

Pricing Authority

November 2024



What is MS?

Multiple Sclerosis (MS) is the most acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 33,300 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

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.

Associate Professor Des Graham President

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NDIS Pricing Reform

MS Australia welcomes the opportunity to provide a submission to the Independent Health and Aged Care Pricing Authority - NDIS Pricing Reform consultation. Over the past nine years, MS Australia has actively advocated on behalf of people living with MS for improvements to the NDIS.

This submission draws on the experiences and expertise of MS Australia's <u>Lived Experience Expert Panel</u> (LEEP) and our state and territory <u>Member Organisations</u>. 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 Member 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 Recommendations

- Implement greater transparency in how pricing decisions are made, including detailed explanations of how individual costs are calculated and how participant funding decisions are reached
- Implement improvements to NDIS pricing including:
 - Regular plan reviews for participants with progressive conditions like MS, allowing for seamless adjustments to their funding as their needs change
 - Introduce tiered pricing that differentiates based on the qualifications and experience of support workers, similar to pricing structures in other professions
 - Adjust pricing policies to remove travel caps in rural and remote areas, allowing providers to charge for actual travel costs
 - Implement mandatory, comprehensive training for Local Area Coordinators (LACs) and Support Coordinators on NDIS funding inclusions, exclusions, and service options
 - Enable participants to use their NDIS funds more flexibly, allowing for creative, practical choices in service delivery that meet their unique needs and preferences
- The NDIS review support coordination and plan management to ensure that:
 - NDIS plans include the appropriate number of support coordination and plan management hours to meet participants needs and allow for associated administrative, problem solving and compliance work
 - Pricing takes into consideration the actual costs of hiring staff under the SCHADS Industry Award
 - Pricing is indexed annually and incorporates increases in the cost of living
- Implement outcome-based pricing for services like therapy and blended payment models for complex needs, where participants require both high upfront costs (e.g., assistive technology) and ongoing support
- Encourage ongoing professional development for support workers by offering incentives for providers that invest in worker training and career progression

- Review the pricing for therapy supports including:
 - A separately funded category for allied health travel costs including an allied health travel budget for participants
 - Remove travel caps for services provided in MMM4 & MMM5 regions and allowing the actual cost of travel to be charged
 - Adjust therapy support pricing to align with current wage increases in allied health industries, ensuring consistency across regions like Western Australia, South Australia, Tasmania, and the Northern Territory
- Allow participants greater flexibility in how they spend their allocated funds to better suit their evolving needs

These recommendations aim to create a flexible, participant-focused, and sustainable pricing model for the NDIS, ensuring that both participants and providers benefit from a system that reflects real costs while encouraging innovation and quality service delivery.

What should be the purpose and guiding principles of NDIS pricing?

The purpose of NDIS pricing should be to provide fair, reasonable and transparent pricing guidelines for participants and service providers. And in doing so, create a system that provides equitable, sustainable and person-centered supports. This system must be flexible enough to accommodate the diverse needs of NDIS participants, particularly for individuals living with progressive neurological conditions like MS. Many MS Australia LEEP members report that current pricing models are too rigid, resulting in services that fail to meet their evolving needs.

The NDIS pricing system must also ensure that providers are fairly compensated for their services, particularly when delivering complex and high-quality care. This balance between participant empowerment and provider sustainability should be the primary purpose of NDIS pricing, ensuring that the scheme remains accessible, effective, and sustainable for all involved.

What could be done to make NDIS pricing more transparent?

Transparency in NDIS pricing must extend beyond the publication of a price list. MS Australia's LEEP members expressed frustration with the lack of clarity regarding how pricing decisions are made and the criteria used to approve or deny services.

An open, step-by-step guide to how pricing decisions are made, what criteria are used, and who is responsible for approving or denying requests would significantly improve trust in the system.

To enhance transparency, NDIS pricing processes should involve:

- Clear communication and education for participants on how pricing decisions are made, using plain language and providing examples rather than relying on technical jargon.
- Providing detailed explanations of how specific costs are calculated, including travel, administrative work, and service complexity. For instance, a breakdown of how therapy costs are determined in remote versus urban areas would be useful to both participants and providers.
- Real-time access to invoices and expenditure tracking for participants, enabling them to have greater oversight of their NDIS plans. This would prevent situations where providers inflate charges because the participant is on a NDIS package.

MS Australia recommends implementing greater transparency in how pricing decisions are made, including detailed explanations of how individual costs are calculated and how participant funding decisions are reached.

What improvements could be made to NDIS pricing?

Several changes are essential to improve NDIS pricing and ensure that the system works effectively for both participants and providers:

- **Flexibility in service delivery:** Participants need the ability to use their funding in more creative and flexible ways. Current rigid service structures often limit participants' ability to make practical decisions about their own care.
- Improved training for Coordinators: Increased education and training for Local Area Coordinators (LACs) and Support Coordinators is critical to ensure participants are well-informed about NDIS funding inclusions and exclusions. Clearer guidance from knowledgeable coordinators would empower participants to make informed decisions and avoid confusion regarding their plans. Enhanced training would promote transparency, reduce misunderstandings, and ultimately lead to more effective, participant-centered support.
- Customisation for progressive conditions: The pricing structure should account for the changing nature of disabilities. Participants living with progressive conditions like MS experience shifting needs over time. The NDIS pricing model should allow for regular plan reviews and easy plan adjustments that enable participants to access services that reflect their current condition without bureaucratic delays. For instance, one LEEP member explained how her NDIS plan covered several therapy sessions that eventually became unnecessary as her condition progressed, but she was unable to reallocate those funds toward more suitable supports like assistive technology.
- Experience-based pricing for support workers: The current system does not account for differences in support worker qualifications. Certificate III qualified workers, who can often obtain their qualifications online without direct experience, are priced similarly to more experienced workers, creating inconsistencies in the quality of care. Introducing tiered pricing based on support worker experience and qualifications would incentivise providers to employ skilled workers, improving the overall standard of care. The current "wedding tax" arrangement where everyone charges the upper price limit regardless of their experience and expertise is not sustainable.
- Travel costs for rural and remote services: Many participants in rural areas experience significant barriers to accessing services due to inadequate travel cost coverage. Current travel caps do not reflect the true costs of service delivery in regions like Tasmania or remote parts of Western Australia. Removing these caps and allowing providers to charge for actual travel costs would improve service delivery to these underserved areas.

MS Australia recommends improvements to NDIS pricing including:

- o Implementing regular plan reviews for participants with progressive conditions like MS, allowing for seamless adjustments to their funding as their needs change.
- o Introducing tiered pricing that differentiates based on the qualifications and experience of support workers, similar to pricing structures in other professions
- Adjusting pricing policies to remove travel caps in rural and remote areas, allowing providers to charge for actual travel costs. This will increase access to quality services for participants in underserved regions, like Tasmania and remote Western Australia.
- o Implement mandatory, comprehensive training for Local Area Coordinators (LACs) and Support Coordinators on NDIS funding inclusions, exclusions, and service options.
- o Enable participants to use their NDIS funds more flexibly, allowing for creative, practical choices in service delivery that meet their unique needs and preferences.

Is the current NDIS pricing approach affecting long-term provider sustainability?

MS Australia believes that the current NDIS pricing model is negatively impacting provider sustainability, particularly for smaller providers and those operating in rural areas. For example, MS Australia's LEEP members have reported that many providers in Tasmania, are struggling to stay afloat under the existing pricing framework. Several providers have been forced to reduce services or close entirely because the cost of delivering services exceeds the prices set by the NDIS.

Feedback from MS Australia Member Organisations is that the delivery of both support coordination and plan management services involves many additional unfunded staffing hours. The coordination of services and management of plans take substantially more time than current NDIS pricing allows for. Providers are also incurring unpaid administrative costs, which further affect their sustainability. Support coordinators and plan managers often spend countless hours advocating for participants, resolving payment issues, and navigating the NDIA's bureaucratic processes. These tasks that are not compensated under the current pricing model. If these trends continue, the long-term viability of many service providers is at risk, ultimately leaving participants without adequate support.

Our Member Organisations advise that the salaries for staff delivering support coordination have been steadily rising over the last few years, with no increase in the relevant pricing to match this. An example of the increased costs of support coordination for one of our Member Organisations is below:

Example

MS Plus provides service to people living with MS in NSW, ACT, Victoria and Tasmania

Salaries for Support Coordination increased by 4.6% in 2022-23, with no indexation, followed by a 5.75% increase in the current financial year 2023-24, also without indexation. At the same time minimum Award increases for staff have seen salaries rise at 8% over the same period.

The Support Coordination services continue to run at a loss that is funded by MS Plus

To address this, NDIS pricing must be adjusted to reflect real operational costs, including administrative work, training, and travel. This would help providers maintain financial viability while continuing to deliver essential services to participants.

MS Australia recommends a review of support coordination and plan management pricing to ensure that:

- NDIS plans include the appropriate number of support coordination and plan management hours to meet participants' needs and allow for associated administrative, problem solving and compliance work
- Pricing takes into consideration the actual costs of hiring staff under the SCHADS Industry Award
- o Pricing is indexed annually and incorporates increases in the cost of living.

What supports and services could benefit from different approaches to NDIS pricing?

Several services could benefit from more flexible or innovative pricing approaches:

- Fee-for-service models: For certain services, such as transportation or household assistance, a fee-for-service model could offer greater flexibility and cost savings. For example, one LEEP member found that hiring a support worker to wash her car was less effective and more expensive than simply using a professional car wash service. Allowing participants to use their funds for more cost-effective options like these would promote greater autonomy and value for money.
- **Outcome-based pricing:** This approach could work well for services like therapy, where the goal is to improve participant outcomes over time. By tying payments to specific outcomes, such as improved mobility or independence, this model could incentivise providers to focus on delivering high-quality, outcome-driven care. This approach would not be suitable for most participants living with a progressive disease such as MS.
- **Blended payments:** For participants with complex needs, particularly those living with progressive conditions like MS, blended payments could provide a more flexible and tailored approach. For instance, blended payments could allow participants to access services with higher upfront costs, such as assistive technology, while also covering the ongoing maintenance and support costs that follow.

MS Australia recommends the implementation of fee-for service models for certain services like transport or household assistance, outcome-based pricing for services like therapy and blended payment models for complex needs, where participants require both high upfront costs (e.g. assistive technology) and ongoing support.

How could NDIS pricing best enable participants to access quality supports and services?

NDIS pricing should prioritise participant choice and control by offering more customisable support options. As highlighted by one LEEP member, many participants prefer to manage their own support in ways that make sense for their lifestyle, such as using Uber Assist for transportation or employing household services through platforms like Airtasker. By providing participants with the flexibility to choose cost-effective services, the NDIS could enable more personalised and higher-quality care.

An MS Australia LEEP member who self-manages her NDIS plan outlined how she avoids telling providers that she is on a NDIS package to ensure she is charged fairly for services. She has changed providers previously due to a lack of transparency around pricing, a disability bed provider wanted to send the invoice straight to the NDIA without quoting a price, insisting that this was standard practice.

Pricing should also encourage providers to deliver services that align with participant goals. For example, offering incentives for providers who meet specific quality benchmarks or who help participants achieve key milestones would raise the standard of care and ensure that participants are receiving supports that genuinely improve their quality of life.

MS Australia recommends encouraging ongoing professional development for support workers by offering incentives for providers that invest in worker training and career progression.

What could be done with NDIS pricing to help participants better meet their goals?

The current pricing system should be restructured to give participants greater flexibility in how they allocate their funds to meet their personal goals. Many participants report feeling frustrated by the limitations placed on how they can use their funds. By allowing for flexible spending options, such as reassigning funds from one service to another as needs evolve, participants would be empowered to make decisions that align with their immediate and long-term goals.

Additionally, regular plan reviews should be built into the pricing structure to ensure participants' needs are being met as their conditions change. For people with progressive conditions like MS, the ability to adjust plans and funding allocations as their disability progresses is crucial to maintaining independence and achieving personal goals.

How could NDIS pricing best reflect the true cost of delivering NDIS services?

NDIS pricing should account for the true and varying costs of service delivery. This includes recognising the unique challenges faced by providers in rural and remote areas, where travel costs, workforce shortages, and operational expenses are significantly higher than in urban centres.

As allied health supports are often delivered face-to-face, travel costs take up a significant portion of the costs associated with delivering these supports. As a result, a substantial portion of the approved hours in a participant's plan may be used for travel costs instead of therapy supports. Introducing a separate category for allied health travel would enable allied health professionals to travel to participants without using therapy support funding. Participants would have a separate therapy budget allocation in their plan. Delivering therapy support to clients in rural and remote locations attracts considerable travel costs that are not met by the current pricing. Given these increased and unpredictable costs, the NDIS pricing should allow providers to charge the actual cost of travel.

Providers should also be compensated for unpaid administrative tasks, which are currently overlooked in the pricing model. As one LEEP member pointed out, the process of navigating the NDIA's systems and resolving claims issues often requires additional hours of unpaid work by support coordinators and plan managers. Reflecting these behind-the-scenes costs in the pricing model would ensure that providers are fairly reimbursed for all aspects of service delivery.

MS Australia recommends a review of the pricing for therapy supports including:

- o A separately funded category for allied health travel costs including an allied health travel budget for participants
- o Removing travel caps for services provided in MMM4 & MMM5 regions and allowing the actual cost of travel to be charged
- Adjust therapy support pricing to align with current wage increases in allied health industries, ensuring consistency across regions like Western Australia, South Australia, Tasmania, and the Northern Territory.

How could NDIS pricing best support a capable, stable workforce for the NDIS?

To support a capable, stable NDIS workforce, pricing must offer competitive wages and encourage ongoing professional development. Pricing structures should reflect service complexity and intensity to manage workloads effectively, reducing staff turnover and promoting continuity of care. Introducing tiered registration levels with incentives, like mentoring and training programs, would improve skill levels.

Pricing could also differentiate by experience, allowing qualified, experienced workers to earn higher rates, similar to career structures in other industries such as hairdressing. Certificate III qualifications alone are insufficient; on-the-job training and a mentorship system would enhance service quality, ensuring workers meet participant needs and reduce reliance on family members

How could NDIS pricing foster innovation in service delivery?

NDIS pricing could foster innovation by providing incentives for providers who implement creative, cost-effective solutions that improve participant autonomy and satisfaction. Encouraging knowledge sharing and collaboration between providers could lead to more adaptable service options. Simplifying plan management processes and enhancing training for plan managers would also promote flexibility and encourage participants to self-manage, reducing overall costs and improving outcomes.

Case Study – Tabitha*, lives in a regional town in NSW

Tabitha, a member of MS Australia's Living Experience Expert Panel (LEEP), lives with multiple sclerosis (MS), a progressive condition that requires her to continually adapt her care plan. Initially, Tabitha's NDIS plan provided her with access to various therapy services. However, the rigid pricing structure made it challenging to adjust her supports as her health needs evolved, often forcing her to navigate between multiple services and piece together ad-hoc solutions.

Tabitha has found creative ways to manage her care efficiently. For example, she frequently travels to Sydney, which is a 1.5-hour drive from her home, for appointments. Rather than hiring a disability support worker to drive her and wait during appointments—a costly and inefficient solution—she books Uber Assist, which accommodates her mobility needs at a much lower cost. The savings from using Uber Assist enable Tabitha to allocate her NDIS funds toward other essential supports. With these savings, she can book a support worker each day to assist with tasks like showering, ensuring she has consistent, practical support throughout the week.

Similarly, Tabitha uses platforms like Airtasker for specific household tasks that her support workers aren't skilled in, such as furniture assembly. This tailored approach allows her to make the most of her NDIS funding and receive support better suited to her needs. Her case highlights how more flexible, innovative pricing within the NDIS could empower participants like Tabitha to manage their care effectively, reduce costs, and increase her independence.

*Name has been changed

What data do you think is most important to consider when pricing NDIS services?

The most critical data for pricing NDIS services includes award rates, time of day, and days of the week to ensure fair compensation across varying schedules. Pricing should also account for the intensity and complexity of support provided, standard tasks within each service type, and geographic location, reflecting the real costs of delivery. Additionally, metrics on service availability, sustainability, quality, and continuity are essential to align pricing with participants' evolving needs and ensure long-term access to quality care.

