NATIONAL LIVED EXPERIENCE COMMISSION
NLEC

National Lived Experience Commission

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Lived Experience, Dignity and System Design in the Support at Home Program

Submission — National Lived Experience Commission

June 2026 | Submitted to the Senate Community Affairs References Committee | Inquiry into the Support at Home Program

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1. About the National Lived Experience Commission

The National Lived Experience Commission (NLEC) is a registered national Australian charity with a recognised charitable purpose of advancing public debate. NLEC converts lived experience into structured systems intelligence — identifying recurring patterns of preventable harm, governance failure and service-system dysfunction across Australia's social, health, justice, housing, disability and community service systems, and publishing evidence-based recommendations for reform.

NLEC is not a government agency, regulator, ombudsman or complaints body. Its authority rests in the quality of its evidence and the rigour of its methodology. NLEC makes this submission in the exercise of its charitable mandate to advance public debate on matters of public importance.

2. Executive Summary

The Support at Home Program represents the most significant redesign of Australia's home-based care system in a generation. It affects older people, people with disability, informal carers, culturally and linguistically diverse communities, First Nations peoples, and people in rural, regional and remote areas. It intersects with the NDIS, the aged care system, the mental health system, the housing system and the income support system.

NLEC's central submission is that the Support at Home Program should not be assessed only as an aged-care funding model. It is a national care-system redesign with profound implications for the lived experience of some of Australia's most vulnerable people. The quality of that redesign — and the extent to which it will reduce or perpetuate preventable harm — depends critically on whether the people most affected by it were genuinely involved in designing it.

NLEC's assessment of the Support at Home Program's co-design process, using its National Co-Design Standards Framework, is that the process has not yet met the standards of genuine co-design. NLEC makes eight recommendations to the Committee, centred on: co-payment hardship protections; thin market service access; carer recognition and support; First Nations and culturally safe services; the disability-aged care interface; and genuine co-design governance.

3. NLEC's Interest in the Support at Home Program

NLEC's interest in the Support at Home Program arises from its reform mandate across multiple domains that intersect with home-based care: Health and Aged Care (assessed as Serious in NLEC's 2026 Intelligence Report); Disability and NDIS (Critical); Social Services and Income Support (Serious); Family Violence and Safety (Serious); and First Nations Systems (Critical).

The Support at Home Program is not a single-domain reform. It is a cross-system redesign that will affect people who are simultaneously navigating aged care, disability, mental health, housing, income support and family systems. NLEC's cross-domain evidence model is specifically designed to capture the lived experience of people navigating multiple systems simultaneously — and it is precisely this population that is most at risk of being overlooked in a reform process focused on a single programme.

4. The Support at Home Program as a Care System Redesign

The Support at Home Program replaces the Home Care Packages Program and the Short-Term Restorative Care Programme, and will eventually absorb the Commonwealth Home Support Programme. It represents a fundamental redesign of how home-based care is funded, allocated and delivered in Australia.

NLEC submits that the Program should be understood not as an administrative reform but as a care system redesign with the following characteristics:

- **Scale:** The Program will affect hundreds of thousands of older Australians and people with disability who rely on home-based care to remain in their communities
- **Complexity:** The Program intersects with the NDIS, the aged care system, the mental health system, the housing system and the income support system in ways that create significant risks of service gaps and system failures
- **Irreversibility:** For many people, the loss of home-based care support leads directly to residential aged care — a transition that is often irreversible and that most people wish to avoid
- **Vulnerability:** The people most affected by the Program are among Australia's most vulnerable — older people with complex care needs, people with disability, people with dementia, people experiencing social isolation, and people in rural and remote areas

NLEC submits that a reform of this scale, complexity and consequence must be designed with the genuine involvement of the people most affected by it — not merely consulted about it after the key parameters have been determined.

5. Co-Payment Design and Hardship

5.1 The Risk of Financial Exclusion

The Support at Home Program introduces a co-payment model that requires participants to contribute to the cost of their care. NLEC's central concern about co-payment design is the risk of financial exclusion — that people who cannot afford co-payments will reduce or forgo care, with consequences for their health, wellbeing and ability to remain in their communities.

The lived experience of co-payment systems in other care contexts — including the NDIS, the mental health system and the pharmaceutical benefits system — consistently demonstrates that co-payments create barriers to access for people on low incomes, people with complex care needs and people who are already managing multiple financial pressures. These barriers are not evenly distributed: they fall most heavily on women, people with disability, people from culturally and linguistically diverse backgrounds, and people in rural and remote areas.

5.2 Hardship Provisions

NLEC welcomes the inclusion of hardship provisions in the Support at Home Program. However, NLEC submits that hardship provisions are only effective if they are: easy to access; widely known; applied proactively rather than reactively; and designed with the involvement of people who have lived experience of financial hardship in care systems.

NLEC's experience of hardship provisions in other systems — including income support, the NDIS and the health system — is that they are frequently underutilised because: people are not aware of them; the application process is complex or stigmatising; providers do not proactively identify people who may be eligible; and the criteria are too narrow to capture the full range of financial hardship experienced by care recipients.

NLEC submits that the hardship provisions of the Support at Home Program should be designed with the genuine involvement of people with lived experience of financial hardship in care systems, and that the Program should include a proactive hardship identification and referral mechanism.

6. Thin Markets and Service Access

NLEC's 2026 National Lived Experience Intelligence Report identifies thin markets as a significant barrier to service access in rural, regional and remote areas across multiple reform domains. The Support at Home Program's market-based service delivery model creates significant risks of thin market failure in areas where there are insufficient providers to meet demand.

The lived experience of thin markets in the NDIS — where participants in rural and remote areas frequently cannot access the supports in their plans because there are no providers available — provides a direct warning for the Support at Home Program. NLEC submits that the Program must include:

- A market stewardship function with clear responsibility for identifying and addressing thin markets
- Provider-of-last-resort arrangements to ensure that people in thin markets can access care
- Specific funding and incentive structures to attract and retain providers in rural, regional and remote areas
- Flexible service delivery models — including telehealth, outreach and community-based models — that can operate effectively in thin markets
- Regular public reporting on service access by geographic area, with specific reporting on thin market areas

7. Carers and the Informal Care System

The Support at Home Program does not exist in isolation from the informal care system. For every person receiving formal home-based care, there is typically an informal carer — usually a family member, usually a woman — who provides additional unpaid care and support. The adequacy of the formal care system directly affects the burden placed on informal carers.

NLEC's 2026 Intelligence Report notes that more than twice as many primary carers are women as men, and that many primary carers live with disability themselves. The reduction of formal care supports — through co-payment barriers, thin market failures or inadequate package levels — shifts caring responsibilities onto informal carers, with consequences for their health, wellbeing, workforce participation and financial security.

NLEC submits that the Support at Home Program must include:

- Explicit recognition of the role of informal carers in the care system and the risks of carer burden and burnout
- Carer support services that are integrated with the Support at Home Program, not separate from it
- Respite care provisions that are adequate, accessible and designed with the involvement of carers
- A carer impact assessment of the Program's co-payment and service access provisions

8. First Nations and Culturally Diverse Communities

NLEC's 2026 Intelligence Report assesses First Nations systems as 'Critical' — with culturally safe services remaining the exception rather than the rule across most system domains. The Support at Home Program must be designed and delivered in ways that are culturally safe for First Nations peoples and people from culturally and linguistically diverse backgrounds.

NLEC submits that:

- First Nations peoples must be involved as genuine partners — not merely consulted — in the design and governance of Support at Home services in their communities, in accordance with self-determination principles
- Community-controlled organisations must be supported to deliver Support at Home services in First Nations communities, with funding models that reflect the higher costs of service delivery in remote areas
- Culturally safe service delivery standards must be developed with the involvement of First Nations peoples and people from CALD backgrounds, and must be subject to independent monitoring and reporting
- Translated materials, interpreting services and bilingual workers must be funded as core components of the Program, not optional extras

9. The Disability-Aged Care Interface

One of the most significant lived experience challenges in the current care system is the interface between the NDIS and the aged care system. People with disability who are ageing, and older people who acquire disability, frequently fall into gaps between the two systems — receiving inadequate support from both.

The Support at Home Program must address this interface explicitly. NLEC submits that:

- People with disability who are ageing should not be required to transition from the NDIS to the Support at Home Program if the NDIS better meets their needs — the principle of "no worse off" must be applied
- The Support at Home Program must include clear, accessible pathways for people who need supports from both the NDIS and the aged care system
- The interface between the two systems must be designed with the genuine involvement of people with lived experience of navigating both systems
- A joint NDIS-aged care interface review should be conducted, with findings published and acted upon before the Support at Home Program is fully implemented

10. Co-Design and Lived Experience Governance

NLEC's National Co-Design Standards Framework establishes seven standards that must be met for a process to constitute genuine co-design. NLEC's assessment of the Support at Home Program's development process is that it has not yet met these standards — particularly in relation to early and sustained involvement, shared power in decision-making, and public accountability for outcomes.

NLEC submits that the Support at Home Program must include a permanent lived experience governance mechanism — not a one-off consultation process — that:

- Includes people with lived experience of home-based care, including older people, people with disability, carers, First Nations peoples and people from CALD backgrounds
- Has genuine decision-making power over the Program's design, implementation and evaluation — not merely advisory influence
- Meets regularly and has access to the information needed to exercise meaningful oversight
- Is fairly remunerated for its work
- Reports publicly on its activities and findings

R1 Proactive Hardship Identification and Protection

The Committee recommend that the Support at Home Program include a proactive hardship identification and referral mechanism, designed with the involvement of people with lived experience of financial hardship in care systems, with hardship provisions that are easy to access, widely known and applied proactively rather than reactively.

R2 Market Stewardship and Provider-of-Last-Resort

The Committee recommend that the Support at Home Program include a market stewardship function with clear responsibility for identifying and addressing thin markets, and provider-of-last-resort arrangements to ensure that people in thin markets can access care, with specific funding and incentive structures for rural, regional and remote areas.

R3 Carer Impact Assessment and Support Integration

The Committee recommend that a carer impact assessment of the Program's co-payment and service access provisions be completed before full implementation, and that carer support services be integrated with the Support at Home Program, with adequate, accessible respite care provisions designed with the involvement of carers.

R4 First Nations Self-Determination and Cultural Safety

The Committee recommend that First Nations peoples be involved as genuine partners in the design and governance of Support at Home services in their communities, that community-controlled organisations be supported to deliver services, and that culturally safe service delivery standards be developed with First Nations involvement and subject to independent monitoring.

R5 NDIS-Aged Care Interface Resolution

The Committee recommend that a joint NDIS-aged care interface review be conducted before full implementation of the Support at Home Program, with findings published and acted upon, and that the principle of "no worse off" be applied to people with disability who are ageing.

R6 Permanent Lived Experience Governance Mechanism

The Committee recommend that the Support at Home Program include a permanent lived experience governance mechanism with genuine decision-making power, fair remuneration, public reporting obligations, and membership that includes older people, people with disability, carers, First Nations peoples and people from CALD backgrounds.

R7 Independent Lived Experience Monitoring

The Committee recommend that the Support at Home Program be subject to independent lived experience monitoring — conducted by a body independent of government and providers — with findings published annually and directed at the

people with the power to act on them. NLEC's National Evidence Collection Program is designed to contribute to this monitoring function.

R8 Genuine Co-Design Before Full Implementation

The Committee recommend that the full implementation of the Support at Home Program be contingent on the completion of a genuine co-design process meeting the standards of NLEC's National Co-Design Standards Framework, with particular focus on co-payment design, thin market provisions, carer support, First Nations services and the disability-aged care interface.

12. Conclusion

The Support at Home Program has the potential to significantly improve the lives of older Australians and people with disability who rely on home-based care. But that potential will only be realised if the Program is designed with the genuine involvement of the people most affected by it — not merely consulted about it after the key parameters have been determined.

NLEC's core submission is that lived experience is not symbolic consultation. It is operational intelligence. The people who know most about how Australia's care systems work — and where they fail — are the people who have lived inside them. Their evidence should shape the Support at Home Program. NLEC's National Evidence Collection Program will gather that evidence and publish it in the public interest.

> ***"A care system that does not genuinely involve the people it is meant to serve in its design will not serve them well. That is not an opinion. It is the lesson of every royal commission, every parliamentary inquiry and every independent review that has examined Australia's care systems in the past two decades."***
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> — National Lived Experience Commission, June 2026

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