Dementia Australia

Support. Change. Prevention.

NDIA Annual Pricing Review

Dementia Australia Policy Position Summary

November 2026

What needs to change?

- NDIS pricing does not always reflect the **true cost of providing appropriate support** to people living with young onset dementia and other progressive neurological conditions.
- People living with young onset dementia may need providers with **specialist dementia knowledge and skills**, continuity of support and services that can adapt as their needs change.
- People in **rural, regional and remote areas** can have even greater difficulty finding appropriately skilled providers.
- Low use of NDIS funding does not necessarily mean low need. People may be unable to use their funding because **appropriate services are not available**.

What is Dementia Australia recommending?

- Set therapy prices that reflect the **real cost of providing appropriate dementia-capable support**.
- Consider young onset dementia and other progressive neurological conditions when developing pricing based on **complexity and quality**.
- Recognise shortages of dementia-capable providers, particularly in **rural and regional areas**, and consider pricing or other measures where services are not available.
- Do not use **low plan utilisation alone** as evidence that people have low support needs or that enough services are available.

If actioned, what impact could these recommendations have?

- People living with young onset dementia could have **better access to skilled, appropriate and consistent NDIS supports**, including as their needs change.
- People could have greater access to dementia-capable services **where they live**, including in rural and regional communities.
- NDIS funding and pricing could better reflect **actual support needs**, rather than relying on overall provider numbers or how much of a plan has been spent.

How has Dementia Australia advocated for this position?

- Consulted people living with young onset dementia, carers and professionals.

- Used lived experience and expert input to inform recommendations.
- Made a submission to the **NDIA Annual Pricing Review 2027–28**, highlighting the pricing and service barriers affecting people living with young onset dementia.
- Raised the ongoing need for **dementia-capable services, appropriately skilled workers and pricing that responds to progressive and changing support needs**.

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NDIA Annual Pricing Review, 2027-2028

Dementia Australia Submission

October 2026

Introduction

Dementia Australia welcomes the opportunity to contribute to the National Disability Insurance Agency (NDIA) Annual Pricing Review for 2027–28 National Disability Insurance Scheme (NDIS) prices.

Dementia Australia is the peak body representing the estimated 446,500 people of all ages living with dementia and their carers across Australia [1]. Dementia is not a normal part of ageing and can affect people of all ages. Young onset dementia refers to any form of dementia diagnosed in individuals aged 18-64. There are also an estimated 1,500 children living with childhood dementia in Australia, arising from more than 100 rare genetic disorders [2].

In 2026, there are an estimated 29,000 people living with young onset dementia in Australia. This figure is projected to increase to 41,000 in 2054 [1]. People living with young onset dementia remain underrepresented in the NDIS, with around 30% accessing supports through the Scheme [3].

As the trusted source of information, education, and support services, we advocate for positive change for people living with dementia, their families, and carers, and support vital research across a range of dementia-related fields.

Dementia affects all people differently, but challenges and barriers are compounded for people living with a disability, Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse backgrounds, people living in rural and regional areas, and other priority populations.

This submission responds to issues outlined in the Participant Consultation Paper (2026) and topics of discussion at the NDIA Sector Town Hall - Annual Pricing Review 2027-2028.

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Dementia and the NDIS

People living with young onset dementia represent a relatively small but distinct NDIS participant cohort. The AIHW reported there were 9,646 approved NDIS plans for people living with young onset dementia in December 2024, the latest data publicly available [3].

Young onset dementia causes progressive cognitive, behavioural and physical changes affecting an individual's capacity to undertake daily activities, this is exacerbated without appropriate supports and enabling environments.

The distinct and age-appropriate needs of children living with childhood dementia must also be considered in the design, delivery and pricing of NDIS supports.

This has important implications for pricing. Meaningful support requires dementia specific capability of support workers, adaptation of communication and service delivery, continuity of support, engagement with families and carers, and a system and supports that are responsive to a person's change in functional and progressive increase in support needs.

Dementia Australia therefore recommends that the NDIA consider whether aggregate market data and external benchmarks appropriately reflect the costs of delivering supports to people with young onset dementia. Pricing analysis should also consider not only overall provider availability and plan utilisation, but participants' access to providers with the specific skills and capacity to deliver dementia support when and where they need it.

Recommendations

1. Ensure therapy pricing reflects the true cost of delivering appropriate supports to participants living with young onset dementia.
2. Explicitly consider young onset dementia and other progressive neurological conditions when developing complexity-based or differentiated pricing arrangements and measures of quality.
3. Ensure the Quality Supports Program pilots and related market evidence adequately capture the experience of people living with young onset dementia.
4. Recognise shortages of dementia-capable services when monitoring regional and rural NDIS markets and consider whether pricing or other market interventions are required
5. Avoid using low plan utilisation in isolation as evidence of low participant need, adequate service supply or appropriate pricing.
6. Ensure Disability Support Worker pricing adequately provides for the workforce development, supervision and other provider costs required to maintain dementia-capable support.
7. Ensure future Supported Independent Living (SIL) pricing and commissioning models recognise the specific needs of people with young onset dementia including providing for continuity and appropriately skilled staffing, responding promptly to changing support needs, and preserving participant choice over providers, living arrangements and decisions within the home.

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Dementia-capable therapy supports

Dementia Australia recommends that the NDIA ensure therapy pricing reflects the actual costs associated with delivering high-quality disability-specific supports to people living with young onset dementia and other progressive neurological conditions.

For participants living with young onset dementia, effective therapy may require additional skills and service adaptations. Relevant costs may include time associated with understanding changing functional needs, adapting communication and interventions, working with a person's support network, coordinating services and undertaking other activities necessary to deliver effective dementia-enabled support.

This distinction is particularly important in the context of the NDIA's current Therapy Pricing Review. The NDIA identifies external benchmarking against comparable government schemes and private health insurance as its principal reference point for assessing therapy prices. At the same time, the review expressly recognises that participant complexity can affect time, skills and workforce planning, and that provider quality and experience should involve training, supervision, innovation, contemporary practice and outcomes measurement.

> I am not aware of other disability support services that would be appropriate for people with young onset dementia as people with young onset dementia require specialised supports. ~ carer

Dementia Australia supports appropriate benchmarking. However, comparability should be demonstrated rather than assumed. An hourly rate observed in another market may not represent an equivalent service if the complexity of the participant, workforce capability required, service model or associated non-direct support work differs materially.

Recommendation: Ensure therapy pricing reflects the true cost of delivering appropriate supports to participants living with young onset dementia.

Differentiated pricing and progressive neurological conditions

Dementia Australia supports further investigation of differentiated pricing where it improves participant outcomes and enables sustainable access to appropriately skilled supports. We do not support using registration status alone as a proxy for quality or capability, as intimated by the 10% reduction in maximum price available for unregistered providers to apply to Social, Community and Civic Participation supports from 1 January 2027 [4].

For people living with young onset dementia, quality service outcomes are predicated on more than provider registration. They include the capability to recognise and respond appropriately to progressive cognitive disability - potentially leading to behavioural and physical impairment - to ensure continuity of support and timely adjustments to service type and frequency as functional needs increase.

Further, differentiated prices should not be introduced on the assumption that participants can absorb higher prices within existing budgets. Where a higher price is justified by participant

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complexity or specialist provider capability, the plan budget must be sufficient to fund the volume and intensity of support reasonably required. Otherwise, differentiated pricing may improve nominal access to specialised providers while reducing the actual quantity of support available.

Recommendation: Explicitly consider young onset dementia and other progressive neurological conditions when developing complexity-based or differentiated pricing arrangements and measures of quality.

Representation in the Quality Supports Program

The Quality Supports Program (QSP) is a foundational component of the NDIA's three-year pricing work program, and findings from its pilots are intended to inform recommendations on future pricing. Dementia Australia therefore strongly advocates for people living with young onset dementia and other progressive neurological conditions and experienced providers being adequately represented in the QSP pilots.

For a comparatively small participant cohort such as young onset dementia, aggregate market measures risk obscuring whether participants can access providers with the dementia capability they require. Dementia Australia receives regular and consistent feedback about the lack of dementia capable NDIS providers. Availability is not necessarily equivalent to appropriate access: a provider may nominally offer a support in a region without having the skills, capacity or service model required to support an individual with progressive disability.

> A "one-size-fits-all" approach will systematically disadvantage people living with young onset dementia. In metro areas, there may be access to more specific services (although not many!) whereas in regional areas, families may be significantly disadvantaged. ~ carer

The pilots and broader market monitoring should therefore collect evidence capable of identifying whether people with young onset dementia can obtain appropriate, sustained and high-quality supports, rather than relying solely on overall provider numbers or aggregate utilisation.

Recommendation: Ensure the Quality Supports Program pilots and related market evidence adequately capture the experience of people living with young onset dementia.

Dementia-capable service scarcity

The National Rural Health Alliance reports fewer providers and a smaller available workforce in rural, regional and remote Australia, noting shortages across allied health professions, long travel distances and limited provider choice [5]. This shortage is compounded for NDIS participants living with young onset dementia in rural and regional Australia, who experience the combined impact of a smaller disability services market and the need for providers with appropriate dementia capability.

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> NDIS deals with generally visible disabilities. Finding staff that can identify and understand and build rapport with someone with dementia has been a five-year journey for me. ~ carer

The current pricing review describes effective market stewardship as identifying gaps in service type, geographic coverage and quality standards, and notes that pricing and other policy and regulatory tools may be required in response.

NDIA market analysis must distinguish between general provider availability and the availability of providers capable of meeting participants' disability specific needs, including young onset dementia. Where persistent scarcity exists, the NDIA should consider whether pricing is contributing to the problem and whether targeted pricing or other market-stewardship responses are warranted.

Recommendation: Recognise shortages of dementia-capable services when monitoring regional and rural NDIS markets and determining whether pricing or other market interventions are required.

Low utilisation is not necessarily low need

Plan utilisation is an important market indicator, but it should not be interpreted in isolation.

This distinction is important for pricing and market monitoring. Low expenditure may reflect low demand, but it may also reflect circumstances in which a participant has funding that cannot be utilised because appropriate services and/or providers are not available.

Utilisation data should accordingly be considered alongside indicators of provider availability, workforce capability, participant choice, waiting times, travel requirements and other evidence of effective access. This would better distinguish genuine low demand from unmet or suppressed demand caused by market constraints.

Recommendation: Avoid using low plan utilisation in isolation as evidence of low participant need, adequate service supply or appropriate pricing.

The cost of dementia-enabled support

Ensuring that participants can obtain quality dementia-enabled support has implications for Disability Support Worker pricing.

The NDIA's current DSW Cost Model estimates the provider cost of delivering a billable hour of disability support across three broad categories: direct worker employment costs, operational overheads and corporate overheads, with an additional margin. Importantly, the current review is examining whether the model's parameters and inputs remain current and appropriately reflect provider cost structures.

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This review provides an opportunity to examine whether the model adequately recognises the costs associated with developing and maintaining workforce capability for participants with young onset dementia.

Dementia capability requires more than an initial staff induction. Providers need an organisational capability to support workers to recognise cognitive and communication changes, respond appropriately as functional needs evolve, maintain person-centred support and continuity of support. This need is evidenced in Action 7 of the National Dementia Action Plan 2024–2034, which establishes building workforce capability to care for and support people living with dementia as a national action [6].

Rather than prescribing a particular training course or mandatory annual accreditation through the pricing review, Dementia Australia recommends that the NDIA test whether the DSW Cost Model makes adequate provision for the reasonable costs of maintaining disability-specific workforce capability, including ongoing training and supervision, and adjust relevant assumptions where the evidence demonstrates a gap.

Recommendation: Ensure Disability Support Worker pricing adequately provides for the workforce development, supervision and other provider costs required to maintain dementia-capable support.

Supported Independent Living and Young Onset Dementia

NDIS data reported by the Joint Solutions Young Onset Dementia Project in 2025 indicates that approximately 5,500 NDIS participants had young onset dementia listed as either a primary or secondary disability in 2024 [7]. The NDIS spent approximately $454 million on Supported Independent Living supports for this cohort in 2023–24 [7]. As dementia progresses, most participants with young onset dementia can be expected to require SIL or other higher-intensity home and living supports.

The suitability of SIL for people living with young onset dementia can vary significantly depending on whether supports are shared or individualised, where they are delivered, and who has control over their design and delivery.

In shared SIL, staffing ratios, housemate compatibility and household routines can make it difficult to appropriately support people with progressive cognitive impairment, changes in behaviour, disrupted sleep or the need for active overnight support. Individual SIL may provide greater consistency and allow supports to be tailored more closely to the participant but can be difficult to secure and challenging to sustain financially as needs increase over time.

Recommendation: Ensure future Supported Independent Living (SIL) pricing and commissioning models recognise the specific needs of people with young onset dementia including providing for continuity and appropriately skilled staffing, responding promptly to changing support needs, and preserving participant choice over providers, living arrangements and decisions within the home.

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Conclusion

Dementia Australia encourages the NDIA to ensure that future pricing decisions recognise dementia-specific capability, account for service scarcity and participant complexity, and do not rely on aggregate provider availability or utilisation as proxies for effective access. Pricing should enable a sustainable market in which participants can access providers with the capability and capacity to meet their needs, wherever they live.

Incorporating these considerations into therapy pricing, differentiated pricing, the disability support worker cost model, future SIL payment models and market monitoring, is essential to participants living with childhood and young onset dementia being able to access appropriate and high quality supports underpinned by pricing that recognise the true cost of delivering care to this cohort.

References

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