intervention supports for early childhood*, and the removal of category 11.

MS Australia recommends the NDIA address the discrepancy in the number of support categories and the numbering of the categories across the consultation documentation.

Are there areas where further explanation, examples or guidance would be helpful? Are there particular support types where more guidance may be needed?

The guidance on the new supports categories could be improved by providing more information on 'real life' examples of how plans could be utilised including specific examples under each category:

'It feels like each of the categories could have a small list of examples written under them, to better acquaint people with the possible uses for each category. I did find this in another doc linked within the fact sheet, but it seems like it would be more helpful in the main fact sheet. It seems too important to tuck away in a further link.' - **LEEP Member Rachel**

The following support types need more guidance:

- Low-cost assistive technology including what is funded under this category and what remains on the funded list and what has moved to the not funded list.
- Therapy supports including how the funding can be used and which types of therapy are funded.
- It is unclear under which category counselling is funded especially when it is directly related to a participant's disability, including any eligibility boundaries or exclusions.
- Disability health supports are called both 'Disability health supports-nursing' and 'Disability health supports' across the consultation documentation. This category also appears to include allied health professionals, so the nursing categorisation does not seem appropriate.

MS Australia recommends that the NDIA improve the information provided on the new support categories by providing more 'real life' examples of how plans can be used including specific examples under each category and more information on what can be funded under low-cost assistive technology and therapy supports, how counselling is funded and consistency on the naming of the disability supports category.

Are there any practical issues, or unintended impacts that need to be considered?

The changes to NDIS framework planning are just one part of many changes happening to the NDIS over the coming months and years. People with disability are already feeling overwhelmed with navigating the current system and are very concerned that the new changes will not improve their experience. More broadly, the disability community feels that their concerns on the recently passed NDIS Amendment Bill were not heard.

LEEP members and other people living with MS regularly provide feedback to MS Australia about their difficulties with navigating the NDIS including the lack of understanding of MS, NDIA staff ignoring reports from health professionals and rapid unexplained changes to their plans. In the past 12 months many people with MS have experienced significant reductions in their supports, especially physiotherapy, exercise physiology, and occupational therapy supports, and changes to their plans that has resulted in distress, uncertainty, and reduced access to essential one-to-one supports. This has led to participants experiencing increased disability and disease progression, hospitalisations and an inability to participate in work, travel and family and community activities.

MS Australia urges the NDIA to listen to the disability community and work with them to implement these new changes. This includes implementing the following:

- Undertaking comprehensive training for NDIA staff in disability awareness, the NDIS rules, communicating with people with disability and understanding and interpreting evidence.
- Choosing a group of NDIA staff to try navigating the new changes as though they were a participant so they can fully understand the participant experience.
- Being more flexible around planning, supports and support categories for people with fluctuating, progressive and degenerative conditions such as MS.
- A focus on working with participants to find solutions in an open and honest way, reducing the need for reviews and reassessments.
- Valuing lived experience and recognising the NDIS participants are experts in their own

conditions and understand best what supports they need.

For people living with MS, access to allied health services and supports are essential to maintaining health and wellbeing and slowing disability progression. These supports are essential to help improve mobility, balance and strength; manage fatigue, maintain independence; improve nutrition, manage bladder and bowel issues and to prevent symptoms from worsening over time. We are concerned that placing therapy supports under the flexible funding category may reduce access to the levels of funds needed for regular access to specialised therapy supports as the funding in the flexible funding category may become diluted by other support needs in the same category. The NDIA need to do further consultation with participants who need regular access to specialised therapy supports to better understand how to reflect the cost of these supports in flexible funding.

MS Australia recommends the NDIA work with the disability community to improve the NDIS in preparation for the changes including comprehensive training for NDIA staff, NDIA staff testing the participant experience, more flexibility for people with fluctuating, progressive and degenerative conditions such as MS, a focus on working with participants to find solutions and valuing the lived experience of people with disability.

MS Australia recommends that the NDIA consult with participants who need regular access to specialised therapy supports to better understand how to reflect the cost of these supports in flexible funding.

What impacts do you think will be experienced as a result of removing replacement supports? What items or services will no longer be available?

Our LEEP members have a range of concerns about removing replacement supports. Many people with disability rely on these replacement supports to undertake daily activities that allow them to maintain independence and remain in their homes. These replacement supports cost significantly less than providing a support worker to do the equivalent work. We are also concerned that the removal of replacement supports will place a greater reliance on informal supports and carers, leading to a loss of independence for both the participant and the carer. Continuing to play an active role in daily life is very important for people with MS and contributes to improved mental health, delayed disability and disease progression and provides a greater quality of life.

We urge the NDIA to delay the removal of replacements supports until the agency has engaged with a range of NDIS participants who use replacement supports and better understands the impact that removing them will have on participants life. An evaluation on the impact of this measure could be completed over six months.

'I do not like the idea of removing funding for replacement supports. So many everyday items that people with a disability may not be able to afford due to limited income could and do actually make a huge difference to living 'ordinary lives' that would cost a fraction of paid support staff. Things like dishwashers, meal preparation, tablets, technology that's voice activated or controlled by apps all could seriously increase someone's independence will no longer be an option and as a result increase the need for paid support staff to be available to assist with this instead'. - **LEEP Member Hannah**

I don't think we will know the full impact until it is in play and we learn the hard way, sadly. In a perfect world, everyone who is currently accessing a replacement support would be contacted / given the opportunity to provide feedback on what their life and condition would look like without those supports. By asking the people currently accessing replacement supports, data the NDIA has ready access to, they can get a much clearer picture of the importance of same, and adapt accordingly.' – **LEEP member Rachel**

MS Australia recommends the NDIA should delay removing replacement supports for six months while they engage with participants and undertake an evaluation of the impact of removing them.

Consultation Resources

What information was most useful?

Our LEEP members found the consultation resources easy to understand and found these elements the most useful:

- Easy read documents
- The factsheets and links to more in-depth information
- 'Real life' examples of how the changes will look.

'I liked the actual examples using fabricated patient data - it allowed me to see how it would look in real life rather than having to imagine it.' - **LEEP Member Rachel**

What questions do you still have?

MS Australia has the following questions relating to the reforms:

- How long will a plan last?
- How do participants get minor changes made to their plan, for example, a misspelled name, without navigating a lot of bureaucracy?
- How will these changes improve the NDIS and reduce expenditure without harming NDIS participants?
- How will these changes reduce fraud and prevent scams?
- How is the NDIA addressing the price increase that comes with paying for NDIS services/products vs paying for the same service/product when not under the NDIS?
- Has the NDIA considered a co-contribution scheme for high-cost items where participants could make a contribution to the costs of an item? This may allow participants to access some items that the NDIA is not willing to pay the full price for and give them more choice.
- How will the NDIA ensure that staff are appropriately trained and supported to deliver the changes?

'We can design the best framework in the world, but if the people using it on the front line are not equipped with what they need to actually enact it properly for every single PWD they engage with, it is pointless. How will the NDIA ensure their staff are adequately trained and supported to implement these changes? How will they ensure their staff have the appropriate training and skills to defer to medical judgement in reports rather than overruling that which they don't understand?' - **LEEP Member Rachel**

MS Australia recommends the NDIA provide more information on plan lengths, making minor plan changes, how the changes will improve the NDIS including reducing expenditure and fraud while not harming participants, addressing additional NDIS costs, exploring co-contributions and staff training and support.

What would help people with disability better understand the NDIS new framework planning rules?

What communication formats would make the information more accessible?

What should the NDIA focus on in future communication products?

Our LEEP members found that the resources provided, including the easy read guides, were clear, concise and easy to understand. However, they also noted that people with disability like to access information in a variety of ways

'Information needs to be provided in a variety of ways. Face to face information sessions, brochures, phone calls, emails etc. Not everyone absorbs information the same way. There is so much to constantly be across - the life admin of someone with a disability (and chronic illness) is already huge and add in more changes only adds stress and anxiety. The NDIS need to be proactive with reaching out in as many ways as possible to connect with its participants to ensure the changes are understood (and ahead of implementation).'

- **LEEP Member Hannah**

We believe that the changes to the NDIS framework planning can be made more accessible with the following:

- Short explanatory videos that include captioning and Auslan.
- Documents that can be used by people using screen reader software.
- A phone hotline staffed with trained NDIA staff that can answer specific questions from NDIS participants and applicants.
- Face to face and online information sessions where people can ask questions.

MS Australia recommends that the NDIA support people with disability to better understand the new NDIS framework planning by providing information in more accessible formats including short explanatory videos with captioning and Auslan, documents that are accessible with screen read software, a NDIA staffed hotline and face to face and online information sessions.

The NDIA can further support the new changes by building trust with the disability community including:

- Clear, open, honest and regular communication.
- Providing clear and concise facts on the changes, the reasons, process and the impact on NDIS participants.
- Providing information on review and reassessment processes so people have all the information they need to advocate for themselves.
- Building stronger relationships with the disability community including with disability advocates so they educate the community.

MS Australia recommends that the NDIA can further support the new changes with clear, open, honest and regular communication, providing clear and concise facts on the changes and impacts on participants, providing information to help people advocate for themselves and building stronger relationships with the disability community.

Conclusion

The new framework planning approach must be implemented transparently, fairly and in genuine partnership with people with disability. MS Australia urges the NDIA to ensure assessments, budgets and plan changes recognise fluctuating, progressive and degenerative conditions, are informed by participant and clinical evidence, and are supported by accessible information and well-trained staff. By acting on these recommendations, the NDIA can build trust and deliver reforms that protect participants' independence, choice and quality of life.

