Dementia Alliance International

Submission to the Australian Government in relation to the New Aged Care Act 2024 Consultation

Submission from: Dementia Alliance International (DAI)

Submitted by: Ms. Theresa Flavin, Human Rights Advisor, on behalf of the Board of Directors and Australian Membership of people with dementia.

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About Dementia Alliance International

Dementia Alliance International (DAI) is a registered international charity dedicated to providing global support for people with dementia. It advocates at local, national, and international levels for timely and accurate diagnoses, improved post-diagnostic support and services, including access to rehabilitation, to enhance quality of life and promote longer independence. DAI campaigns for the human rights of all people living with dementia, in community and residential care and for equitable inclusion in the community, and for dementia to be supported as a condition causing disability (WHO:2024). DAI is the global voice *of* people with dementia, whose vision is a world where all people are valued and included.

Notably, for this submission, Dementia Alliance International is the only NGO exclusively representing people diagnosed with any type or cause of dementia, regardless of age. These individuals are recognized as people with disabilities, entitled to equal human and disability rights, including access to the Convention on the Rights of Persons with Disabilities (CRPD) and the Optional Protocol to the Convention Against Torture (OPCAT).

DAI is the only organisation representing people living with dementia exclusively in Australia; it is the only independent and autonomous voice of people of any age, diagnosed with any type of dementia in Australia, and globally.

Overview

Chapter 1, Part 1, Section 4

DAI welcomes the opportunity to provide commentary on the Age Care Rules, however we also acknowledge that people living with dementia and our care partners were not included in the Age Care Task Force team and that many older people and people living with dementia were passively excluded from the consultation process.
A simplified (Accessible) outline of the instrument was not supplied with the consultation draft. This omission significantly impacts the ability of the community to provide meaningful commentary or feedback to the Department. Last minute consultations were held, with a very short lead time, which were not well attended as they were simply not accessible to anyone in the community with a disability, in particular people living with dementia.

Upfront, DAI wish to draw attention to the fundamental disparity between disability support through the NDIS, and the absence of disability specific support under SAH. This gap is catastrophic to the quality of life for older people living with disability in Australia. Older people consequently live without any meaningful protection from the Convention for the Rights of People living with a Disability (CRPD) of which Australia is a signatory. The inevitable outcome of capping in home services at a dollar amount that will approximate an absolute maximum of[1] 4 hours of the most basic support 5 days per week. This extraordinary sparse level of support appears to be in place only to drive the institutionalisation of older people should they be unfortunate enough not to 'age well'.

[1] $78,000 x 90% = $70,200 net funding after 'care management payment'.NDIS Price Guide (example) Self Care, daytime,Standard - $67.56. Assuming no services after hours, weekends or public holidays. - maximum hours of support for highest package is $70,200 / $67.56 = 1039. 1039 hours/52 weeks = 20 hours per week. 4 hours of support, 5 days a week maximum. Also assuming no clinical care,allied health or other services more expensive than the most basic.

This gap is now further compounded by the contribution requirements of older people to their 'independence' and to their 'everyday living' supports, which comprise the fundamental tenets of human rights as understood in 2024. Erosion of the ability of older people to live with sufficient resources to meet their basic needs is compounded by the financial impost of a significant contribution to every hour of support for independence and everyday living, which includes access to the community and hygiene that they will access through the Support at Home program. These contributions will further impair the quality of life, dignity and security of all older people, particularly those on the full and part pension, thus penalising the most vulnerable and marginalised of Australian society even further. The lack of insight to the detrimental effects of this contribution scheme is quite bewildering given the 'cost of living' crisis, exorbitant power, food and rent costs, massive interest rises, with an almost insignificant rise in the Age Pension. Contributions in their current form will deeply affect the ability of older people to access the community in any safe or meaningful way, and of course this will have a significant impact on the disease trajectory of any older person living with dementia. It is also unfortunate that the 'assets test' does not appear to be adjusted to protect the older persons liquid assets with a view to contributing to their services, Assistive Technology and Home Modifications.

The human rights implications of the Rules in relation to contributions and caps as published are startling for our older people, and the effects will be felt for generations to come. The withholding of appropriate support through caps, and the financial pressure to find the funds from already stretched family budgets combine to make a powerful driver of old people into institutional care, potentially against their will. The Rules as presented,represent coercive control through fear of debt and insufficient support directly contravene the rights of older people and older people living with a disability, to meaningful choice to remain in the community, and to 'age in place'. As more older people are routinely institutionalised without regular and unimpeded access to their family and

community, into an environment - often 'secured' are a one way pathway to increased violence and sexual assault, with existing reports through the SIRS scheme remaining outrageously high.

DAI contend that the significant limitation of support by means of caps, coupled with a contribution scheme that is discriminatory by nature will attract significant international attention in the Human Rights context, and that the increase in institutionalisation of our older people due to systemic and significant limitation of in home support services, Assistive Technology and Home Modification for older people living with disabilities will eventually lead to numerous and costly redress enquiries and reparations to affected families. Many older people lived through the stolen generation, and many more are care leavers who are currently living through the redress process. They are now in the desperate position of knowing that the childhood trauma that led to their current poor health and disability will result in their institutionalisation. Directly due to this current policy, many of whom will be handed over to the same institutions that took them as infants and young children. The only difference being that they will be required to financially contribute to their 'incarceration'.

AIHW statistics demonstrate that a very significant proportion of older people who will access age care services now and in the future live with disability. Disability of course intersects with people whose first language is not English, people unfamiliar with interpretation of legislation and the many people living in Australia who do not have a significant level of literacy skills who have no meaningful pathway to provide any meaningful feedback. In other words, the very people this will affect the most have been passively excluded from the direct consultation process. While government funded advocacy organisations and peak bodies provide excellent 'representation', this is advocacy 'for' us and not 'by' us. DAI acknowledges that some vignettes have been

provided online, for older people who happen to chance upon them, however this appears to take the form of information as opposed to an invitation to comment.

DAI also note that the capped amounts as published, are somewhat misleading to many readers, as it is not clearly explained that the maximum capped amount of each service level is a gross amount, and that the available net amount is actually 10% less. It would be helpful if future information campaigns advertised the net amount of funding available for direct support, so that older people are better empowered to manage their budgets.

DAI understands that conversation is taking place in the community between older people and their service providers in advance of Support at Home, in relation to making advance arrangements and plans to reduce their levels of support to avoid the co contribution. This of course will result in most older people who do not have 'flexibility' in their budgets to pay the new and substantial contribution to their independence, and everyday living by at least 5% and 17% respectively.

Recommendation 1 Accessible Consultation

DAI recommend that future drafts from the Department of Health and Age Care include an accessible version which provides worked examples which includes clear details of the current context of contributions and the proposed contributions. This will ensure that in particular people living with dementia and our supporters will have clear visibility of the financial impact on their care and wellbeing going forward. This accessibility measure must include hard copy options for background information and context, sufficient time to organise support for travel arrangements and online consultation to be made by the older person. People living with dementia are notably excluded from any meaningful consultation in relation to the Rules, and this is inconsistent with expectations of the Convention for the Rights of People with a Disability (CRPD). DAI further suggest that

consistent terminology be used throughout documentation provided for consultation, with improved definitions for terms that may be changing or unfamiliar to the general public.

Subdivision C - Base individual amounts (Commonwealth Contributions)

194A Classification type ongoing

The language of classification based on the length of the service program, in particular in relation to the palliative care classification presents a challenge to the human rights and dignity of older people. Legislation framed in ageist and ableist language simply further embeds prejudice and hopelessness, and deeply disempowers older people. The concept of such classification runs contrary to the rights based ideals of the new Act, and is absolutely unacceptable in its current form. Classification Short Term is appropriate for the restorative care service, as there is the positive expectation of recovery, but absolutely unacceptable for the palliative care service.

Recommendation 2 Language Conventions

DAI strongly recommends that classification of older people using words that reflect their life expectancy, or utility be removed from any future iteration of the Rules, and that the terminology used for classification be urgently reviewed through a Human Rights lens.

Recommendation 3 Flexibility in Classification Short Term

DAI recommend that greater flexibility be provided to the restorative care and palliative care classification. It is difficult to understand how short term restorative care can be limited to alternate quarters, in the event of repeated ‘trigger’ incidents outside of the proscribed limits. These limits also appear to rule out short term reablement for people

with degenerative ongoing conditions. It also appears crude to limit palliative care support in the event that the older person does not die on schedule.

Part 2 Subdivision E Primary person centred supplements

196A Supplements circumstances and amounts

Dementia Supplement

While it is positive to see recognition of additional needs of older people in the form of supplements, it is most discouraging to find that the dementia supplement in the current arrangements appears to have been discarded. Even though the existing dementia supplement is difficult to access, and is not a material amount in terms of supporting a family to keep their loved one in the community, the complete removal of dementia from the rules implies to us that our particular form of disability does not incur any additional support outside of traditional age care. While DAI appreciate that dementia is covered in the Integrated Assessment Tool, its specific absence from the Rules in relation to care and provider supplements implies to the community that dementia is not being recognised equally with the disabilities outlined in 211B of the rules.

In the absence of a National Dementia Action Plan, DAI are extremely concerned that people living with dementia have no specific access to additional dementia specific services, and are not referenced in any way in the Rules.

Oxygen Supplement

In respect of the oxygen supplement applicability - 196B, DAI are quite unclear whether the supplement is designed to cover the costs of equipment hire and maintenance, or the process of administration and monitoring of the oxygen itself. Oxygen is widely used by

older people who are capable of self administration and monitoring under supervision of the prescribing practitioner. DAI are also unclear on the reasons supporting the requirement for service type nursing, to qualify for oxygen supplementation. Many older people in the community use oxygen generators, both fixed and portable As well as canisters. Oxygen providers deliver training on setup and administration of oxygen to the older person, and any support person who wishes to avail of the training. Outside of very serious end of life and very high levels of clinical care, oxygen can be safely self administered, in many cases with the support of a carer that is not a nurse. This is a matter for the older person and their prescriber, and is not a matter for the government to determine. It is also disappointing to see 196B(c) limiting the oxygen supplement to individuals with a continual need. Many older people need oxygen supplements at night, or sporadically during the day to manage symptoms. Will these individuals simply not qualify?

Mismatched Expectations between needs identified in the Integrated Assessment and Service Levels

DAI have also been told of older people having inadvertently been given much higher expectations of support at home, due to the high quality person centred integrated single assessment process. It was an extraordinarily disappointing surprise to participate in an assessment process that intimated that the supports actually needed would be provided. There is an inherent and fundamental mismatch between the assessment and the actual service levels available. For example, it is quite peculiar to have a cognitive assessment that does not result in additional funding for any specific additional support.

In relation to supplements in general, community feedback indicates that diversity screening and reporting to providers is not working as hoped. The information is not

flowing from the assessor's to the providers, leaving providers to seek the same information all over again. This process of duplication does not feel integrated or single to the older person. The concept of a single assessment where eligibility for various supplements is not directly linked to the appropriate supplement is confusing and inconsistent.

Recommendation 4 Dementia and Disability Supplement

DAI recommends that consideration be urgently given to a pathway to a specific dementia and disability supplement that recognises the additional care needs of people living in the community with dementia. This must be created in addition to the capped service level amounts, and consistent with the CRPD that such disability specific services do not attract a contribution from the individual.

Recommendation 5 Oxygen Supplement

In relation to S 196(b), DAI recommends that the oxygen supplement be reviewed, as it is unclear if $98 per week will actually be sufficient to cover hire of appropriate equipment such as home oxygen generators. Alternatively if hire of oxygen equipment is included in ATHM, this will use a significant portion of that already low capped amount, thereby greatly limiting access to life affirming ATHM . We also recommend review of the direct requirement noted in 196B(a) to require service type nursing care to comprise the only pathway to applicability and the direct requirement for 'continual need' to be revisited.

Recommendation 6 Automatic Eligibility for Person Centred Supplements

DAI strongly recommend that eligibility for person centred supplements be automatically collected in the single assessment process, and appropriately recorded to avoid duplication.

DAI recommend that in the event that SAH support levels remain capped at the current levels, that Assessor's be provided with further training to manage the expectations of older people in relation to the meeting of needs identified in the assessment process. Assessing an older person at the highest level of need, only to find that services are capped at levels that are absolutely insufficient to support them to live independently is heartbreaking and demoralising.

Division 2 - provider based subsidy

Subdivision D Provider Based Supplements

205B Care Management subsidy

DAI notes and respects the applicable criteria provided in the draft rules, however 205B(a) to (e) does not provide eligibility to a care management subsidy to people living with dementia or other disability.
People living with dementia really do require a greater level of support in administering care arrangements than many in the population. This applies in most cases for people living with disabilities. Without access to a supplement, many providers will be forced to limit interpersonal supportive contact with their older disabled and vulnerable clients, invariably resulting in early institutionalisation and/or hospitalisation. As dementia is a progressive condition, needs can change rapidly, often requiring several reassessments in a given year. This will drain pooled resources unfairly within provider systems, with an unintended consequence that other older people will receive fewer hours of care management, and/or people living with dementia will not represent good value for providers, and service wilL be declined.

Recommendation 7

DAI strongly recommend that people living with disabilities particularly dementia and other neurocognitive conditions be eligible for the care management supplement, and that the eligibility be assessed and linked to the single assessment process, and recorded in the individuals account information to avoid duplication of effort.

Part 3 And 4 Subsidy for Assistive Technology

211B Account period for classification type short term.

As previously noted in this submission, language conventions of naming people with predetermined health conditions, people requesting palliative and restorative care as being 'short term' individuals is unacceptable.
The listing of qualifying conditions for assistive technology under this short term banner is equally unacceptable. Section 211B in its entirety is absolutely inconsistent with all human rights conventions, most particularly the CRPD. This section completely undermines the much vaunted 'rights based care' narrative, and represents the exact opposite of 'person centred care'. DAI further note that dementia is not included in the sad and limiting list of conditions eligible for shortterm classifcation for Assistive Technology. Perhaps we have disappeared.

It is also notable that 211B (8)(b) stipulates how a registered provider may apply for reconsideration of a decision. 211D(2) also specifies that a 'registered provider' apply for a determination. In no part of this section is there any reference to inclusion of the older person in this communication.

Recommendation 8 Removal of Specified Conditions

DAI strongly suggest that a specified list of conditions identified by the Government is inconsistent with person centred care. Most particularly when the leading cause of disability and death for older women is notably absent from the list.

Recommendation 9 Individual Right to be Informed

DAI suggest that in the interests of 'person led' and human rights based care,that at the very least, the individual concerned must be included in all correspondence. DAI also request that further resources be developed to inform older people of their rights to self advocate, be informed on the progress of their application, and how platform based providers who do not interact personally with the individual will conform to this system as described.

Recommendation 10 Recourse for Individual to Challenge decisions

DAI recommend that further detail be included giving direct recourse to older people and their supporters to advocate and challenge decisions directly as well as in partnership with their provider. It is difficult to understand how the provider to system governor system of communication will empower older people, and promote person centred anything. The older person should also be included in any communication in relation to their application.

Recommendation 11 Review of time and access limits

DAI strongly recommend removal of the access and time limits in place for both restorative care and palliative care as well as reviewing limits on ATHM. It is somewhat cruel to load administrative tasks to an individual and their provider just because they didn't manage to have their home modifications completed or their assistive technology

delivered on a predetermined schedule, or that they inconveniently fell in 2 successive quarters.

Division 3 - Tier amounts 212 A and B

Continence products appear to be capped at $1000 per year for older people in classification type ongoing. It is unclear if this $1,000 will be deducted from the already capped ATHM budget. DAI also note that capping continence products is not compatible in any way with the Statement of Rights or clinical standards.

Recommendation 12 Caps on continence products

DAI strongly recommend review of annual caps on continence products that are fundamental to human dignity, quality of life, skin integrity and safety.

Part 4 Home Modifications

DAI note the low caps on home modifications, and the potential for the older person to contribute financially to such home modification.

Recommendation 13 Appropriate levels of Home Modification

Access to home modification to ensure that an older person can remain in their home and in the community as long as possible is an intrinsic human right in any modern equitable society. Limiting home modification to a level that will barely cover the most basic adjustments for those assessed as 'high need' is frank discrimination, and is absolutely unacceptable.

DAI strongly recommend that ALL older people who are assessed as being in need of home modification are eligible and fully funded without caps as envisaged in the CRPD and NDIS.

Chapter 8 Funding of aged care services - individual fees and contributions

A simplified outline of this chapter would have been deeply appreciated, however in its absence, DAI make the following observations based on community commentary.

The older people DAI engage with both within DAI networks and in the broader community in Australia. primarily live with dementia. Broadly speaking, they understand that making a financial contribution to their care and support in the community is not only a signal of how they value this care and support, but such contributions also make them feel as though they are entitled to a say in how these services are delivered.

They also say however, that they are very overwhelmed and demoralised by the complexity of the contribution calculations, even for people on the full age pension, who cant currently afford their rent and power bills. They are frightened to commit to services that they simply cannot afford at this time.

Further to this, older people on existing arrangements fear that reassessment will bring them into the new support at home system, thus triggering these contributions. The practical outcome is that many many older people will not seek reassessment in cases of genuine and increasing support needs, as they deeply fear getting into debt with the government. This fear was particularly striking from our CALD members and our Original Australian members.

The unintended consequences of a complex financial assessment on an already marginalised group of older people, who mostly live with disabilities well below the

poverty line will be reflected in increased hospitalisation, and 'placement' into institutions which they deeply fear.

DAI recommend that the Department consider a flat daily or weekly co-contribution, which will not change for people on the full pension. The amount should reflect the fact that the contribution is a token of respect from the older person, an acknowledgement that they are the 'consumer' of the service, and provide empowerment.

In relation to the part pensioners and the independent retirees, the message was equally fearful. Again, most older people did indeed wish to contribute in some way to the cost of their supports, however, it was important to them that this contribution would not impact their housing security, or their families ability to provide additional support. Furthermore, the complexity of the calculations promoted tremendous fear and anxiety - again driving older people to not enter the government funded age care system at all.

From the examples and vignettes provided, many self funded retirees in Australia said they would absolutely not enter the age care system in this form. It felt like a trap - 'a one way trip to the home'. Older people suggested they would engage private support workers, au pairs, seasonal workers and many other creative ways to obtain the support they needed and wanted, in a manner where they could control the cost and quality of service. DAI find this extremely demoralising, as these older people will not have coverage of the Age Care Standards, no SIRS reporting or any other quality and safety mechanisms of government funded age care. Inclusion of asset testing has created considerable consternation in the community. It is unclear whether this was discussed exhaustively with older people, but in cases where there is family care and support, this is often provided on a 'quid pro quo' basis, where adult children and other family members sacrifice their income and superannuation to provide care, with the understanding that

they will have the future security of an inheritance. This unofficial 'quid pro quo' arrangement is particularly prevalent in CALD communities, and without the future security of some form of compensation for foregone income, the unpaid carer system will crumble and quickly disappear. This unintended consequence of asset testing will very likely result in vastly increased demand for government funded residential age care, which is in not in the interests of either the older person, the community or the taxpayer.

DAI have also heard that the pressure to keep their family members as part of the care team greatly limited the appetite and willingness of these older people to access funded age care services. It is quite likely that older people who rely heavily on unpaid family support will find themselves under pressure to transfer or gift their assets in advance, in an attempt to protect their family relationships, and retain their involvement in their care. This not only leaves them financially vulnerable, but will greatly increase the vulnerability of the older person to abuse, and the likelihood of forced institutionalisation/VAD requests.

It is also notable that while a small proportion of older people consulted had some superannuation, these members were mostly male and Anglo heritage who had been working consistently since the inception of the Superannuation Guarantee. Women who had little to no superannuation, and only the family home as an asset were significantly over represented. DAI also suggest that the superannuation system is still not mature for older people, and for women, migrants, people living with disability and other intersections. The ability and appetite of many minority older people to contribute to their age care as suggested in this version of the rules is simply absent.

DAI acknowledge reference to financial hardship provisions, however at the time of writing, there is no older person in Australia in 2024 who receives the full age pension, that has the qualifying 15% of their pension left over after food, rent, heating, cooling,

clothing, personal hygiene and other basic necessities. There does not appear to be any significant financial savings to the taxpayer in gatekeeping the financial hardship provisions by way of an extensive, potentially inaccessible application process. Consideration could be given to automatic eligibility for financial hardship for all older people on the full age pension, with a cross check for savings over the $44k cap.

DAI further wish to call attention to the likely scenario of service refusal for older people who have accrued debt to providers, older people with poor credit history or are otherwise considered likely to place the provider in an untenable financial position. Likewise, older people living with cognitive impairment, dementia and other communication and functional impairments may struggle with budgeting constraints, and lack appropriate support to pay their contributions in a timely manner. DAI request further information on how service providers can continue to provide services in situations where co-contributions are not paid due to error, lack of functional ability and lack of budgeting support.

Recommendation 14 Unintended Consequences of contributions

DAI strongly recommend that the matter of contributions be reviewed, with a view to simplification and automation of the hardship provision.

Recommendation 15 Expansion of Carer Allowance/Payment Scheme

While outside of the scope of this consultation, DAI recommends that the Department consider working with Services Australia to open up the Carer allowance/payment scheme to multiple carers. This would facilitate more family members being able to participate in the care of older people, helping them remain in the community with trusted supporters, lessening carer burden and burnout, and reducing cost to the wider community and taxpayers.

Recommendation 16 Pro Forma contract for Privately Funded Age Care Services

In the event that the contribution rules are enforced without change, DAI strongly recommend that the DOHAC release a pro forma contract for age care services. The older people who choose to take a private route to choice and control should have the same access to quality care and support as those who choose government funded schemes. This template would empower older people to at least have a fighting chance of using State and Territory consumer law to ensure quality and safety into the future. DAI further note that private in home support contracts will not attract any legal or human rights protections at the federal level, and will be subject to State and Territory Fair Trading legislation. This is an extremely unsatisfactory situation.

Recommendation 17 Fiscal Responsibility for Contributions

As noted, the contribution rate calculation is extremely complex, and the responsibility for change in circumstances rests firmly with the older person. This is interesting as all other aspects of the rules appear to be interactions between provider and system governor. DAI appreciate that ultimate fiscal responsibility will rest with the older person, however when the older person lives with dementia, does not have technology access, a trusted person etc etc, the fear of being caught out becomes overwhelming. There is also the matter of scams and other nefarious activities that target older people. DAI recommends that further thought be given to mechanisms to update changes in circumstances with the assistance of providers, and other pre-existing information sources available to services australia.

Dementia Alliance International

Prepared and submitted on behalf of the Board of Directors and Members

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