NDIS ANNUAL PRICING REVIEW SUBMISSION 2025–26

Executive Summary

The MJD Foundation welcomes the opportunity to contribute to the 2025–26 NDIS Annual Pricing Review. As a specialist provider supporting Aboriginal and Torres Strait Islander families living with the progressive neurological conditions MJD and SCA7, we operate in some of Australia's most remote and culturally complex environments. Our submission highlights the profound mismatch between current NDIS pricing structures and the real cost of delivering safe, high-quality, culturally grounded disability supports in these settings.

We outline five key challenges:

1. **Unfunded compliance and quality requirements**
   The administrative burden placed on providers has increased substantially, yet current pricing does not recognise the distributed compliance workload across our workforce, the cultural complexity of obtaining evidence, or the additional time required to meet quality and compliance expectations in remote communities.

2. **Lack of recognition of cultural safety costs**
   Culturally safe practice is not optional. Our "Our Way" two-worker model — pairing Aboriginal Community Workers with non-Aboriginal clinicians — is essential for safe, effective service delivery, yet largely unfunded. Translation, cultural brokerage, kinship navigation, and relational engagement underpin service quality but fall entirely outside NDIS pricing logic.

3. **Pricing that fails to reflect remote delivery realities**
   Uniform NDIS prices do not consider the significantly higher costs of travel, staffing, accommodation, vehicle use, and supply chains in remote communities. Providers absorb substantial unfunded costs when NDIS plans cannot meet these expenses, including funding and repairing essential mobility equipment when the system cannot respond fast enough to disease progression.

4. **Payment mechanisms that undermine quality and sustainability**
   Hourly pricing cannot fund supervision, professional development, audit preparation, or the cultural work required to keep participants engaged and safe. Group supports and On-Country programs provide great value but are poorly supported by existing rules. Meanwhile, our organisation faces a projected $400,000 deficit due to underfunded work and declining grant availability.

5. **Weak market stewardship in thin markets**
   In many communities, the MJD Foundation is the only consistent provider. Without proactive stewardship and pricing that reflects baseline operational capacity, essential remote services risk further erosion, leaving families with limited or no access to safe supports.

To address these issues, the MJD Foundation calls for:

- **Cost-neutral differentiated pricing** that recognises the true cost of cultural safety, complexity, and remote delivery
- **Alternative funding models**, including blended or block funding, to support flexible, culturally grounded practice
- **Independent pricing through IHACPA** that genuinely reflects remote and cultural cost drivers
- **Stronger market stewardship** to maintain access and continuity in thin markets

With appropriate pricing reform, the NDIS can better uphold its commitment to equity and ensure that Aboriginal families living with MJD and SCA7 receive the safe, culturally legitimate and clinically strong supports they deserve. The MJD Foundation stands ready to work with the NDIA and IHACPA to design a pricing system that reflects the real cost — and real value — of delivering disability services in remote Aboriginal communities.

Who is MJD Foundation

The MJD Foundation is a national leader in supporting Aboriginal and Torres Strait Islander families living with Machado-Joseph Disease (MJD) and Spinocerebellar Ataxia 7 (SCA7) — two rare, inherited neurological conditions that cause progressive loss of mobility, coordination, and independence.

What makes the MJD Foundation unique is our "Our Way" approach — a culturally grounded, two-way model that embeds Aboriginal Community Workers at the heart of our work. This ensures services are not only clinically effective, but delivered with cultural safety, family leadership, and enduring trust.

We provide specialist, place-based support in some of Australia's most remote regions, where few others operate. Our value lies in our ability to walk alongside families over generations, provide long-term holistic support that honours cultural priorities and community context, and combine clinical and genetic expertise with Aboriginal knowledge and lived experience.

Our embedded Aboriginal Community Workforce is essential to delivering services in a culturally safe and meaningful way. We navigate complex systems — including the NDIS and mainstream health services — acting as a trusted bridge for families in remote communities who face significant access and equity barriers.

We partner with families to co-design supports and resources grounded in culture, language, kinship and Country, while driving systems change through research, advocacy and sector leadership. In everything we do, we are guided by our families, and by the belief that people living with MJD and SCA7 have the right to live with dignity, choice, connection and strength — their way.

The Real Cost of Quality and Compliance for Registered Providers

As a registered NDIS provider operating in some of Australia's most remote and culturally complex service environments, the MJD Foundation carries significant compliance, quality and safeguarding costs that are inadequately recognised in current NDIS price limits.

Compliance, Quality and Governance – Distributed Workload, Significant Cost

The MJD Foundation does not have a dedicated quality or compliance role. Instead, these responsibilities are distributed across the organisation, including among staff who are primarily employed to deliver clinical or community support. This results in substantial unfunded labour across multiple levels of the workforce.

Based on internal estimates:

- Senior client-facing staff spend approximately 5–10% of their time meeting compliance and evidence requirements, representing $55,787–$111,574 per annum in labour cost.
- The Executive and Senior Management teams dedicate 20–30% of their time to quality, safeguarding, audits and registration requirements, equating to $121,220–$181,830 per annum.
- Software and systems needed for evidence collection, record-keeping, reporting and governance cost approximately $25,000 per year and the cost of staying connected (phone and internet) in remote communities across multiple locations is approximately $50,000 per year.

While non-billable time has increased, we do not have formal quantitative data to evidence this. However, the rise is most likely linked to the need for higher levels or new types of documentation and payment-integrity evidence — particularly in cross-cultural remote settings, where these tasks require significantly more time and effort.

Compliance Challenges in Remote Aboriginal Community Contexts

Remote contexts exacerbate compliance burden in ways not reflected in the NDIS pricing model:

- Requests for evidence often require multiple attempts because services such as health, allied health and assessments are limited or irregular in remote communities. This can result in:
    - delayed plan reviews
    - insufficient plans being rolled over without proper reassessment
- NDIS rules are complex, technical and highly Western in concept, making translation into Aboriginal languages and worldview extremely time-consuming and unfunded.
- Many clients do not value or understand the administrative requirements of the Scheme, meaning obtaining signed documents or formal consents is culturally incompatible and frequently unsuccessful — complicating audit preparation and increasing non-billable effort.
- Staff may have to return to the same community or home three times to achieve a single medical appointment, due to cultural obligations, competing priorities, weather, transport access or Sorry Business — none of which are recognised in pricing.

The Unfunded Cost of Cultural Safety Through Aboriginal Community Workers

The MJD Foundation currently employs 19 Aboriginal Community Workers (ACWs) across its regions. These roles are essential to delivering culturally safe and clinically effective services, yet most ACW positions are not funded through NDIS plans. This is because:

- ACWs work side-by-side with non-Aboriginal workers to support cultural safety, translation, community navigation, trust-building and family-led practice — functions not priced or recognised in the NDIS support catalogue despite the scheme's orientation to 'choice and control', which are both underpinned by effective communication.
- Plans do not contain sufficient funding to cover the real cost of two-worker models required for safety and cultural integrity.
- The organisation avoids charging standard cancellation fees because plans cannot sustain them, resulting in further lost revenue and absorbed cost.

ACWs also require:

- Clinical supervision by non-Aboriginal staff, adding additional unfunded time
- assistance with administrative tasks such as timesheets, leave, rostering and shift notes
- support to navigate digital systems, which often requires significant staff input due to limited digital literacy and the progressive nature of MJD

The organisation would like to invest more in training and developing ACWs skill and autonomy—including pathways into therapy assistant roles and accredited training — but current pricing does not allow for the additional time and energy required.

Cultural, Linguistic and System-Translation Work – Critical but Unfunded

Culturally safe service delivery requires continuous translation between Western systems and Aboriginal cultural contexts, including:

- interpreting NDIS concepts into first languages
- contextualising Western disability and compliance expectations
- navigating kinship structures, gender-specific roles, avoidance relationships and community obligations
- providing system translation that ensures informed decision-making and avoids misunderstanding

- bridging digital literacy gaps that prevent ACWs from confidently engaging with NDIS claiming processes

All of this is essential to safe, high-quality service delivery, but entirely unfunded under current NDIS price settings.

Differential Pricing for Real-World Service Delivery

Uniform NDIS pricing does not reflect the real cost of delivering services to Aboriginal families in remote communities, nor the complexity inherent in supporting people with progressive neurodegenerative conditions such as MJD or SCA7. For the MJD Foundation, differential pricing is not only justified — it is essential for sustainable, safe, culturally appropriate service delivery.

Complexity and Progression – Real Costs of Supporting High-Needs Participants

MJD and SCA7 are progressive conditions with varied and unpredictable pathways. This contrasts with the scheme's goals of improving independence and reducing support requirements. As clients transition between stages of the disease, support needs can change rapidly, requiring urgent coordination, advocacy and reassessment. In practice this means:

- Substantial coordination efforts are required when clients enter a new phase of disease progression, or transition to out-of-home care, including preparing reports, gathering evidence, arranging multiple assessments and advocating for increased plan budgets. Much of this work is unfunded because the pace of progression frequently exceeds the responsiveness of the NDIS.
- Clients may require rapid access to equipment, such as mobility aids or hoists or increased ratios of care provision. When the NDIS does not update plans quickly enough, the MJD Foundation has at times paid for essential equipment or support from its own funds to ensure safety and wellbeing.

These needs cannot be met within flat, uniform pricing structures that assume stability, predictability or easy access to services — none of which exist in the communities we serve.

Remote Delivery – The True Cost of Geography

Delivering services in very remote Aboriginal communities introduces substantial cost pressures that uniform pricing neither recognises nor accommodates. These include:

If staff live in community:

- Housing costs, where market supply is scarce and prices are inflated.
- Remote allowances and incentives needed to attract and retain staff.
- Vehicle wear, fuel and servicing, all significantly more expensive than in urban areas.
- Higher cost of everyday supplies (e.g. cleaning products, PPE, groceries).

If staff do not live in community:

- Frequent flights or long-distance drives to access communities.
- In some locations, only one client holds an NDIS plan, while many others require support but do not have funded access. In these cases, the organisation must absorb travel costs, because a single plan cannot reasonably cover all travel for multiday or multipurpose visits.
- The need to store a vehicle in community — often without secure storage — or attempt to borrow one from local organisations at cost. Both options come with substantial risk, administrative effort and logistical barriers.

"Our Way" – A Necessary Two-Worker Model

Our "Our Way" model is not an optional enhancement; it is the foundation of safe, effective and culturally legitimate service delivery for Aboriginal families affected by MJD and SCA7. It bridges the gap between a completely western oriented individualised scheme and Aboriginal communities.

- The model pairs an Aboriginal Community Worker (ACW) with a non-Aboriginal clinician or support worker.
- This two-worker model is required for cultural safety, linguistic bridge-building, system translation, navigation of kinship structures, gender protocols and community obligations.
- ACWs also reduce shame, build trust and ensure service engagement, but cannot be consistently funded through NDIS line items, leaving their roles largely unfunded.

This model is essential not only for cultural legitimacy but for clinical safety, as ACWs:

- interpret disability, health and therapeutic concepts
- translate NDIS rules
- support informed decision-making
- assist with appointment access
- ensure clients understand and consent appropriately

Differential pricing is necessary to reflect the cost of this *required* two-worker model — a model that ensures NDIS services are delivered ethically and effectively, without cultural harm.

Thin Markets – Limited Choice and Provider Scarcity

The MJD Foundation is one of very few, and in some locations the only, provider of regular NDIS supports:

- Ngukurr: MJDF is one of the only providers offering consistent, culturally grounded in-community supports.
- Elcho Island: MJDF remains one of the few reliable providers with ongoing service presence.
- Groote Eylandt: Other providers exist, but service consistency varies significantly. Clients overwhelmingly prefer MJDF due to cultural safety and trust.

Thin markets magnify the cost to providers because baseline operational capacity, continuity of service, travel and cultural engagement must be maintained even when volumes are low or plans inadequate. Without differential pricing, providers like MJDF are disincentivised from operating in the remote areas where supports are most needed.

Reforming Payment Approaches to Enable Quality and Sustainability

Current NDIS payment structures are not fit-for-purpose for remote Aboriginal service delivery or for providers supporting people with progressive neurodegenerative conditions. Essential quality, cultural-safety and clinical activities remain unfunded, leaving organisations like the MJD Foundation unable to sustainably deliver the level of support required to keep families safe, connected and thriving.

Unfunded Quality Activities – Essential Work Not Reflected in Pricing

A range of activities essential to high-quality, safe service delivery remain unfunded under NDIS hourly pricing. For the MJD Foundation, these include:

- Professional development and training, including cultural mentoring, clinical upskilling, and guidance for staff working in high-complexity environments.

- Supervision, particularly for Aboriginal Community Workers (ACWs) who require additional support to navigate digital systems, NDIS documentation, disability principles and the emotional load of supporting family and community.
- Audit preparation and quality assurance, which is significant because signed documents, formal consents and other administrative requirements are difficult to obtain in remote Aboriginal contexts.
- Evidence-gathering for plan reviews, which often requires multiple attempts due to limited local services and slow availability of health or allied health assessments.

These functions are not optional add-ons; they underpin safety, cultural integrity, payment integrity and clinical outcomes. Yet providers must absorb their cost into already inadequate pricing structures.

The Financial Impact – Unsustainable Deficits Driven by Unfunded Work

In 2025–26, the MJD Foundation is projected to operate at a $400,000 deficit. This deficit is driven by:

- A decline in NDIS income, which no longer keeps pace with the real cost of delivering supports.
- Reduced availability of grants, despite grant funding historically being used to cover the significant cultural-safety costs of the "Our Way" model.

This illustrates a fundamental structural issue: the NDIS pricing model assumes Western, individualised, predictable service delivery, and fails to account for cultural, relational, and community-led work required in remote Aboriginal settings. All exacerbated by a caseload living with progressive, complex disability.

On-Country and Group Supports – High Value, Poorly Fitted to Current Pricing Rules

The MJD Foundation delivers On-Country programs on Groote Eylandt — holistic group-based supports designed around culture, community and wellbeing. These activities:

- Are deeply culturally grounded and central to maintaining health, identity and connection.
- Required special approval from the NDIA due to the unique billing structure.
- Do not fit cleanly into standard group-based NDIS pricing.

While group supports are technically possible under NDIS rules, in practice they are extremely difficult to administer because:

- Clients may come and go unpredictably, influenced by cultural obligations, weather, transport, Sorry Business and family responsibilities.
- Providers must choose between billing accurately (with huge admin load) or absorbing lost revenue.
- There is a real risk of over-charging or under-charging clients' plans if the fluctuation is not managed perfectly, creating compliance risk.

The administrative burden of group billing in remote communities — especially across languages and cultural contexts — is disproportionate and unsustainable.

A Case for Block Funding – Evidence From Other Systems

The MJD Foundation has had strong success with grant funding from the Australian Government Department of Health for some primary health care services. This funding model clearly outlines what is expected to be achieved and results in improved efficiencies such as:

- Staff spend their time on what matters, rather than completing timesheets, shift notes and micro-billing.

- The reporting requirement is a single annual activity and narrative and financial report, enabling flexibility and responsiveness.
- The model allows holistic, preventive and culturally grounded work that is impossible to deliver under strict hourly billing.
- Provides opportunity for community and skills development for Aboriginal staff in remote locations

This demonstrates the value of blended or block funding models that:

- Reduce administrative burden
- Enable culturally safe, flexible service delivery
- Support community-driven practice
- Promote long-term stability and workforce sustainability

Block funding would allow the MJD Foundation to maintain its two-worker model, respond rapidly to clinical need, and deliver supports in ways that respect culture, community and Country — rather than forcing services into rigid billing structures.

Why Reform is Needed Now

For remote Aboriginal communities, pricing reform is not a theoretical improvement — it is essential to:

- Maintain continuity of care for people with rapidly progressing conditions
- Sustain the ACW workforce
- Support culturally safe, community-led approaches
- Prevent further provider withdrawal from thin markets
- Reduce the burden on Aboriginal families navigating Western systems without adequate translation, cultural brokerage or support

The risk is clear: without alternative payment mechanisms that fund quality and cultural safety, the NDIS will continue to underfund the very providers who are keeping Aboriginal families safe, connected and supported.

Independent Pricing and Transparency

The MJD Foundation strongly supports the transition to independent pricing through IHACPA, provided the process explicitly recognises and adequately funds *culturally safe, community-led supports* for Aboriginal families in remote Australia. Independent oversight will only achieve its purpose if it moves beyond mainstream service assumptions and genuinely reflects the structural, geographic and cultural cost drivers inherent to remote disability support.

Why Independent Pricing Matters for Remote Aboriginal Communities

For providers like the MJD Foundation, pricing stability and transparency are essential. Sudden changes to price limits, unclear rationales behind pricing decisions, and the absence of culturally grounded cost modelling create ongoing uncertainty that directly impacts organisational planning and service sustainability.

Independent pricing offers a pathway to greater:

- Predictability — enabling long-term planning for workforce, service delivery and infrastructure.
- Transparency — ensuring that pricing reflects real cost structures, including the complexity of supporting people with progressive neurological conditions in remote communities.

- Trust — improving confidence for participants, providers and government.

However, independent pricing must be informed by realistic lived conditions of remote Aboriginal service delivery. The unique cost drivers associated with cultural safety, remote logistics, first-language work, and the "Our Way" two-worker model must be explicitly accounted for.

Impact of Pricing Uncertainty on Organisational Decision-Making

Pricing uncertainty has had tangible impacts on the MJD Foundation's ability to operate sustainably. In recent years, the organisation has regularly delayed or deferred essential expenditure because NDIS revenue has not kept pace with the cost of delivering safe, culturally anchored supports. This includes delays in:

- Infrastructure upgrades, including clinical spaces, storage, and housing for remote staff.
- Vehicle replacement, despite the extreme wear and tear caused by remote road conditions.
- Purchase of program assets, such as specialised equipment for therapy, community engagement or On-Country programs.

These delays are not discretionary — they are a direct consequence of insufficient NDIS income and reliance on grants to cover the unfunded costs of the "Our Way" model. As noted above, our organisation is projected to operate at a $400,000 deficit this year, with reduced grant availability compounding the challenge.

Independent pricing must therefore recognise that:

- Remote providers face capital and asset renewal cycles that are both essential and extremely costly.
- Delaying infrastructure, vehicle and equipment investment carries safety risks and limits service reach.

Block or blended funding approaches may be essential to enable culturally safe, responsive care where unit-hour billing cannot capture the real work required.

What Independent Pricing Should Include

To deliver meaningful reform, independent pricing should incorporate:

- Cost models grounded in remote delivery realities, including travel, accommodation, vehicle depreciation, freight, and the cost of living in remote communities.
- Recognition of cultural safety costs, including the ACW workforce, health literacy discrepancy, first-language communication, kinship navigation, relational practice, and the two-worker model.
- Funding for supervision, professional development, and workforce sustainability — critical in small, high-complexity teams.
- Methods for capturing rapid changes in need for people with progressive conditions, enabling plan budgets to adjust quickly and appropriately.
- Approaches to block, blended or base-funding models to reduce administrative burden and maintain essential standing-ready capacity in thin markets.

Independent pricing must not reinforce inequity — it must correct it.

Market Stewardship

Sustainable, high-quality disability support in remote Aboriginal communities depends on strong, proactive market stewardship from government. Providers like the MJD Foundation operate in environments where

market forces alone cannot sustain safe, culturally grounded services. Current pricing, policy instability and constant reforms compound workforce strain and undermine the viability of remote service delivery.

The Impact of Constant Reform and Complex Rules

The pace and scale of ongoing NDIS reforms — combined with increasingly complex rules and payment integrity requirements — create significant workforce and organisational pressure. The MJD Foundation must employ staff with deep technical knowledge of the NDIS, while also expecting them to manage complex, high-intensity non-mainstream caseloads for people with progressive neurodegenerative diseases.

Maintaining this expertise requires:

- Professional development to stay across constant regulatory and policy changes.
- Skilled management and executive oversight to ensure the organisation remains compliant and responsive.
- Time and financial investment that disproportionately affects small, remote providers.

Finding staff with the right combination of cultural competency, technical NDIS knowledge and clinical/community expertise is challenging — and upskilling existing staff requires resources that are not funded through NDIS plans or current pricing structures.

Travel, Access and the Realities of Remote Service Delivery

In remote communities, the cost of accessing clients can exceed what NDIS plans can sustain. When flying or driving into communities, the MJD Foundation must carefully sequence and ration trips based on available plan budgets.

This can mean:

- Reducing the number of trips, even when need is high.
- Altering timing of visits, sometimes delaying support until travel becomes financially feasible.
- Making difficult decisions about how to distribute limited travel funding across multiple clients — particularly where only one person in a community has an active NDIS plan, while others remain unfunded or underfunded.

This dynamic directly affects continuity of support and highlights why remote markets cannot function without system-level intervention.

Provider Scarcity and the Need for Stewardship in Thin Markets

The MJD Foundation is not just a provider — it is the only provider offering culturally safe disability supports tailored to people with MJD and SCA7. This deep disease-specific expertise, combined with cultural grounding and longstanding community relationships, means MJDF is uniquely positioned to deliver high-quality, appropriate services.

The absence of strong market stewardship risks further shrinking the pool of qualified remote providers. Without intervention, thin markets become thinner, access becomes inconsistent, and families are forced to rely on emergency or crisis-based responses.

Why Market Stewardship Must Change

Market stewardship must do more than monitor provider numbers — it must actively shape market conditions to ensure that people living in remote communities, especially Aboriginal communities, have equitable access to safe, quality supports.

This requires:

- Funding mechanisms that recognise baseline operational capacity and the cost of remote travel, supervision and cultural safety.

- Pricing that reflects real-world wage costs, caseload complexity and remote logistics.
- Policy stability, giving providers the confidence to invest in workforce, infrastructure and vehicles.
- Partnership approaches, where the NDIA collaborates with providers to identify structural issues and co-design solutions.

Without this shift, providers will continue absorbing unfunded costs, reducing services, or exiting remote communities altogether — leaving families without culturally safe supports and placing further pressure on under-resourced local systems.

Conclusion

The NDIS must work for all Australians, including Aboriginal families in remote communities who face profound barriers to accessing safe, culturally grounded and clinically appropriate supports. For the MJD Foundation, the current pricing and payment structures do not reflect the real cost of delivering services to people living with progressive neurodegenerative conditions in some of the most remote and culturally complex locations in the country.

We strongly support the move toward **independent pricing**, but only if it recognises and adequately funds the true cost of culturally safe practice, the essential role of Aboriginal Community Workers, the realities of remote logistics, and the need for baseline operational capability in thin markets. Without this, reform risks entrenching inequity rather than addressing it.

Our organisation — and the families we walk alongside — cannot continue to absorb unfunded cultural-safety work, clinical and coordination time, travel, infrastructure delays, and the increasing administrative burden required to remain compliant, responsive and safe. The projected $400,000 operating deficit we face this year is not the result of inefficiency; it is the direct outcome of a pricing model that assumes a service context fundamentally different from the one we operate in.

We therefore urge the NDIA and the Independent Pricing Committee to adopt reforms that:

- **Introduce cost-neutral differentiated pricing** for registered providers.
- **Recognise cultural safety and remote delivery as core cost drivers**, not optional extras.
- **Fund the real cost of supporting people with progressive conditions**, including rapid responsiveness to changes in need.
- **Establish blended, block or grant-based funding models** that enable flexible, culturally grounded support rather than forcing services into restrictive fee-for-service rules.
- **Embed transparency and evidence in all pricing decisions** through independent oversight.
- **Strengthen market stewardship**, ensuring families in remote communities are not left without choice, quality or continuity of support.

The MJD Foundation remains deeply committed to delivering safe, culturally legitimate and clinically strong supports through our "Our Way" model — a model built over generations with families, Elders and communities. With appropriate pricing and funding reform, we can continue to walk alongside families, honour culture and Country, grow capacity and ensure that people living with MJD and SCA7 receive the care, dignity and choice they deserve.

We appreciate the opportunity to contribute to this Review and stand ready to work with the NDIA, IHACPA and government to design a pricing system that truly reflects the real costs — and the real value — of culturally safe disability support in remote Australia.