



# NDIS Proposed New Framework Planning Rules

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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 2.8 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 debilitating disease.

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 robs people of quality of life, primarily driven by the impact of MS on pain, independent living, mental health and relationships.

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  
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# NDIS Proposed New Framework Planning Rules

MS Australia welcomes the opportunity to make a submission to the National Disability Insurance Agency (NDIA) on the National Disability Insurance Scheme (NDIS) proposed New Framework Planning Rules. Over the past ten years, MS Australia has actively advocated on behalf of people living with MS for improvements to the NDIS and have submitted a range of [NDIS submissions](#).

This submission draws on the experiences and expertise of MS Australia's [Lived Experience Expert Panel](#) (LEEP) and our state and territory [Member Organisations](#). The LEEP is a panel of people who either live with MS or are a carer for someone living with MS who provide MS Australia with expert advice to inform our advocacy work. Our Members Organisations are registered NDIS providers and deliver a range of supports and services to people living with MS including support coordination, plan management, allied health, accommodation, respite, social support and in-home care. Some Member Organisations also support people living with other neurological conditions including stroke, Parkinson's disease, Huntington's disease, acquired brain injury and Motor Neurone disease.

MS Australia makes the following recommendations:

## MS Australia Recommendations

- The NDIA engage in true and meaningful co-design before implementing this proposed New Framework Planning process mid-2026 by engaging with participants, families, the disability community, and service providers from the earliest stages of concept and rule development.
- The NDIA provide appropriate training for NDIS Accessors, Delegates, and decision makers involved in the NDIS new framework planning process that includes:
  - Training for NDIS planners and decision makers in evidence-based and participant focused supports.
  - Clear guidelines for planners and decision-makers on how to assess and meet the needs of participants with progressive neurological conditions, whose symptoms can fluctuate and change unpredictably.
  - New requirements that NDIS planners cannot remove or reduce supports from participants' plan without adequate evidence that it is no longer required or should be reduced and must provide a full explanation to the participant.
  - Participants should not be moved to NDIS managed plans without adequate evidence that this is necessary and engagement with the participant regarding the decision.
- The NDIA develop clear, user-friendly fact sheets and guidance materials to help participants understand the new planning framework and prepare for the support needs assessment. To ensure transparency, participants should be informed in advance about why and how their plans may change, how their impairment will be assessed, how to prepare, expected timelines, and whether they can involve a support person.
- The NDIA include the following in the support needs assessment process to and the support needs assessment report:
  - Include a broad range of information, prioritising the participant's lived experience, their views on the supports most beneficial for managing their condition, raw assessment scores (e.g., I-CAN), and any supporting reports, while ensuring the participant's goals and articulated support needs are meaningfully incorporated into the support needs assessment.
  - Ensure assessment tools accurately capture needs related to MS and other

degenerative conditions and take into consideration reports and participant statements.

- Prevent NDIS Assessors from relying on raw I-CAN scores alone, ensure this tool is not automated, and provide participants their raw scores and a clear explanation of how these scores impact their NDIS plan budgets.
  - Provide details on how the NDIA assessor workforce will be recruited and trained.
  - Provide training on MS and other complex degenerative conditions to NSID Assessors and NDIS Delegates.
  - Include a step to allow the participant and their nominees to review and provide feedback on the draft support needs assessment report before the report is finalised and shared with the NDIA Delegate.
- The NDIS Assessor, not the NDIS Delegate, be involved in both the support needs assessment and the replacement needs assessment, prior to a plan being created by the NDIS Delegate.
  - The NDIA provide clear details on how replacement needs assessments will operate, including when they can be requested, what the assessment process involves, and how decisions will be made, prior to these rules being implemented.
  - The NDIA should not include informal supports in the budget method rules as informal supports cannot be assumed, treated as guaranteed for participants and therefore should not be used to justify reduced plan budgets and must not replace professional supports or drive budget decisions.
  - The NDIA rules related to plan variations be shared as part of step 3, to building the plan, in the case that the plan might need to change, instead of step 4 when the plan is finalised and implemented.
  - The NDIA establish various methods of providing participants with clear, consistent communication throughout the planning process, ensuring various opportunities for participants to have the option to speak directly with the NDIS Assessor and NDIS Delegate, before their plan is finalised so changes can be discussed early and share how a participant's budget aligns with their needs assessment.
  - The NDIA should provide all information about the new planning framework in clear, plain, user-friendly language. A single, succinct guide that consolidates all steps and explanatory materials is needed, as the current information is difficult to understand and fragmented across multiple resources.

## Concerns About the Impact of the proposed new NDIS Planning Framework

The proposed NDIS framework planning rules present several emerging risks that may have significant and detrimental impacts on people with disability, their families, and the organisations that support them. While the consultation discussion and emails to NDIS participants presents the proposed rules and new planning framework processes as routine reform that will be “rolled out over a number of years,” the proposed planning changes are amount to a structural shift that could undermine participant rights, destabilise supports, and narrow the flexibility required for people with disability to live safely and independently.

These concerns are reflected in the ongoing experiences of people living with MS and current NDIS planning processes. Many people with MS have recently experienced plan changes resulting in 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.

People living with MS benefit from regular access to therapy supports delivered by qualified allied health professionals including exercise physiologists, physiotherapists, and occupational therapists. Participants report having their therapy supports drastically reduced, removed and/or replaced with a therapy assistant. Additionally, plans are being developed without consideration of medical reports and participants individual goals. The below case studies highlight the impact of reducing and removing these supports:

### **Case Study: Janine Watson**

Janine is a Taekwondo Paralympic athlete who has won four World Championships, and at the Tokyo 2020 Paralympic Games won Australia's first ever Paralympic medal in the sport of Taekwondo. She now travels the world assessing para-athletes to determine if they meet classification requirements. She is also a mentor, coach and inspirational speaker.

Janine requested more capacity building funds for therapy supports to help her maintain her independence. Janine was contacted by a NDIA planner who had a 10-minute conversation with her and asked her a few questions about her plan review. She was told during this phone call that her therapy supports would be increased.

When Janine received her new plan, the NDIA had reduced her physiotherapy supports from two hours per week to 12 hours a year. She was also given 52 hours a year for a therapy assistant to supervise a therapy program or accompany her to the gym, and a support worker to assist with daily activities such as grocery shopping. The evidence based and individualised support provided by a qualified allied health professional cannot be replaced by a therapy assistant or support worker.

There was no formal planning session with Janine prior to her being sent this plan. The NDIA planner made assumptions about her needs and individual goals. Janine wants to be able to independently undertake daily tasks and not rely on a support worker, all of which was clearly stated in Janine's NDIS goals.

The lack of access to allied health professionals has already resulted in Janine sustaining injuries after a heavy fall on Boxing Day. The changes in Janine's plan will result in a further reduction in her independence, decreased quality of life, increased mental health issues and ultimately reliance on higher support needs due to the progression of her MS.

"My new NDIS plan feels generic, as if it was copied from someone else rather than made for me. I'm frustrated because I put a lot of time and effort into preparing thorough evidence and reports for my plan review, yet it seems like none of it was considered. Now, I have a NDIS plan that doesn't suit my needs and leaves me worse off."

## Case Study: John

John\* lives with MS and is a NDIS participant whose goals focus on continuing in employment and study, keeping his mobility, and slowing the impact of his condition so he can stay healthy and independent. John works in construction, which is physical work, so maintaining his strength is essential for him to stay employed. He works half days on site and half days in the office because his mobility has declined. The agreed approach was to work with allied health to build a targeted plan to improve his mobility, strength, and endurance.

John was approved for a 12-month NDIS plan in 2024 with a total budget of \$9,300 with all funds allocated to Improved Daily Living Skills.

In May 2025 John made a plan change request so that he could submit an occupational therapy assessment and physiotherapy report detailing an increased need for therapy supports. However, an administrative error by the NDIA resulted in the plan change request being closed before the documentation was submitted and considered. As a result, when John had a new plan approved in November 2025 that did not take into consideration his needs

John's new plan has increased marginally to \$21,700 over 24 months and does not take into consideration the need for more therapy supports. Additionally, some of the current therapy supports that were assisting John have been replaced by a therapy assistant. The evidence based and individualised support provided by a qualified allied health professional cannot be replaced by a therapy assistant. A request for psychologist was rejected based on the support not meeting NDIS criteria, because 'another government service is responsible for providing this'. This rationale conflicts the approved NDIS goals in John's plan.

John received a NDIS decision letter which contradicts the funding detailed in the plan's budget breakdown and states that 'therapy supports from Improved daily living skills has not been included'.

Without the increase to John's therapy supports, he cannot maintain his mobility, strength and endurance and this will impact his ability to maintain employment and stay healthy and independent.

\*John's name has been changed to protect his identity

Families fear losing one-to-one supports, leaving loved ones at risk of being placed in group homes or prematurely moved into aged care. Through their interaction with the broader disability community, MS Australia is aware of alarming reports of participants facing hospitalisation or even expressing thoughts of assisted dying due to the pressure and uncertainty. This reflects a system under significant strain. These impacts suggest the NDIS proposed framework, as currently proposed, may not adequately safeguard participant wellbeing or uphold the principles on which the NDIS was founded.

The NDIA needs to delay implementation of the proposed planning framework, so it is not implemented in mid-2026. It would be beneficial for the agency to review the consultations shared prior to already implementing what is being proposed and use the time to meaningfully engage with people with disabilities, their families, and the organisations that support them. This pause is essential to ensure the framework reflects lived experience, addresses emerging risks, and does not unintentionally reduce access to the supports people rely on to live safely and independently.

**MS Australia recommends** the NDIA engage in true and meaningful co-design before implementing this proposed New Framework Planning process in mid-2026 by engaging with participants, families, the disability community, and service providers from the earliest stages of concept and rule development.

## Understanding Multiple Sclerosis: A Critical Gap in NDIS Planning

MS Australia supports the NDIA's recognition that the NDIS planning process must improve by focusing on a participant's individual disability support needs rather than relying solely on diagnosis or functional impairment. However, to genuinely meet the needs of people living with MS and other neurological conditions, it is essential that NDIA Planners, Assessors and Delegates deepen their understanding of MS. Without this knowledge, the NDIS cannot deliver fair, accurate or appropriate decisions throughout the planning process.

Feedback from MS Australia's LEEP highlights that the NDIS often does not understand the nature of MS. MS is a complex neurological condition that is unpredictable, progressive and different for every person. Symptoms can fluctuate from day to day, needs can shift suddenly, and the condition can change significantly over a lifetime. For this reason, MS cannot be managed through blanket rules, standard assumptions or one-size-fits-all planning and funding decisions.

### NDIS Participant Quote from our LEEP Member Anne:

"The NDIS needs to know that the agency cannot treat everyone with MS the same. MS affects people differently, and the level of support someone needs can change dramatically over time. For almost 30 years, I didn't need any help at all. But as my MS progressed into Secondary Progressive MS, and as I've gotten older, my needs have increased significantly.

When a person says they need something, the NDIS' response cannot simply be based on the fact that they have MS. It must be assessed at an individual level, because MS is not a one size fits all condition. Each person's experience, symptoms, progression and functional impact are unique.

I understand that truly personalising decisions might slow down approvals, and the system already struggles with delays. If the NDIS wants to provide fair, accurate and meaningful support, it must recognise that MS varies widely and cannot be managed with blanket assumptions."

The NDIS must also recognise the profound ways MS affects daily life – many of which are invisible. Fatigue, pain, cognitive changes and spasticity may not be outwardly apparent but can be deeply disabling. Flexible and responsive supports are critical to maintaining function, independence and quality of life. Planning decisions must be informed by the lived experience of people with MS, rather than by generalisations about the condition or assumptions about what someone "should" need. When the NDIS understands MS properly, supports can finally align with the real lives, needs and challenges faced every day by the MS community.

### NDIS Participant Quote from our LEEP Member Erin:

"The NDIS needs to understand a fundamental truth: no two people with MS are the same. It cannot assume it already knows what someone needs based on a diagnosis alone. Genuine support starts with listening – really listening – to people living with MS, because each person's symptoms, progression, and daily challenges are unique.

Right now, there's a disconnect. On one hand, the NDIS says it wants to support independence. On the other, it removes the very therapies – like physiotherapy and other capacity-building supports – that make independence possible. Increasing home assistance while cutting essential therapies doesn't preserve function; it accelerates decline. That approach doesn't build capacity. It manages deterioration.

People with MS rely on ongoing therapies to stay mobile, safe, and independent. These supports are not optional extras – they are preventative care. When they're taken away, people lose function. And when capacity is lost, the need for more intensive, more costly supports inevitably rises. Investing in therapies now isn't just compassionate – it's practical. It protects independence today and prevents far greater costs tomorrow."

Ongoing therapies are essential for people with MS, not to “improve” disability but to maintain mobility, strength, safety and independence over time. Several supports are available for a reason and while some support therapies may be similar each play distinct and complementary roles in MS management, yet they are often incorrectly treated as interchangeable. When these therapies are reduced or removed, people can deteriorate quickly, resulting in increased support needs and greater long-term cost to the NDIS.

### **NDIS Participant Quote from our LEEP Member Janine:**

“The NDIS needs to understand that MS is a progressive disability, but it progresses differently for every person. There is no single pattern, no predictable timeline, and no standard way the condition unfolds. In addition, the NDIS needs to recognise that MS does not improve over time, it is permanent, and while symptoms may fluctuate, the underlying condition does not get better.

Despite this, NDIS funding decisions are often based on whether a person’s disability will ‘improve.’ This approach doesn’t work for people living with MS. Many therapies are not intended to produce improvement, they are essential to maintain function, prevent decline, or slow disease progression. Removing or reducing these therapies can cause people to deteriorate faster, which ultimately leads to higher support needs and costs.

NDIS plan reviewers also need to understand what each allied health professional actually does. A physiotherapist is not the same as a neurophysiotherapist, and neither of them does the same work as an exercise physiologist. Each profession plays a different role in managing MS, and each one supports a different aspect of function, mobility, strength or symptom management.

Yet participants are often told that these therapies are ‘the same’ and therefore can’t all be funded. This misunderstanding leads to the NDIS making inappropriate plan cuts and removing vital supports that people with MS rely on to stay safe, independent and mobile.”

LEEP members also describe the NDIS system itself as difficult to navigate. The administrative burden of gathering reports, providing evidence, completing forms and coordinating appointments can feel like a part-time job. For people experiencing MS-related cognitive impairment and cognitive fatigue, this workload is not only burdensome but genuinely exhausting, often worsening symptoms. Planning processes must reduce, not intensify, the strain on people already managing a complex neurological condition.

### **NDIS Participant Quote from our LEEP Member Jess:**

“Many of the disability impacts of MS aren’t visible to most people. Symptoms such as fatigue, pain and spasticity may not be obvious from the outside, but they are genuinely disabling and debilitating.

The NDIS needs to understand that providing access to therapies earlier can prevent deterioration and may reduce the amount of funding required in future years. Early intervention is cost effective and protects long term function.

The NDIS also needs to understand how their own system is difficult to navigate. The processes, paperwork and administrative steps are too complex for people experiencing cognitive impairment or cognitive fatigue – both common symptoms of MS. This complexity means people are often forced to rely on family members and informal supports to fill the gaps, which should not be a substitute for proper formal supports.

Funding should be based on a person’s worst day with MS, not their best. This ensures that services are available and accessible when a flare or relapse suddenly increases their needs. Plans must also be flexible and able to be adjusted quickly. Finally, the NDIS needs to value lived experience. Decisions should be collaborative, with participants treated as experts in their own condition.”

In addition, LEEP Member Brigitte reported recently being moved to a NDIS managed plan without explanation and as a result losing control over their choice of exercise physiologist.

### **Case Study: Brigitte**

Brigitte lives with MS and until recently had a self-managed NDIS plan. Through this she has been able to choose a range of flexible supports including an exercise physiologist who is not a registered NDIS provider.

The NDIS moved Brigitte to a NDIS managed plan without notice or explanation. As a result, Brigitte can no longer use her plan to access her regular exercise physiologist who has a comprehensive understanding of her MS needs and who she has built rapport and trust with over many years.

Brigitte lives in a regional area where there is limited access to exercise physiologists and as a result has been unable to find an appropriate one. The resulting impact on Brigitte is that her functional ability has dramatically declined, limiting her independence and ability to undertake daily tasks.

Brigitte is actively engaged in health and disability advocacy and her work in this space is severely limited due to the impact of not having access to an exercise physiologist. This includes not being able to attend MS Australia's national conference as a representative of the LEEP.

Above all, people with MS emphasise the importance of valuing lived experience. Participants should be recognised as experts in their own condition, and planning decisions should reflect their individual symptoms, progression and daily challenges. More NDIA staff with specialised knowledge – or dedicated teams with expertise in neurological conditions – would help ensure more consistent, accurate and appropriate outcomes.

**MS Australia recommends** the NDIA provide appropriate training for NDIS Accessors, Delegates, and decision makers involved in the NDIS new framework planning process that includes:

- Training for NDIS planners and decision makers in evidence-based and participant focused supports.
- Clear guidelines for planners and decision-makers on how to assess and meet the needs of participants with progressive neurological conditions, whose symptoms can fluctuate and unpredictably change.
- New requirements that NDIS planners cannot remove or reduce supports from participants' plan without adequate evidence that it is no longer required or should be reduced and must provide a full explanation to the participant.
- Participants should not be moved to NDIS managed plans without adequate evidence that this is necessary and engagement with the participant regarding the decision.

Please see our responses to the NDIS Proposed New Framework Planning Rules consultation questions below. Our responses draw on the real lived experience of our LEEP members who are currently navigating the NDIS as people with living with MS. Some members have chosen not to share their name as they are concerned about the impact on their individual NDIS plan.

## **Step 1: Preparing for the support needs assessment process**

Thinking about the information the NDIS shared about Step 1: Preparing for the support needs assessment process, is there additional information you think participants should receive during Step 1?

While the consultative paper and rule outlines that participants will be notified by the NDIA and provided a notice of impairments and a notice to have a new framework plan, LEEP member Jodi,

noted that the existing fact sheets and explanatory documents need to be revised to be more user-friendly for participants. Currently the information about the steps involved in the new framework planning process are documents are very technical. The fact sheets and explanatory documents, in this step as well as the other four steps as outlined and are not written to be person-centred for participants to understand the revised process, which may cause some participants to be anxious and confused. LEEP member Rachel has appreciated the NDIS easy read guides previously shared in a variety of formats.

To ensure NDIS plans are person-centred, strengths-based approach, and fairer, participants are asking that the planning process to be more transparent and plans be more flexible. Julie, a member of MS Australia's LEEP shared that

“In addition to the information about preparing for the support needs assessment, it is important to be informed about a rough timeline for when this would occur for the individual, any further information that is required (so the participant has ample opportunity to be prepared for the assessment), as well as if there is the option of a support person to be involved in the assessment process.”

Another member of our LEEP Anne, shared that participants will need “information about why the current plan needs to change, what are the benefits or losses that may be incurred and who decides the impairment.” Another LEEP member shared that participants would like to be informed about what triggered the agency to determine a planning conversation is necessary. LEEP Member Rachel said that “a minimum notice period of at least 12 weeks for plan changes or reviews is essential to properly gather and prepare the increasing number of required reports. The NDIS planning process depends on detailed evidence to secure appropriate supports and without adequate time to prepare supporting documentation, people with neurological conditions risk being dangerously under-supported.”

The proposed rule's documentation does not specify how and what the NDIA will do to determine the type of impairment category or categories for which the participant meets to access to the NDIS and participants deserve to know what is involved. According to the explanatory document, the impairment categories include (a) intellectual; (b) cognitive; (c) neurological; (d) sensory; (e) physical; and/or (f) impairments to which a psychosocial disability is attributable, yet there is a lack of transparency from the NDIA about how the agency determines what category or categories the participant meets.

#### **NDIS Participant Quote from our LEEP Member Rachel:**

“Because MS isn't always well understood by the NDIS, I work hard to make sure I can clearly explain what's happening with my MS. I take detailed notes throughout my plan period so I can track changes and symptoms as they arise. I also make sure I get access to medical reports earlier than I technically need them, even around the mid-point of my plan. This helps me be fully prepared to communicate my needs and demonstrate the real impact of MS on my daily life.”

Regarding the notice to have a new framework planning process, the consultative papers state that participants will have support from the NDIA, but that more details will be shared in the coming months, presumably after the rules and process goes into effect. Feedback as part of the consultative processes only works effectively when the complete information is shared prior to rules going into effect.

**MS Australia recommends** the NDIA develop clear, user-friendly fact sheets and guidance materials to help participants understand the new planning framework and prepare for the support needs assessment. To ensure transparency, participants should be informed in advance about why and how their plans may change, how their impairment will be assessed, how to prepare, expected timelines, and whether they can involve a support person.

## Step 2: The support needs assessment

Thinking about the support needs assessment report requirement to identify a participant's disability support needs, the following additional information is important to include in the report:

- Raw assessment scores (e.g. I-CAN)
- Description of support needs for each I-CAN sub-domain (e.g. walking and moving)
- Other information and evidence used to create the report
- Further information a participant is required to obtain for more specific supports (e.g. quote for a wheelchair)
- Other - If other, please share below.

Members of the LEEP selected all of the options presented to be included in the support needs assessment, including the raw assessment scores (e.g. I-CAN); Description of support needs for each I-CAN sub-domain (e.g. walking and moving); Other information and evidence used to create the report; Further information a participant is required to obtain for more specific supports (e.g. quote for a wheelchair) and our LEEP member Julie shared the following for the other option:

“There should be an opportunity for the participant to specify the supports that are most needed and beneficial to assist in day-to-day life. If the participant or their nominee can clearly indicate through past experiences the best types and frequency of supports, this information is invaluable and should be taken on board by the NDIA Assessors.”

LEEP member Rachel shared that including all of these various aspects for the support needs assessment is important, but it is essential that the support needs assessment remains person-focused. A participant should never be reduced to a collection of test scores or diagnostic outputs. These tools should be used to understand how best to support individuals, not as mechanisms to exclude them from support. Rachel also supports the idea of including an optional participant statement in the support needs assessment report that could include what they would like to achieve, what is going well and what challenges they are currently experiencing, in their own words. All of these provide a comprehensive picture of participants' experience and support needs.

### NDIS Participant Quote from a LEEP Member:

“I have had to regularly spend over \$1,200 to prove to the NDIS why I need occupational therapy supports in my plan. Every time a planner changes or delays the process, I'm expected to pay for new assessments just to explain the same needs all over again.”

Another member of the LEEP, as well as Rachel, also expressed serious concern of the support needs assessment being automated, including the I-CAN tool. Full transparency of how the tool will be used by NDIA Assessors will be essential. As part of the process participants should receive their raw scores and a clear explanation of how these scores impact their NDIS plan budgets.

Equally, our Member Organisations have expressed several concerns with the inclusion of the raw assessment scores (e.g. I-CAN), noting that it isn't clear that the I-CAN is suitable for all disabilities and are concerned that the tool will not adequately capture the needs for participants with MS and other degenerative neurological conditions. While the NDIA has shared that this version of the I-CAN tool will be a shorter version that is completed in up to 3 hours, the original I-CAN assessment took a lot longer, and so again there are strong concerns that the I-CAN assessment will not adequately capture the needs of participants living with MS and/or other degenerative neurological conditions. Given the degenerative nature of the conditions our Member Organisations support they are unclear whether there will be the ability and capacity to redo this assessment quickly when a participant needs more support.

In addition, our Member Organisations have grave concerns there will not be the workforce to do the assessment process in a timely manner and people that are in dire need of package review will wait without the supports they need. The NDIA needs to clarify how the agency plans to recruit the NDIA Assessors, as our Member Organisations are concerned this will create workforce wage inflation as this becomes another body recruiting for the same/similar skills as other government departments, health services, and providers.

Our Member Organisations are worried that the outcome of this support needs assessment will include automation to create an NDIS plan using an AI (or similar) solution and the fear is that a human will not be involved in the new framework planning process for participants to address their needs.

Again, MS Australia has heard from multiple NDIS participants living with MS that the NDIA does not understand MS. The proposed language notes the NDIA Assessor will check the information discussed with the participants, prior to creating the support assessment report. Consistent with what the disability sector shared in the “what we’ve heard” report<sup>1</sup>, participants and their nominees should have the opportunity to review the draft support needs assessment report and provided an opportunity to provide feedback and corrections before the report is shared with the NDIA Delegate. Including an additional step in the support needs assessment process that includes the participant reviewing and having the opportunity to provide feedback on the draft support needs assessment report could prevent issues or the need for participants to go through the replacement needs assessment if the participant identifies potential issues within the written report, before the report is provided to the NDIA Delegate.

**MS Australia recommends** the NDIA include the following in the support needs assessment process to and the support needs assessment report:

- Include a broad range of information, prioritising the participant's lived experience, their views on the supports most beneficial for managing their condition, raw assessment scores (e.g., I-CAN), and any supporting reports, while ensuring the participant's goals and articulated support needs are meaningfully incorporated into the support needs assessment.
- Ensure assessment tools accurately capture needs related to MS and other degenerative conditions and take into consideration reports and participant statements.
- Prevent NDIS Assessors from relying on raw I-CAN scores alone, ensure this tool is not automated, and provide participants their raw scores and a clear explanation of how these scores impact their NDIS plan budgets.
- Provide details on how the NDIA assessor workforce will be recruited and trained.
- Provide training on MS and other complex degenerative conditions to NSID Assessors and NDIS Delegates.
- Include a step to allow the participant and their nominees to review and provide feedback on the draft support needs assessment report before the report is finalised and shared with the NDIA Delegate.

Thinking about the proposed idea that a replacement needs assessment may be undertaken before a plan is approved. In what circumstances do you think a replacement support needs assessment could be considered?

There could be several circumstances for the need for a replacement needs assessment to be undertaken before an NDIS plan is approved. The following quotes from NDIS participants who are also our LEEP members noting situations where it could be valuable for NDIS Assessors to consider a replacement support needs assessment:

### **NDIS Participant Quote from our LEEP Member Jodi:**

“Where the support needs assessment report is factually incorrect or where the participant feels that their needs are not accurately captured either because things were not discussed at the assessment meeting or they have been interpreted incorrectly.”

### **NDIS Participant Quote from our LEEP Member Anne:**

“With a progressive illness the symptoms are changing constantly so this person might need reviewing constantly unless they are given the worst case out come from the start. Some people will not ask for help until they need it, so when they apply for help, they should not need to wait for 12 months to get it.”

### **NDIS Participant Quote from our LEEP Member Julie:**

“A replacement support needs assessment could be considered if the participant or their nominee believes the initial assessment report is inaccurate or there is more information that should be considered.”

### **NDIS Participant Quote from our LEEP Member Rachel:**

“A replacement support needs assessment could be considered when situations do not require a plan review. For instance, I recently purchased two pairs of shoes recommended by my podiatrist to support my MS-related gait issues. They were zip-up shoes designed for easy on/off, with removable soles to accommodate AFOs and orthotics, features chosen specifically for my mobility needs. Despite having available funds, the NDIS rejected the purchase because the shoes were considered ‘too fashionable’ and I was told that I would need a full plan review to access them without removing existing podiatry supports.”

The consultative paper notes that a replacement assessment can only be requested before a plan is approved and that the NDIA Delegates will make the decisions on whether or not to undertake a replacement assessment or not and that there will be rules clarifying what the NDIA Delegate must consider when deciding if a replacement needs assessment should be completed. The proposed approach places decision-making solely with NDIA Delegates, despite Delegates not being involved in either the support needs assessment itself. This structure is counter-intuitive and risks reducing transparency.

**MS Australia recommends** the NDIS Assessor, not the NDIS Delegate, be involved in both the support needs assessment and the replacement needs assessment, prior to a plan being created by the NDIS Delegate.

### **Is there anything else you would like us to consider for the support needs assessment rules?**

MS Australia supports the proposed idea that a replacement needs assessment be undertaken prior to a NDIS plan being created with the NDIA Assessor, not the NDIA Delegate. This framework planning process should not require NDIS participants to apply and participate in the current replacement support application process. Again, NDIA Assessors should be required to provide NDIS participants a copy of their draft support needs assessment report and an opportunity for discussion if the participant believes the support needs assessment may require a replacement assessment and that can occur prior to the report being sent to the NDIA Delegate before a plan is created.

Our LEEP member Jodi also mentioned how there is still needs to be “opportunities for the participant to review and correct the support needs assessment when it is at the Assessor level and before it goes to the Delegate and needs to have a formal reassessment process applied.” Similarly, LEEP member Julie emphasized that “the NDIA needs to consider that each participant will have very specific and individualized needs. The supports are definitely not a one-size-fits-all solution. To this end it is so important to really listen to the participants' input and make a plan that will be highly beneficial and include supports that are not only value for money but are 100% the best supports for the participant.”

**MS Australia recommends** the NDIA provide clear details on how replacement needs assessments will operate, including when they can be requested, what the assessment process involves, and how decisions will be made, prior to these rules being implemented.

### Step 3: Building a plan

#### Do you have any concerns or questions about the examples of the types of stated supports?

The NDIA could provide greater clarity and guidance around the assistive technology supports, as the language in the explanatory document currently states “precise language and description of this category may evolve to ensure consistency with other NDIS rules currently under development”.<sup>2</sup> One of our LEEP members, Anne, noted how it’s unclear whether the list will increase as there’s so many supports that could be identified as stated supports. In addition, LEEP member Jodi shared concerns that for “assistive technology assets it depends how prescriptive the state support is. If it is for a general category of assistive technology, that could be okay, but if it locks the participant into a particular item or cost then that may greatly limit flexibility once the participant trials items or explore solutions.”

#### How should the budget method rules reflect the informal supports available to a participant?

The NDIA should exclude informal supports within the budget method rules for the proposed new planning framework and should fully fund plan budgets without assuming unpaid care is available. Expecting family, friends, and other community connections to provide ongoing support as a default places unreasonable pressure on households, contributes to burnout, reduces wellbeing, and undermines their workforce participation. NDIS plans must be created on assessed need, not on assumed availability of unpaid labour. Formal supports should be fully funded to ensure participant safety, sustainable support arrangements, and long-term efficiency.

#### **NDIS Participant Quote from LEEP Member Julie:**

“Informal supports are really important and valued by participants, however these are not always available. Carers often burn out, have jobs, family and other commitments. The budget method rules should reflect that not every participant has the same level of informal support, and also ensure supports are available to assist the informal support person and their sustainability to continue to provide informal support into the future.”

LEEP members with NDIS plans consistently note that relying on unpaid care leads to carer burnout, undermines wellbeing, removes carers from the workforce, and is neither sustainable nor equitable. Treating informal supports as a predetermined expectation risks placing inappropriate pressure on families and friends who most likely have limited capacity to provide care. Formal supports must be funded on the basis of need, not on assumptions about unpaid care.

If the NDIS budget method rules are required to include informal supports, they should only be acknowledged as optional contribution. The NDIS should recognise that carers, including family and friends, often juggle jobs, children, ageing parents, and health needs of their own. Assuming family, friends, and other community connections can fill gaps as informal supports often reduced formal support received in NDIS plans and can unfairly burden carers and shifts costs rather than saving them.

Informal supports should not influence decisions about funding periods or reductions in funded supports such as transport, shared tasks, or personal care. LEEP members have shared that they have experienced reductions in their plans supports simply because they had a partner or family member who could “help,” even though this creates additional economic and emotional strain.

Informal supports should not be included in NDIS plan budgeting decisions. Participants and their service providers, not family members, are best placed to advise on appropriate support needs. Any consideration of informal supports must recognise capacity limits, sustainability, and the long-term toll on relationships.

**MS Australia recommends** that the NDIA should not include informal supports in the budget method rules as informal supports cannot be assumed, treated as guaranteed for participants and therefore should not be used to justify reduced plan budgets and must not replace professional supports or drive budget decisions.

### Is there anything else you would like us to consider in rules about building a new framework plan?

The NDIA should provide participants and their nominees with clearer, more direct communication throughout the NDIS planning process. LEEP member Rachel noted that information is currently passed between too many people, leading to confusion, double-handling, and plans that do not reflect earlier conversations. She stressed the longstanding need for participants to review a draft plan before finalisation so errors can be corrected early.

LEEP members also raised concerns regarding how the new framework will serve people with progressive neurological conditions. NDIS plans should reflect a participant's worst day to ensure adequate support during MS relapse or sudden decline. This is particularly critical in rural and regional areas where provider options are limited, and the only practical services may not fit standard NDIS categories. When funding rules are too rigid, participants may be left unable to access necessary supports even when funding is available in their plan.

#### **NDIS Participant Quote from a LEEP Member Kate:**

“MS is unpredictable, highly individual, and affects people in very different ways. MS is a new adventure every day, and the disease course varies widely from person to person. Because of this, applying blanket funding rules or rigid service access criteria simply doesn't work for participants living with MS.

People in rural and regional areas also need flexibility to access services and therapies in ways that might fall outside the NDIA's usual 'approved' definitions. Participants living outside major cities often have limited provider options, and sometimes the only viable therapy or support doesn't fit neatly within standard categories. Without flexibility, people may be unable to access an approved support which could deny them the service they require and might leave them with funding they can't actually use.

It is also important that LACs who work with people living with MS understand what the condition looks like day-to-day. MS can change quickly and can involve a mix of fatigue, pain, cognitive challenges, mobility issues and relapses. Without that understanding, the impact is often underestimated. Training every LAC in every condition may not be realistic, but having dedicated teams who specialise in certain conditions, like neurological conditions, would help ensure more informed, appropriate, and consistent support.”

Our LEEP Member Anne highlighted that when capital building supports are requested, participants should have the option to choose a different provider, even if the participants cover any additional cost themselves, to ensure flexibility and respect for participant choice.

Similarly, LEEP member Julie shared that it is important the NDIA recognises that support need assessments and NDIS plan decisions must remain highly individualised, not based on blanket assumptions about particular disabilities, and that participants or nominees are often best positioned to explain what supports are needed.

**MS Australia recommends** that the NDIA rules related to plan variations be shared as part of step 3, to building the plan, in the case that the plan might need to change, instead of step 4 when the plan is finalised and implemented.

## Step 4: Using a plan

Thinking about the information above, is there additional information you think participants should receive during Step 4 to use their plan effectively?

Our LEEP members have highlighted ongoing uncertainty about what information participants will receive and what information they will be expected to provide. LEEP member Rachel noted that without clarity on these details, it is difficult for participants to prepare. She also reported that while her last plan explained changes better, communication remains inconsistent, sometimes she receives updates, other times she hears nothing after contacting the NDIA. She stressed the importance of speaking directly with the NDIA Delegate and being able to adjust the plan when circumstances change, but noted this depends heavily on NDIA staffing and has not previously been reliably delivered.

Whereas LEEP member Jodi questioned the process for adjusting funding periods or restrictions when a participant's capacity changes over time. She noted that such changes would not be covered by the current proposed rules and should not require a new assessment, leaving a gap in the proposed framework.

LEEP member Julie added that participants could benefit from an implementation meeting that clearly links their budget to their needs assessment, helping them understand how their funded supports relate to the evidence provided. Lastly LEEP member Anne suggested the NDIA should establish a dedicated hotline so participants can seek help or clarification at any point in the planning process.

**MS Australia recommends** the NDIA establish various methods of providing participants with clear, consistent communication throughout the planning process, ensuring various opportunities for participants to have the option to speak directly with the NDIS Accessor and NDIS Delegate, before their plan is finalised so changes can be discussed early and share how a participant's budget aligns with their needs assessment.

## Additional Questions

What is your preferred way for us to provide information about the new rules to support participants, families and carers?

- Factsheets
- Online forums (webinars)
- Online videos
- Website updates
- Social media updates
- Other - If other, please list below. (Small text box)

LEEP members strongly prefer information about the new rules in clear, easy-to-read factsheets, but also value having the rule content available in multiple accessible formats.

Do you have any other feedback, suggestions or questions about the new framework planning process?

MS Australia also is concerned why the NDIA is not consulting on all aspects of the new planning framework rules. The consultation paper indicates that additional information, particularly about budgets, will be published later. This lack of clarity represents a major gap, as meaningful consultation cannot occur when the agency does not make all of the aspects of the planning framework process available before implementation.

**MS Australia recommends** the NDIA should provide all information about the new planning framework in clear, plain, user-friendly language. A single, succinct guide that consolidates all steps and explanatory materials is needed, as the current information is difficult to understand and fragmented across multiple resources.

## Reference

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<sup>1</sup> Australian Department of Health, Disability and Ageing (13 January 2026). *NDIS new framework planning: what we've heard summary report*, retrieved 10 February 2026 from <https://www.health.gov.au/resources/publications/ndis-new-framework-planning-what-we-heard-summary-report>.

<sup>2</sup> Australian Department of Health (23 January 2026). *Draft National Disability Insurance Scheme (Getting the NDIS Back on Track No. 1) (Stated Supports) Transitional Rules*, retrieved 23 February 2026 from [https://consultations.health.gov.au/ndis/nfp-public-consultation/user\\_uploads/explanatory-document---stated-supports-1.pdf](https://consultations.health.gov.au/ndis/nfp-public-consultation/user_uploads/explanatory-document---stated-supports-1.pdf).



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