

17 August 2025

The Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600
Phone: +61 2 6277 3515
community.affairs.sen@aph.gov.au

Re: Inquiry into aged care service delivery - Submissions Close 22 August 2025.

https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Agedcareservice

Dear Senators,

Please find on the following pages a submission to the Senate Committee inquiring into aged care service delivery. The Australian Self-managed Support At Home (ASSH) Consumer Core Group represents about 6,000 older Australians (and their carers) who live at home and self-manage their Home Care Packages (HCPs). We are extremely concerned about the unacceptable waiting times for the allocation of HCPs, aspects of the Aged Care Act 2024 and government reforms that we believe will be harmful to many older Australians receiving aged care funding.

Our group acknowledges the work done by government to implement these reforms; however, this is a generational opportunity to get the aged care system “right”, and our lived experience of the current and proposed reforms tells us that is not happening.

Our members live the daily reality of aged care funding and we offer Senators a “grass roots” perspective from within the aged care system that is often not presented to government by larger government-funded advocacy organisations (OPAN, COTA, NOPRG and the Council of Elders), who rely on this funding to continue their work.

We thank the Senators for considering our submission and we hope that your work will lead to a best practice Aged Care system for current and future older Australians.

Yours Sincerely,

Brian Corless on behalf of:

The Australian Self-managed Support At Home (ASSH) Consumer Core Group

Lesley Forster (WA)

Peter Willcocks (VIC)

Susan Watts (TAS)

Hanna Law (SA)

Peter McRae (SA)

Paul Absalom (NT)

Stella Perkins (NSW)

Peter Freckleton (VIC)

Brian Corless (NSW)

*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

Parliamentary Submission to the Senate Standing Committees on Community Affairs

Inquiry into Aged Care Service Delivery

Submitted by: Australian Self-managed Support At Home (ASSH) Consumer Core Group

Date: 17 August 2025

Submission to: Senate Standing Committees on Community Affairs

Inquiry: Aged Care Service Delivery

Contact: Brian Corless

Living with the Realities of Aged Care in 2025

Executive Summary:

The **Australian Self-managed Support At Home (ASSH) Consumer Core Group** thanks Senators for considering the implications of what we see as policy in aged care that is harmful to older Australians. In accordance with the Standing Committee's Terms of Reference, we bring to the Senate's attention the lived experience of home care funding with:

- Long waiting times for the allocation of funds.
- Unaffordable individual contributions as fees.
- An absence of enforceable rights in the Aged Care Act 2024.
- Insufficient funding caps for assistive technology and home modifications.
- Inadequate relief mechanisms for financial hardship.
- An undermining of self-management and consumer-directed-care.
- A lack of medical and allied health prescription in clinical care services.

Our core aged care advocacy group, on behalf of our 6,000 members, asks Senators to heed these views as the lived reality of aged care in Australia in 2025. This lived experience demonstrates that aspects of current reforms risk worsening rather than improving outcomes for older Australians. As we strive to remain living at home, these consequences of the reforms are not often seen by politicians and policymakers in the representations of larger government-funded advocacy groups.

We urge the Senate to recommend urgent interim measures viz., the immediate release of home care funding, and to amend flawed elements of the Support at Home program and Aged Care Act 2024 before they cause avoidable harm. We invite Senators and their colleagues to view our short film and to meet with us and learn more about what it is like to be receiving aged care funding now.

*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

About this Group:

The **Australian Self-managed Support At Home (ASSH) Consumer Core Group** is a group of aged care advocates who are either self-managing their funding under the current Home Care Packages (HCP) program or are carers for someone who does. We represent the lived experience of older Australians who receive aged care funding and who want to remain at home rather than enter a residential aged care facility. Most members of this group have differing levels of disability and complex health needs requiring higher levels of funding and we represent 6,000 individuals in similar circumstances to us through their membership and discussions on our Facebook page and website.

Our lived experience of Aged Care funding at home and its confronting realities gives us insights into the deficits of the Aged Care system that are not always represented fully by larger government-funded representative bodies such as OPAN, COTA, NOPRG and the Council of Elders. We believe that the funding of large advocacy organisations by government in its current format increases the likelihood that their criticism of government policy will be diminished. The end result from our experience is that often the concerns of many aged care recipients are either not heard or are ignored by government.

Our core group meets weekly and we welcome any Senators and their colleagues who want to attend and learn more about the lived reality of the current and proposed Aged Care system for those of us who want to remain living at home longer.

We urge Senators to **look at the short film “Keeping Our Lights on at Home”**, featuring some of our group and a finalist in an international short film competition, and to share it with your Parliamentary colleagues.

<https://www.focusonability.com.au/FOA/films/3711.html>

Members of the Australian Self-managed Support At Home (ASSH) Consumer Core Group supporting this submission are:

Lesley Forster (WA)

Peter Willcocks (VIC)

Susan Watts (TAS)

Hanna Law (SA)

Peter McRae (SA)

Paul Absalom (NT)

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*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

Our Submission:

Our core advocacy group of older Australians receiving aged care funding thank Senators for advocating on behalf of individuals on waitlists and raising broader concerns that many of us have about existing and proposed changes to the aged care system.

Our concerns are about *the implications for older Australians, their families, carers, service providers and state and territory health systems of the Government's decision to delay the commencement of the new Support at Home program until 1 November 2025 while also withholding the release of any additional Home Care Packages*, and for the *well-being and quality of life* of these older Australians in what is becoming a punitive aged care system.

We ask Senators to consider our responses below to the following Terms of Reference items:

- (a) the impact of the delay on older Australians waiting for support at home, including unmet care needs and the wellbeing of seniors and their carers;*
- (c) the impacts on aged care service providers, including on their workforce;*
- (d) the impacts on hospitals and state and territory health systems;*
- (f) the adequacy of the governance, assurance and accountability frameworks supporting the digital transformation projects required to deliver the aged care reforms on time;*
- (g) the implementation of the single assessment system and its readiness to support people to access a timely assessment now and beyond 1 November 2025.*

Long waiting lists for Home Care Packages will have dire consequences for older Australians and their carers.

Long waiting lists for the allocation of Home Care Packages (HCPs), including those awaiting upgraded levels of funding, has the potential for catastrophic consequences for older Australians. We understand that as of 30 June 2025, waiting times between assessment and allocation of funding for those assessed as medium priority for HCPs can be up to 8 months. For those assessed as having the highest and most complex Level 4 needs the wait for medium priority clients is up to 6 months and for some up to 13 months. Many may require hospitalisation or die in that time.

Delays in the allocation of funds affects the physical and psychological health and the quality of life of older people and their carers. As of 31 March, 2025 it was estimated that over 87,500 older people were waiting on the allocation of HCPs, with one estimation that this figure could balloon out to 100,000 by November, 2025.¹

There is no guarantee that the Support at Home program will be ready and viable for commencement on 1 November, 2025 which increases the urgency for those awaiting funding to stay at home. Service providers, airing their concerns about the lack of funding packages and calling this week for the release of HCPs now, said that they are ready to employ new staff for a roll out of unallocated HCPs, but cannot do so until the packages are released.² Further delays in this funding could see providers being unprepared and the 1 November target becoming unviable.

*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

No-one undergoes an aged care assessment because they are planning early for a better old age later on. Assessments are undertaken when older adults and their carers have reached that critical point in their life where they need urgent financial support to remain at home now, not administrative delays. An aged care assessment itself can be challenging without the delays.

For many older people and their carers, assessment for aged care funding is complex, convoluted and often stressful at this critical point in their life. A member of our core advocacy group living regionally experienced a phone reassessment due to urgency to meet a change in health status. Unfortunately, an incorrect diagnosis was registered in the final assessment uploaded to My Aged Care. The consumer was unable to have this diagnosis redacted. The rationale given for not correcting the information was that the document was the final version uploaded on a government website. Mistakes in assessments add a layer of unnecessary stress to consumers navigating unfamiliar processes.

The consequences of delays in allocating HCPs will see increased hospitalisations and the direct entry of older people into residential aged care, thus bypassing the home care package program altogether. Australian estimates show that delays in allocating home care funding increases frailty and health decline, carer burnout, inappropriate hospitalisations and early entry into residential aged care.³ But, this data is not new. In 2020-2021 it was estimated that 8,000 people died while waiting for HCPs and an additional 11,000 entered residential aged care⁴, yet the government fails to heed these warnings.

It cannot be stressed enough that it is unconscionable for this lack of action arising from administrative delays to be downplayed by government and not acted upon immediately. Despite the government's assurances, there is no way to describe these delays other than as a failure of governance with the potential to see more older Australians dying before they receive aged care funding to stay at home.

Older people need action on waiting lists now to restore some degree of their quality of life and dignity, not more rhetoric from financially-focussed bureaucrats.

Solution:

- *We urge the Senate Standing Committee to recommend to Parliament that the government must act now to reduce waiting lists for those approved for Home Care Packages and not wait for the Support at Home Program roll out on 1 November, 2025 or later.*

We ask Senators to consider our responses below to the following Terms of Reference item:

(h) any other related matters.

Our aged care advocacy group acknowledges the work done by government to implement aged care reforms. However, some of these reforms will have a detrimental effect on the health and quality of life of recipients of aged care services. We ask Senators to consider these other aspects of the government's aged care reforms and their damaging impact on older Australians.

*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

Individual contributions in the Support at Home program are unaffordable and will impact negatively on the health and quality of life of many older Australians.

In 2021 the Aged Care Royal Commission reported that 80% of older people want to age at home. For many, this goal will be unaffordable as the introduction of individual contributions for critical in-home support services will pose significant financial hardship for full pensioners, part-pensioners, and self-funded retirees with limited resources. These demographics typically rely on fixed incomes that are already strained by fundamental living expenses including housing, utilities, food, and medical costs. Imposing additional out-of-pocket costs for vital services such as domestic assistance, garden maintenance, and personal care support will place unsustainable strain on already constrained household finances. These services represent fundamental necessities rather than discretionary spending - they are crucial for maintaining daily safety, personal hygiene, and continued independence.⁵

This particularly applies to many of those currently on waiting lists who were assessed as eligible for a HCP prior to 12 September 2024 and remain unallocated. Whereas, under the proposed Support at Home program those receiving funding prior to 12 September 2024 will be “grandfathered” with a “no worse off” policy, those who are on waiting lists will have to pay full individual contributions when their funding arrives. In the interim they remain unsupported. In terms of human costs, this represents a “double jeopardy” for them in the ongoing denial of aged care funding.

The dire implications of a flawed Support at Home model are seen in this example:

The Department has provided a case study as an example and shows a person who is retired and receives a part Age Pension. They own their house and have \$10,000 in a savings account in addition to superannuation income. Their total income, including the age pension is \$45,500. They are assessed as eligible for Support at Home services after 1 November 2025. As they are a new participant, they are subject to new arrangements and will make a total contribution of 14.0% to their Support at Home services. The government covers 86.0% of the cost of care.

The two flaws that we see in this model are:

- **The more services you have, the more you pay – but your income stays the same.**

Some consumers may cope with 4 hours a fortnight of services but the majority of people living at home with disability and/or complex health needs will struggle with anything less than 12 hours a week of services. In many cases their family carers need respite where nothing less than 20 hours a week is needed to supplement and maintain their own 24/7 care contributions.

- **Support at Home contributions do not account for life expectancy or how older people might need to spread their savings over that time.**

Most older Australians want to stay at home until the end of their lives. They try to stretch their savings so they can afford help at home for as many years as they’ll need it. But the proposed individual contributions model calculates fees based on how much money they have right now,

*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

without considering future needs. This means contributions are “front-loaded” – older people will use their savings too quickly, leaving them with less money later in life.

Based on the Department’s projections, the person in the case study is expected to pay an individual contribution of about \$2,500 per year. In less than 4 years they will have no savings. What do they do then? Live in poverty or be admitted to hospital or go into residential aged care. All of which will cost the government more than forcing them to pay individual contributions.

In this flawed model, the Department is ignoring predicted average life expectancy and lifetime budgeting in its estimates. In 2021-2023, AIHW predicted that men and women over the age of 65 could live a further 20.1 years and 22.7 years respectively.⁶

Several Australian analyses confirm that it is far less expensive for governments to support older people to remain living at home than to move them into residential aged care.^{7,8} Home support programs not only deliver better financial outcomes but also align with the preferences of older Australians to “age in place.”

Some staff at Services Australia are well aware of the basic flaws in the design of the “Individual Contributions” model viz. that the *“user pays a set percentage of what you use”*.

Greater and immediate engagement of consumer representatives (including those other than OPAN, COTA, NOPRG and the Council of Elders) with Services Australia is needed to lead the discussion back to the current manageable model of income tested fees. Individual contributions via a percentage was an ill-conceived idea and is just another example of changes made where none were realistic nor needed.

Solution:

- *Amend the rules for the Support at Home program under consideration by the Senate.*
- *Delete all references and calculations to Individual Contributions and replace these with the language to support a continuation of the current practice of Income Tested fees.*

The new Aged Care Act is NOT a Rights-based act.

The lived experience of our aged care core advocacy group is that the new Aged Care Act commencing 1 November, 2025 is not genuinely a “rights-based” Act for these reasons:

- **Rights are not enforceable**

Although the new Aged Care Act 2024 nominally introduces a rights-based framework and espouses keeping the focus on an older person’s rights, it has been described as “aspirational” rather than “enforceable” and stops short of granting legal rights that individuals can enforce in court. The rights listed in the Act are described as human rights, but this does not mean legal rights and many who read government publications and advocacy documents will assume that the two are equal. They are not, and this is a serious shortcoming in the Act.

*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

Despite containing a “Statement of Rights” in the new Act, Clause 24(3) explicitly states these rights are not enforceable in courts or tribunals. Instead, enforcement is left to regulators, which makes the rights “principles” rather than empowered “entitlements”.

We see this aspect of the Act as largely symbolic and not real. Providers face fewer consequences, and government **can avoid** its own role in ensuring that older people receive genuine consumer-directed (or person-centred)-care.

This abrogation of responsibility by government through failing to legislate aged care rights led Professor Stephen Duckett to comment in 2024:

“The Act “smacks of ‘rights washing’ ... rhetoric is simply there to placate consumers and advocates allowing providers to continue on their way unimpeded and government to eschew any role in creating and steering a consumer-focused service system.”⁹

The following is an example of what our group believes are the deficits in the new Aged Care Act compared with what could be a genuine “rights based” Act.

An example of what could be a genuine “rights based” Act:

An older person, age 82, lives alone and receives government-subsidised home care. Her provider regularly sends carers at the wrong time, ignores her request for female staff, and sometimes skips scheduled visits. This affects her hygiene, safety, and ability to leave home.

Under the Aged Care Act 2024 (effective from 1 November 2025)

Step	What Happens	Source
1. Statement of Rights	The person’s rights (independence, choice, privacy, cultural needs) are in the <i>Statement of Rights</i> (agedcarequality.gov.au , health.gov.au).	Clause 24(1) of Aged Care Bill 2024.
2. No direct legal action	She cannot sue under the Act for breach of these rights (aph.gov.au , clause 24(3)).	Senate Committee Report, Ch. 3.
3. Regulator complaint	She can complain to the Aged Care Quality and Safety Commission . The Commission may investigate, issue an improvement notice, or fine the provider.	agedcarequality.gov.au .
4. No guaranteed compensation	Even if the provider is found non-compliant, there is no automatic right to damages or service refunds — only the regulator can pressure the provider to fix services.	Inspector-General of Aged Care submission, Senate inquiry (aph.gov.au).
5. Alternative legal avenues	She could try consumer law or negligence claims, but these are costly, complex, and don’t rely on the Aged Care Act itself.	accc.gov.au .

*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

Under a True Rights-Based Law

Step	What Happens	Example
1. Legally enforceable rights	The person's rights to autonomy, choice of carer gender, reliable service, and dignity are legally binding duties on the provider.	Similar to UK <i>Human Rights Act 1998</i> or QLD <i>Human Rights Act 2019</i> .
2. Direct cause of action	She can file a complaint in a tribunal or court if her rights are breached, without relying on a regulator's discretion.	QLD Human Rights Act, s. 59–62.
3. Binding remedies	Tribunal/court can order the provider to: <ul style="list-style-type: none"> • Stop the behaviour • Deliver services as required • Pay compensation for harm suffered 	Human Rights Act cases: <i>Certain Children v Minister for Families and Children</i> [2016] VSC 796.
4. Provider accountability	Legal risk motivates providers to comply consistently - not just when the regulator steps in.	UK Human Rights Act model in social care enforcement.

The harmful effects of not legislating “true” rights is seen in the 2025 class action lawsuit against BUPA Aged Care, a provider of residential aged care. This class action is based on allegations that BUPA failed to provide quality of care to its residents as required under the Act.¹⁰ We find it impossible to understand why, through its failure to include “enforceable” rights in the Act, the Government and the Department leaves it up to older people to seek class action lawsuits as a means for legal recourse whenever their rights are transgressed.

- **No provision in the Aged Care Act 2024 for older people with disability.**

Of those Australians aged over 65, more than half (52.3%) had a disability; nearly all (95.9%) lived at home; and around 2 in 5 (39.8%) needed assistance with daily activities.¹¹

Despite these statistics, older people living at home with disability are not referenced in the Aged Care Act 2024. Not only have many older people been excluded from the NDIS because they are older than 65 which is discriminatory, but government continues to overlook our needs in its ongoing discriminatory legislation and policies. There is no intersection between ageing and disability in the Aged Care Act 2024.

Whereas the government's view is that the Act aligns with international rights instruments including the Convention on the Rights of Persons with Disabilities (CRPD), the final text does not include direct reference to disability or define disability-inclusive rights alongside or within the framework of aged care rights.

Although the Government refers to the Assistive Technology and Home Modifications (AT&HM) scheme for aged care in its proposed Support at Home program, it is inferior to the AT&HM scheme in the NDIS¹² and is fraught with the funding problems referred to below. The Royal Commission into Aged Care Quality and Safety (RC), Recommendation 72 states:

*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

By 1 July 2024, every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person under the age of 65 years with the same or substantially similar conditions.

Despite the RC's Recommendation 72, inequity and inequality of outcomes for older people with disability highlights the differences between aged care and the NDIS.

In our opinion older people living at home with disability are invisible under the Aged Care Act 2024 and given the funding disparity between the NDIS and aged care, and despite RC's Recommendation 72, this constitutes another form of government-led systemic discrimination against many of us.

- **No “dignity of risk” with mandatory surveillance of HCP recipients**

In 2021 the RC's Final Report titled “*Care, Dignity and Respect*” highlighted the need for the notion of a “*dignity of risk*” in its core principles stating that “...older people deserve to live with respect and dignity...”, and have “...autonomy, the presumption of legal capacity, and supports for decision-making...”.

The RC also highlighted instances where older people experienced “elder abuse” while living at home. Rightly, the RC recommended adopting protective policies for vulnerable older people at home.

Our group acknowledges the need to protect vulnerable older people at home, but not all of us are vulnerable to abuse or unable to protect ourselves from abusive situations, yet the surveillance and reporting on older people is mandated for all consumers. The reality of this practice now is that for some older people there is no “*dignity of risk*” and no mechanism to opt out of this mandatory reporting. In justifying this intrusive breach of rights, the Department explains that providers have a “...*duty of care under the regulatory model*...” yet it fails to show balance in its comments by not referring the principle of a “*dignity of risk*” for older people living at home and in particular those self-managing funds.

Further contradictions in the Department's knee-jerk reaction to the RC's findings are seen in the following example of this poorly conceived policy. It is common practice for service providers to compel 3rd party workers e.g., gardeners and cleaners, to report on the well-being, including the physical and mental health, of consumers.

These workers, who self-managing consumers hire directly, often do not want to make these well-being assessments, and are certainly not qualified or skilled to do so, yet believe that they are compelled carry out this task by provider guidelines. In creating this policy that espouses a duty of care for providers to fulfill, the Department has behaved recklessly. In one instance, a negative report to a provider from a cleaner assessing a recipient's mental state was in fact inaccurate and overstated, with a consequent serious negative impact on that consumer.

*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

Many older people remain cognitively capable of protecting themselves from elder abuse in their homes and have been doing so all of their adult life. This ageist and discriminatory practice of reporting contravenes the basic rights of older people not to be surveilled. There is no mechanism to opt out of this reckless policy or to accept a *dignity of risk* while living at home.

Solutions:

- *Amend the Age Care Act 2024 to become legally enforceable by individuals.*
- *Provide direct access to tribunals or courts for aged care recipients when rights are breached.*
- *Provide a mandatory redress schemes for harm caused by provider breaches.*
- *Add explicit recognition of older people living with disability in the Act.*
- *Adopt the Royal Commission's Recommendation 72.*
- *Create joint funding protocols between the NDIS and Aged Care for older people who are excluded from the NDIS because of their age (65).*
- *Enforce a genuine dignity of risk for those who choose to have the right to not be surveilled and reported on by providers.*

Insufficient Funding Caps for Assistive Technology and Home Modifications

The proposed \$15,000 lifetime limit for the Assistive Technology and Home Modifications (AT-HM) program represents a critically inadequate allocation that fails to acknowledge the evolving needs of aging Australians. Aging constitutes an ongoing process rather than a singular event. Individual requirements change over time, mobility may progressively decline, and modifications suitable at age 75 may prove insufficient at age 85. Bathroom safety modifications alone frequently exceed this allocation, particularly when incorporating essential safety elements including accessible showers, support rails, and slip-resistant surfaces. Similarly, structural modifications for access ramps, mechanical lifts, or other mobility improvements often surpass the specified limit. This financial constraint will prevent numerous older Australians from implementing crucial modifications necessary for safe, independent home living. Without appropriate and timely modifications, many individuals will face premature residential aged care placement, contradicting the fundamental objectives of the Support at Home program.

Industry experts, including Home Modifications Australia (MODA), have expressed concern that this cap may force people into residential aged care prematurely, resulting in financial distress and increased hospitalization rates from preventable accidents, particularly falls—a significant contributor to ambulance delays and hospital bed shortages throughout Australia. Occupational Therapy Australia has similarly criticized the cap as fundamentally inadequate, noting that comprehensive modifications can cost upward of \$50,000, while even minor adjustments can rapidly exhaust allocated funding.^{13,14,15}

Solution:

- *Remove the Assistive Technology and Home Modifications (AT-HM) funding cap.*

*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

Inadequate Relief Mechanisms for Financial Hardship

Whereas the pricing structure incorporates hardship provisions for individuals unable to meet co-payment obligations, the access pathway for this assistance contains fundamental flaws. These provisions are both burdensome and intrusive, demanding disclosure of sensitive financial information that many older adults find uncomfortable to share. The application process is complex and must be initiated by the recipient which assumes that they are aware of this provision. Many recipients will not be aware of this, nor will some have the capacity (language and memory) or support to understand and complete an application.

Additionally, the process has concerning delays and lacks adequate transparency. We have documented instances where hardship applications required over seven months for processing, only to result in rejection without sufficient explanation. Such experiences create disincentives for other applicants, effectively excluding vulnerable funding recipients from essential services and increasing their risk exposure.¹⁶

Within financial hardship provisions there is a safety net floor viz. a level below which no fees are paid. Our group believes that eligibility for the full pension should be the floor. Hardship applications should only be required above this floor and there needs to be a process of regular informing of its existence in accessible formats.

Solutions:

- *Better and more widely distributed information on hardship provisions.*
- *Streamline and humanise the hardship application process to ensure rapid, non-invasive, trust-based assessments with defined resolution timeframes and clear appeals procedures.*
- *Set the safety net floor for hardship at eligibility for the full age pension.*

Self-management and consumer-directed-care (CDC) rights are being undermined,

Consumer-directed-care (CDC), which includes person-centred-care, and the self-management of home care funding aims to empower older Australians by letting them choose 3rd party workers, services and supports, and schedule and manage those to best suit their needs. Previously CDC was included in the *Aged Care (Living Longer Living Better) Bill 2013*, and at the time espoused a move away from “*a service provider focus (towards) a more consumer-oriented approach.*”¹⁷

The basis for self-management of aged care funds, in self-determination theory, evidences a significant positive effect of self-management on physical health, wellbeing and older people thriving while ageing at home.¹⁸ In practice, however, CDC was replaced by person-centred-care in the Aged Care Act 2024 and has failed many older people receiving aged care funding. Consumer rights are being undermined by systemic barriers such as inflexible and confusing rules around what services are included and excluded. Providers retain the balance of power in the funding of services and are often afraid of being sanctioned by the Safety Commissioner

*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

for making the wrong decision, so are apt to decline reasonable requests for funded services more often than before. Some providers seem also to continue to be driven by a profit-motive in their decisions about approving or declining reasonable requests for services.

Many funding recipients are living with this imbalance of power between the service provider and consumer heavily tipped towards the former. The lived reality for many older Australians is often less services and less autonomy and empowerment, the antithesis of either Consumer-Directed-Care or Person-Centred-Care.

In 2023 our aged care advocacy group conducted a survey of the mental health of over 140 self-managing aged care funding recipients and their carers following changes to provider guidelines which saw stricter exclusion criteria for funding. The results of the survey showed that **over 70% of participants living at home reported high to very high levels of psychological distress as a direct result of the changed guidelines for providers.** According to research estimates **65% of those self-managing** recipients and **70% of their carers** met the DSM-V criteria for a **diagnosis of major depression.** “**Very High**” levels of distress as measured on the K10 psychological distress scale **should flag the need for further assessment and the presence of suicidal ideation.**¹⁹ The Minister and Department are aware of these alarming results yet have ignored the data and invitations for consultation and continue with the current punitive inclusions/exclusions model.

Authentic consumer choice requires a collaboration with consumers, where their choices and needs are met in an equal balance of power. Some providers have embraced CDC principles which has benefitted some consumers. However, many providers either remain too scared of making a mistake in their decisions or are focussing on balance sheets and profits, to the continued detriment of our lived experience of aged care.

Solution:

- *Allow more flexibility in the approval of requests for services and items and revise the current restrictive inclusions/exclusions policy to reflect genuine consumer-directed-care.*

Clinical care needs to be medically supervised not randomly assigned or denied.

Currently, under the Department’s inclusions/exclusions guidelines, requests for medically necessary services from Home Care Packages (HCPs) are approved or denied by unqualified service provider staff without reference to or heeding the advice of recipients’ treating medical and allied health professionals. It appears that under the proposed Support at Home program to commence on 1 November, 2025 this policy will continue and become more complex.

Prior to January 2023, HCP managers approved clinically required supports recommended by recipients' treating medical and allied health professionals within an individual’s HCP budget, based on interpretation of the Quality-of-Care Principles 2014, a Legislative Instrument of the Aged Care Act 1997. Changes to provider guidelines in January 2023 saw more restrictions

*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

placed on requests for services based on extraneous criteria assessed by unqualified provider staff, with the increased and alarming levels of distress referred to above.

HCP recipients reported that items such as medically necessary non-PBS medications for pain management or medically necessary heating and cooling at home were excluded. Many recipients could not afford these costs from their meagre income or savings.

More restrictions in the form of funding exclusions will be added to the Support at Home program further reducing service provider's capacity to create effective individualised care plans. In addition, under current HCP rules service providers can approve new services such as urgent nursing wound care. In the Support at Home program, it seems that adding urgent nursing wound care services to a care plan may require partial reassessment involving unknown wait times.

An example of these restrictions comes from one of our core advisory group members:

I manage a respiratory disease and air quality in my home is essential to my good health. Some consumers have thermo-regulatory conditions and others have lung disease. If we don't have clean air via regular and professionally cleaned heating cooling equipment and dust free carpets etc., we are likely to end up in hospital or worse. Support at Home Rules must be amended to provide for timely and professional cleaning/servicing of equipment in the home to ensure appropriate environmental temperature and air quality, as it does in Residential Aged Care. The alternative is more catastrophic consequences for older people living at home.

Solutions:

- *Categorise all medically necessary and recommended services and items as clinical care, thus not attracting individual contribution fees.*
- *Remove the onus of approving or declining requests for medically necessary and recommended services and items from service providers and back to treating medical and allied health professionals without any further aged care assessment process.*

The **Australian Self-managed Support At Home (ASSH) Consumer Core Group** thank Senators for the opportunity to again present to Parliament the lived reality of some of the government's aged care reforms. We also acknowledge the work done by government to implement these reforms; however, this is a generational opportunity to get the aged care system "right", and our lived experience of the current and proposed reforms tells us that is not happening.

Our lived experience is a "grass roots" perspective from within the aged care system that is not often presented to government by government-funded advocacy organisations (OPAN, COTA, NOPRG, the Council of Elders), who rely on this funding to continue their work. We hope that Senators will view this submission as an attempt to shine light on the deficits of the aged care system now and help us create best practice aged care for current and future older Australians.

*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

Recommendations:

We ask Senators to consider the following recommendations:

1. **Release Additional HCPs Immediately** — do not wait for November 2025.
2. **Retain Income-Tested Fees** — abolish percentage-based individual contributions.
3. **Make Rights Enforceable** — direct court/tribunal access, mandatory redress scheme.
4. **Include Older People with Disability in Legislation** — adopt Royal Commission's Recommendation 72 and establish joint NDIS/Aged Care funding protocols.
5. **Protect Dignity of Risk** — opt-out from mandatory surveillance where not at risk.
6. **Remove or Substantially Raise AT-HM Cap** — align funding to evolving assessed needs.
7. **Reform Hardship Provisions** — automatic floor at full pension level; streamline and publicise process.
8. **Restore Genuine Consumer-Directed-Care** — flexible inclusions/exclusions; co-designed care plans.
9. **Return Clinical Decisions to Health Professionals** — classify medically necessary supports as exempt from individual contributions.

Submitted by:

The Australian Self-managed Support At Home (ASSH) Consumer Core Group

Lesley Forster (WA)

Peter Willcocks (VIC)

Susan Watts (TAS)

Hanna Law (SA)

Peter McRae (SA)

Paul Absalom (NT)

Stella Perkins (NSW)

Peter Freckleton (VIC)

Brian Corless (NSW)

17 August 2025

*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

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*Australian Self-managed Support At Home (ASSH) Consumer
Core Group - Senate submission on Aged Care August 2025*

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