Supported Independent Living (SIL)

Dementia Australia Policy Position Summary

10 September 2026

What needs to change?

- The current Supported Independent Living (SIL) market does not consistently provide suitable options for people living with young onset dementia.
- There are not enough providers with dementia knowledge or living environments designed to support people with cognitive impairment.
- People may experience long hospital stays or be offered accommodation that does not meet their needs. Families and carers may face growing pressure while suitable support is sought.
- Support and funding do not always adjust quickly as dementia progresses. This can leave providers without enough funding for overnight support, higher staffing levels or increased supervision.
- Limited service options can limit where a person lives, who they live with and who provides their support, particularly in regional and remote communities.

What is Dementia Australia recommending?

- Improve government planning and oversight of the Supported Independent Living market, supported by better information about demand, service availability and unmet need.
- Develop and sustain dementia-capable providers, workforces and living environments.
- Maintain flexible and individualised support that responds promptly as a person's needs change.
- Ensure funding reflects the staffing, supervision and overnight support each participant requires.
- Protect participants' rights, choice and control, including through supported decision-making.
- Use commissioning to increase suitable service options.
- Improve links between disability, health, community and dementia-specific services so changes can be addressed before a crisis occurs.

If actioned, what impact could these recommendations have?

- People living with young onset dementia could have greater access to safe, appropriate and sustainable support.
- Participants could remain involved in decisions about where they live, who they live with and how their support is provided.
- Earlier adjustment of support could reduce crises, avoidable hospital admissions and delayed hospital discharge.
- Families and carers could have greater confidence that support will respond as the person's needs change.
- Providers could be better equipped to deliver consistent, person-centred support in environments that promote familiarity, independence and meaningful community connection.

How has Dementia Australia advocated for this position?

- Provided a submission to the Department of Health, Disability and Ageing consultation on Supported Independent Living commissioning.
- Shared feedback and experiences from people living with dementia, families, carers, advocates, staff and service providers.
- Recommended that any future commissioning model protect participant rights while addressing gaps in service availability, workforce capability and suitable accommodation

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Dementia Australia Submission

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Introduction

Dementia Australia welcomes the opportunity to provide feedback on the Department of Health, Disability and Ageing's consultation regarding the potential introduction of a commissioning approach for Supported Independent Living (SIL).

Dementia Australia is the peak body representing the estimated 446,500 people living with dementia and their carers across Australia.[1] 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 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 an estimated 41,000 in 2054.[1] People living with young onset dementia remain underrepresented in the NDIS, with only a minority accessing supports through the Scheme.

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

Different SIL arrangements and implications for young onset dementia

There are an estimated 4,742 National Disability Insurance Scheme participants whose primary disability is young onset dementia. Based on the most recent available data approximately 30 per of this cohort were receiving SIL supports. 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 challenging 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 financially sustain as needs increase over time.

Where SIL is delivered in Specialist Disability Accommodation (SDA) or provider-controlled housing, people with young onset dementia may face the combined problem of unsuitable environments and limited dementia capability among support staff. Participants may also have little choice over their housemates, routines or provider when options are scarce. SIL delivered in a person's existing home may allow participants to maintain familiarity, relationships and independence, but often relies heavily on family carers and may not be sustainable as dementia progresses.

Some participants and families use self-directed home and living supports, which may provide greater flexibility to select, train and roster workers around the person's needs. However, this depends on the participant or their nominee having the capacity to manage complex administrative and workforce responsibilities and the sufficient funding being approved within a persons individualised budget.

Any commissioning approach should therefore recognise the different implications of shared, individualised, provider-controlled and self-directed arrangements for people living with young onset dementia.

While this submission focuses primarily on people living with young onset dementia, future SIL arrangements should also account for the needs of NDIS participants who develop dementia or experience cognitive decline as they age within the Scheme. As the NDIS participant population ages, dementia-capable workforces, living environments and support models will become increasingly important beyond the current young onset dementia cohort.

The current market does not consistently deliver appropriate SIL options for people with young onset dementia. Limited access to dementia-capable providers and appropriate living environments has significant consequences. These include avoidable hospital admissions and delayed discharges, people being offered living arrangements that may not appropriately meet their needs, pressure on family carers to keep loved ones at home and reduced participant choice and control.

There is also limited publicly available information about how people living with young onset dementia use SIL, including service availability, unmet demand, utilisation patterns and barriers to access. Dementia Australia recommends that the Department and NDIA undertake targeted market analysis of the accommodation and higher-intensity support needs of people living with young onset dementia, including their use of SIL. This should inform future commissioning decisions and help determine whether current market settings are meeting participants' need.

Dementia Australia supports further exploration of commissioning approaches to address market failure where the current SIL market is not meeting participant needs. Any future approach should improve access to dementia-capable accommodation and supports, protect participant rights, choice and control, and support the development of services that can respond as needs change over time.

Recommendations

1. Improve market stewardship and SIL planning for people with young onset dementia, including better data and analysis on accommodation need, unmet demand and service availability.
2. Maintain flexible, individualised supports that can respond to changing needs over time.

3. Develop and sustain dementia-capable supports, workforces and living environments for people with young onset dementia.
4. Ensure commissioning expands rather than restricts participant choice, control and supported decision-making.
5. Enable proactive review and adjustment of supports before crises occur.

Which SIL participants could benefit most from additional government oversight?

People living with young onset dementia may have support needs that are complex, highly individual and likely to increase as dementia progresses. Changes in cognition, communication, behaviour, mobility, sleep and insight can affect the type and intensity of support required. Some participants may need active overnight support, specialist behavioural support, higher staffing ratios or frequent and timely changes to their support arrangements.

The needs of people living with young onset dementia also vary considerably according to dementia type and stage, symptoms, living circumstances, location and personal preferences. For example, a person with young onset Alzheimer's disease seeking support to maintain independence may require a very different arrangement from a person living with behavioural variant frontotemporal dementia who needs behavioural support and active overnight supervision.

Providers may have limited capacity or incentive to develop services for participants whose needs differ significantly and may increase over time. These challenges are particularly pronounced in regional and remote areas where there are generally few providers and limited alternative accommodation options. As a result, people can experience prolonged hospital stays, living arrangements that cannot safely or appropriately meet their needs, or increasing pressure on family carers while suitable supports are sought.

> "He remains in hospital unable to be placed... There needs to be a space within the NDIS system that reflects the support required to care for someone with young onset dementia..." ~ Dementia Australia Staff Member

> "She has been in hospital since November, awaiting SIL placement…The family has been desperate to find appropriate SIL accommodation" ~ Dementia Australia Staff Member

Additional government oversight could help identify current and emerging demand, plan for dementia-capable services where suitable options are limited, set clear expectations for provider capability and monitor whether participants are receiving appropriate and sustainable supports. Commissioning could also support the development of specialist capacity in markets where participant demand may be too small or dispersed for suitable services to develop without government intervention.

Dementia Australia therefore considers there is merit in exploring more active forms of market stewardship and oversight for participant groups experiencing these types of market failures. However, any future commissioning approach should be designed specifically to address gaps in service availability, workforce capability and accommodation suitability.

What do high-quality SIL supports look like?

For people living with young onset dementia, high-quality SIL is underpinned by an understanding of dementia and is flexible, person-centred and consistent. It should provide continuity and familiarity while adapting promptly as a person's needs change over time.

How these principles are applied will differ across SIL arrangements. In shared SIL, quality can depend on compatible housemates, flexible household routines and staffing arrangements that respond to each participant's individual and overnight needs. Individualised SIL may enable greater consistency and personalisation but requires sufficient funding and workforce capacity to remain sustainable as needs increase.

> "It seems that younger onset dementia people have far less options - they are funnelled into disability homes, and these environments are too unpredictable and noisy for people experiencing significant sensory processing problems." ~ Carer

Recent mandatory registration requirements for providers that manage and deliver SIL are an essential step towards stronger regulation and oversight. Relevant providers are required to meet registration conditions, undergo certification audits and comply with the SIL Practice Standards. Any future commissioning approach should build on these safeguards by setting clear expectations for dementia capability.

Across SIL arrangements, Dementia Australia's engagement with people living with dementia, families, carers, advocates and service providers has identified several features that are critical to high-quality SIL for people living with young onset dementia.

Dementia-capable workforce

Consistent feedback from people living with dementia, carers and service providers is the importance of receiving support from staff with the skills, knowledge and confidence to support people with cognitive impairment and progressive neurological conditions such as dementia.

People living with young onset dementia often experience symptoms that differ from those commonly seen in other disability cohorts supported by the NDIS, including progressive cognitive decline, changes in communication, mobility, behaviour, and increasing support needs over time. Yet disability support staff generally do not have dementia-specific expertise.

> "From a SIL perspective staff in the disability space are often poorly trained in the dementia space." ~ Dementia Australia Staff Member

We have heard reports of situations where providers were either unwilling or insufficiently trained to support people living with dementia, despite having capacity to deliver disability supports more broadly. This can limit the availability of appropriate SIL options and affect both participant outcomes and workforce confidence.

Flexible and appropriately funded supports

Dementia is progressive, and a person's support needs may fluctuate from day to day while still increasing over time. High-quality SIL therefore depends on assessment and funding

decisions that accurately reflect the participant's required hours, staffing ratio, support intensity and overnight arrangements, and can be adjusted promptly as their needs change.

Dementia Australia is aware of cases where participants required significantly more support (active overnight support, one-to-one assistance or substantially greater supervision) than was approved in their budget. In some cases, providers absorbed the cost of additional staffing to maintain participant safety and meet their duty of care. This is not sustainable and may discourage providers from supporting people with young onset dementia.

> "Provider worked hard but as clients' needs increased more staff were required (including overnight and more 2:1 support) …the SIL provider lost money, services suffered as the company tried to control financial losses, relationships broke down."
> ~Dementia Australia Staff Member

Commissioning could help by developing and sustaining providers with the capability and staffing models needed to support people with progressive and complex needs. However, commissioning must operate alongside responsive NDIA assessment, funding and reassessment processes. Commissioned providers cannot deliver increased staffing if the participant's approved funding does not cover it. Any future model should therefore support early identification of changing needs and timely adjustment of funded supports, rather than requiring a crisis before an appropriate level of support is approved.

Dementia-enabling living environments

While SIL is primarily a support model, the physical environment within which SIL support is delivered remains an important contributor to participant wellbeing and independence.

Most SDA currently used for SIL is designed with an emphasis on physical accessibility rather than dementia-enabling design.

For people living with young onset dementia, SIL should be delivered in dementia-enabling environments that promote familiarity, provide clear visual cues and wayfinding, reduce unhelpful stimulation, support safe movement and engagement, and offer opportunities for both privacy and social connection. Environments should also reflect the person's identity, preferences, routines and desired way of life.

Dementia Australia recommends that the design, selection and review of environments used to deliver SIL draw on established dementia-enabling environment principles.

Continuity of staff and relationships

People living with dementia often rely heavily on familiarity, routine and trusted relationships. Frequent changes in support workers can contribute to confusion, distress, anxiety and reduced quality of life.

Maintaining stable relationships with support workers can significantly improve participant wellbeing and continuity of care. High-quality SIL should therefore seek to minimise unnecessary workforce turnover and support continuity of relationships and support wherever possible.

Choice, autonomy and meaningful lives

Most people living with young onset dementia have lived independently, worked, raised families and participated actively in their communities for most of their lives. SIL should support people to maintain autonomy, continue participating in activities that are meaningful to them, and remain connected to family, friends and their broader community.

Services should be tailored to individual goals, preferences, routines and interests rather than adopting a one-size-fits-all approach. This is particularly important for people with young onset dementia, whose circumstances and aspirations may differ substantially from other disability types or older people living with dementia.

Partnership with families and carers

Families and carers often continue to play a central role in supporting people living with young onset dementia.

Dementia Australia has heard repeated concerns about the difficulty families face when trying to access appropriate accommodation and support arrangements. One example involved a man living with behavioural variant frontotemporal dementia who remained in hospital for approximately nine months because a suitable support arrangement could not be identified. Other carers have described prolonged periods waiting for accommodation with appropriately trained staff and adequate levels of support.

High-quality SIL should actively work in partnership with families and carers, recognising their knowledge of the person, respecting their role as advocates, and ensuring they have confidence that their family member is receiving safe and appropriate support.

How should SIL supports protect the safety, health, wellbeing and rights of participants?

Supported decision-making and autonomy

People living with young onset dementia should be supported to participate in decisions about their lives, supports and living arrangements for as long as possible.

Dementia Australia considers supported decision-making should be embedded throughout SIL service delivery. Participants should be assisted to understand options, communicate preferences and maintain control over decisions wherever possible. Safeguards should protect individuals from harm without unnecessarily restricting their autonomy, relationships, daily routines or participation in activities that are meaningful to them.

Access to clinical and specialist support

As previously outlined, support needs for people with dementia progress and change over time. Participants requiring increased supervision, behavioural support or overnight support often experience delays in accessing additional supports. Dementia Australia is aware of a number of cases where, support increases only after hospitalisation, a serious incident or a crisis for carers and families.

People living with young onset dementia require timely access to medical, allied health, dementia-specific and behavioural support as their health and support needs change. High-quality SIL should include clear pathways for staff to identify and escalate changes in cognition, behaviour, function or health, and to seek specialist advice before concerns develop into a crisis. This could include access to the Dementia Behaviour Management Advisory Service (DBMAS), which can provide dementia-specific assessment, clinical advice and practical strategies for people living with dementia, carers and support staff.

Any commissioning model should require providers to establish effective links with health professionals and specialist services, and clear processes for escalating changes in participant needs.

How can innovation be encouraged?

Current support systems are often designed around the assumption that participant needs remain relatively stable or are primarily focused on capacity building. Dementia presents a different challenge, and innovation should be encouraged to develop models of support that provide greater flexibility and responsiveness as needs change.

Assistive technology, communication aids and appropriately designed smart-home or monitoring systems may also help some participants maintain safety, independence and connection.

Innovation may also be encouraged through stronger collaboration across sectors. People living with young onset dementia interact with multiple systems and services simultaneously, yet their care and support can often be fragmented. Innovative approaches that improve coordination between disability, health and community supports may improve participant outcomes, reduce service gaps and support continuity of care.

How should participant choice and control be protected?

Dementia Australia strongly supports the principles of choice and control that underpin the NDIS and considers these principles should remain central to any future commissioning approach.

However, meaningful choice requires meaningful options. Dementia Australia's engagement with people living with young onset dementia, families and carers suggests that many people experience significant challenges accessing dementia-capable SIL providers and accommodation. In practice, many participants have limited options, particularly where they require specialised supports, behavioural support expertise, active overnight support or accommodation capable of supporting cognitive impairment. In these circumstances, theoretical choice does not translate into genuine choice.

If commissioning is introduced, Dementia Australia considers it essential that it expands participant choice. While stronger market stewardship may improve service availability in areas experiencing market failure, it should not result in people being directed towards a small number of providers or required to accept support arrangements that do not align with their preferences, goals or needs.

Choice and control extend beyond selecting a provider. For people living with young onset dementia, choice includes where they live, who they live with, who provides their supports, how supports are delivered and the ability to adjust arrangements as needs change. These decisions can have a significant impact on quality of life.

Dementia Australia also considers supported decision-making should remain central within SIL. People living with young onset dementia should be supported to participate in decisions affecting their lives for as long as possible, with safeguards that protect both autonomy and wellbeing. Where substitute decision-making is required, it should be used only as a last resort, and decisions should prioritise the person's will and preferences.

Broader reform context

Dementia Australia notes that this consultation is occurring alongside broader NDIS reforms that affect planning, reassessment, support determinations and access to supports. Across these reform processes, Dementia Australia has consistently highlighted the importance of flexible, individualised and dementia-capable approaches for people living with progressive neurological conditions, including young onset dementia. These principles are equally relevant to any future commissioning model for SIL.

This consultation is also occurring alongside reforms to the aged care system. Recent changes that restrict access to residential aged care for people under 65, except in limited circumstances, have reinforced the importance of ensuring appropriate alternative pathways exist for people living with young onset dementia. While Dementia Australia supports efforts to reduce the number of younger people entering residential aged care, we continue to hear concerns from people living with young onset dementia, carers and service providers regarding the lack of suitable alternatives when care at home is no longer sustainable.

Feedback consistently identifies gaps in access to dementia-capable accommodation, supports and appropriate care pathways for people with more advanced dementia.

> "A SIL is not equipped for dementia patients, I would be concerned that she would become more confused and frighten. And we are not allowed access to Dementia Care Units due to age." ~ Carer

Any future model should recognise the increasing need for dementia-capable supports and living environments for people with young onset dementia, including those whose needs may not be adequately met through existing SIL models. Future arrangements should support timely responses to changing needs, avoid reliance on informal carers, recognise the progressive nature of dementia and maintain flexibility to respond to individual circumstances.

Conclusion

Dementia Australia supports exploration of a commissioning approach for parts of the SIL market where there is clear evidence of market failure and unmet participant need. People living with young onset dementia represent one such cohort.

Any future commissioning model should prioritise participant outcomes, safeguard rights, support informed choice and drive the development of specialist, high-quality and sustainable supports capable of responding to the changing needs of people living with dementia.

For more information, please contact the Dementia Australia Policy and Advocacy team on **policy@dementia.org.au**.

References

1. Dementia Australia. *Facts and Figures*. 2026; Available from: **https://www.dementia.org.au/about-dementia/dementia-facts-and-figures**.
2. Childhood Dementia Initiative. *Childhood dementia facts and statistics*. 2025; Available from: **https://www.childhooddementia.org/health-professionals/understanding-childhood-dementia**.