Dementia Alliance International

Submission to the Department of Health and Age Care in relation to the Age Care Rules

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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Table of Contents

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 of any age in Australia, who are also people with disabilities with equal human rights and disability rights to all others 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 globally.

Preamble

Dementia Alliance International (DAI) welcomes the opportunity to provide feedback to the Age Care Rules 2025. This is a large tranche of information and given the limited time to prepare a full submission, we have elected to focus on specific areas of concern to people living with dementia, specifically sections relating to restrictive practice. DAI further notes that the restrictive practice rules only appear to apply to the residential care setting despite most people living with dementia living in a community setting.

Placement into an institution is never easy, and while systemic institutionalisation through capping support at home represents a breach of numerous international human rights treaties, DAI remain optimistic that one day all people living with dementia will be supported to choose to live at home and in their communities with access to the same human rights as everyone else across Australia despite age or disability.

Numerous reports have highlighted the poor treatment of older people and people with dementia, in particular the Royal Commission on Abuse and Neglect of older people. Since the findings in the report were made public, and some recommendations have begun to be implemented, the matter of the disparity in quality of care, safeguarding, human rights protections and institutional abuse remains unaffected. SIRS reports remain stubbornly and unacceptably high, with older people living in oppressive circumstances, with providers demonstrating high levels of control over

their everyday lives. Many older people in such institutions don't feel safe enough to express their emotions without fear of being labelled. Normal human responses to fear, confusion, pain both physical and emotional, sensory deprivation, and loss of human connection and interaction must be smothered and hidden lest the individual be labelled as 'manipulative, attention seeking, problem wandering, absconding, irritable (As noted in the Behaviour Resource Utilisation Assessment section of the AN-ACC). Such labels are very likely to result in the enlivenment of a 'behaviour support plan'.
It is not well understood how much shame is attached to living under the auspices of a behaviour support plan. I would liken it to being on 'probation'. It brings extra shame when the BSP is imposed on you, without your having been closely involved in its development. Consultation is not co-design as noted in the Draft National Plan to end the abuse and mistreatment of older people.

Behaviour support planning was originally developed to be a collaborative mechanism for people to work with professionals to develop palatable, practical and accessible pathways for de-escalation, to promote individual autonomy and provide consistent and reliable methods to promote the safety and wellbeing of the individual and their support partners. Together with a specialised practitioner and a supporter (independent advocate) if the individual wishes, the plan would be developed and trialled, with the ultimate goal of mutual risk assessment, and improved safety for the individual and their circle of support. Unfortunately behaviour support planning and operationalisation within the age care sector operates more as a 'behaviour suppression plan', created often by an automated system, with some limited input from care providers who can only base their bsp on observation, and not from a place of common understanding. In practice, ongoing research which is examining the quality of behaviour support plans in residential age care facilities, in terms of compliance with existing legislation shows that despite the ‘good faith’ efforts of providers, behaviour support plans have a low level of compliance, limited personal information about the individual, modest evidence of consent from the individual, and moderate evidence of authorisation provided by a care partner or other authorised person. Some providers use 1 BSP document with a separate restrictive practice plan, others have multiple documents with no particular ‘source of truth’. It is clear from this early stage of the research that despite the best efforts of providers, their understanding of development, implementation and documentation of positive behaviour support is still emerging.

In the context of such low levels of expertise in the behaviour support landscape, the reliance in the draft rules on binary concepts of ‘capacity’ and ‘emergency’ without definition and associated guardrails appear to represent a considered methodology to replace immunity provisions from days gone by, thus making provision for defence of activities that may well be indefensible from a human rights perspective. This terminology represents a ‘passport’ for providers to continue to use restrictive practices in ways that facilitate their business model, at the expense of the individual. Without a significant uplift in behaviour support skills and access to specific behaviour support practitioners with expertise in restrictive practices, our older people will continue to be supported and controlled improperly.

This situation must be addressed as a matter of urgency.

In an Australia where services and systems were not siloed, an individual would be offered support shortly after a diagnosis of dementia, to create an anticipatory 'advanced social directive' as well as the traditional financial arrangements. This planning would also comprise a personal risk plan, a behaviour support plan, and an advance social directive, which sets out the will and preference of the individual for matters they consider to be 'material' to their wellbeing. The only way to rebalance the power dynamic that currently exists in the behaviour support/crowd control space is to embed the views and wishes of the individual for their future, well in advance of the moderate to end stages of dementia. We have a human right to support us to make decisions, however there are no pathways to give voice to our unknown future, that we can have any assurance will be respected. DAI draws your attention to the 500,000 care leavers in Australia who were removed from their families and communities. They now live with the knowledge that this is probably going to happen to them again - with the same organisations waiting with open arms to receive them back into their 'care'. Similarly our First Nations Peoples live in fear of re-institutionalisation, and the associated methods of control that will be imposed on them.

In the Age Care setting, systemic ageism which has a baked in expectation that all older people are (or should be) the 'silent generation'. These are the same people that were told by their parents to be 'seen but not heard'. Systemic institutionalisation of older people across Australia has resulted in 200,000 older people leaving their own homes and community and being 'placed' into a strange institution, amongst people they don't know or trust, often being cared for by people they don't necessarily trust with their bodies with no way out except for death. (A major driver of care refusal especially when the person has no trust based relational care available to them)

This is a painful life to be sure, and it is hardly surprising that many older people respond with frustration, resentment and ‘irritability’. When the older person lives with dementia, they are less able to rationalise and suppress the feelings of fear and loss, and their bodies produce a response that is quite often inconsistent with the core nature of the individual. This natural human response to an extremely challenging terminal disease has unfortunately been labelled as Behavioural and Psychological Symptoms of Dementia. While dementia may impair one's ability to moderate one's responses to a difficult situation, dementia itself is not causing the so-called behaviour. It is simply a disconnect between what the mind is experiencing and how the body is responding to that internal experience. Sometimes it is related to the environment and sensory overload, and sometimes it is related to unresolved trauma or a million other things. It is important to understand that with dementia, one does not fade away and disappear - in fact we feel everything, more akin to hypervigilance, however our ability to communicate our fear and discomfort is impaired, therefore our body does its best to call for help, and yes this can sometimes be unsociable. I will provide a personal example. I fell outside, and i forgot that i fell. For weeks and weeks I was walking and walking. My family thought I was ‘wandering’, but I am the most fortunate of people, as I have an autistic daughter who took the time to ask me lots of questions so she could better understand how to help me, or if I needed help at all. It turned out I had a wedge fracture in my upper back. Because I no longer can actively recognise pain and know what to do, I was feeling the pain for sure, but it simply didn’t occur to me to either speak about it or do anything about it, but my clever body was trying to propel me forward, away from the pain in my back. When you actually understand it, it makes perfect and logical sense. So what you see on the outside, may only have the barest resemblance to what we are experiencing inside. I can also confirm that a person living with moderate to severe dementia does not have the intellectual capacity to ‘manipulate’ or ‘plan out’ how to be a nuisance. It’s the only form of communication left to us, and we desperately hope that somebody somewhere cares enough to try and find out what’s actually wrong.

The restrictive practice provisions in the draft rules are a great improvement on the existing provisions, however they have lost sight of the actual purpose of behaviour support planning. The whole point of a BSP is safety for the individual and their supporters, however in practice, it feels like a crowd control framework, using capacity and emergency as leverage for suppression.

It doesn’t have to be this way. It is not more expensive to do this better, it just requires appetite for change, courage and leadership.

Data from the Quality Indicator Program April to June 2024 notes that while 17.9% of eligible residents were receiving antipsychotic medication, only 9% had a diagnosis of psychosis. It is difficult to understand how this quality indicator can remain broadly consistent since data collection began. If an older person has the misfortune of living in institutional age care in the Northern Territory, they can look forward to only 4.3% of their co residents living with psychosis, but a whopping 15.3% being prescribed anti psychotics. Similarly in the NT, 27.3% of institutional residents are in secure units - almost double the Australian average.

34.3% of eligible residents were prescribed 9 or more medications, and 32.6% of eligible residents had recorded falls. There appears to be at least a superficial connection between these statistics.

DAI and our members and all older people across Australia whether they live in the community or in an institution deserve protection from arbitrary restrictive practice for the sake of efficiency and expediency. This is not a good enough reason to treat us as ‘less than’ the wider community.

Part 2 - Definitions - 6-20

6-10 Definition of Representative

DAI understands that the term ‘representative’ has been superseded in the New Age Care Act, and proceeds under the assumption that inclusion of this definition is an administrative oversight

6-15 Nominating restrictive practice nominees

Section 6-15 and throughout the restrictive practice section of the draft uses the term ‘informed consent’. Use of the term *consent* implies somehow that the views of the individual under restrictive practice is irrelevant. While commentary on terminology may be perceived as ‘pedantic’, it is important to understand that providers and the wider community look to the government for leadership, and use of terms such as *consent* for a process that is in fact *authorisation* passively implies that the ‘individual’ is childlike or somehow unimportant.

Recommendation 1

DAI recommends that the term ‘consent’ be replaced with ‘authorisation’ when a decision is made by anyone other than the individual concerned

6-15(2)(a) introduces the concept of ‘capacity’ yet no definition of capacity is provided. Further, no information or guidance is provided which explains exactly how such ‘capacity’ is to be determined and by whom. It is unclear if a ‘polite no thank you’ to the offer of restrictive practice will be interpreted as a lack of capacity. It is further unclear if the aforementioned ‘capacity’ is in relation to a specific restrictive practice, a particular incident or capacity determined “in the moment”. As the Department is aware, decision making ability for people living with dementia can often fluctuate, and the analysis of an individual's ability to make a decision must be based on more than perceived ‘antisocial behaviour’, or a negative response.

DAI considers the reliance on undetermined capacity assessments as a basis for obtaining authorisation for restrictive practice to be inconsistent with the supported decision making provisions, and the statement of rights more broadly.

Recommendation 2

DAI very strongly recommends that a framework be developed and implemented to properly assess and record an individual's capacity to say yes or no in relation to restrictive practice, prior to any external authorisation for restrictive practice of any kind. Such a framework must set out the particular qualifications required to assess capacity.

Recommendation 3

DAI very strongly recommends that this whole section be reviewed with a view to adding a layer of support for decision making in restrictive practice which is compatible with the statement of rights

6-15(2)(c) notes that the same unclear ‘determination of capacity’ is applied to the individual nominee. It is quite unclear how this might look in practice. DAI looks forward to further detail on how capacity assessments will be performed and recorded for both the ‘individual’ and the ‘nominee’, and the skills required to perform such an assessment.

Recommendation 4

DAI recommends that proposed nominees or RP-SDM’s undertake the same capacity assessment by the same professionals prior to authorisation of a restrictive practice.

6-20(5) notes that a nomination, variation or revocation of a restricted practice nominee must be made in writing. This is indirect discrimination towards older people with diminishing ability to read/write or who have resorted to 'mother tongue'. It is further discriminating against people in the moderate stages of dementia, not to mention that pens and paper are rarely on hand in secure units.

6-20(9) further sets out the requirements for the individual to state order of precedence when a group of nominees is involved. While precedence is important and useful to a provider, as they will know who to contact first, it further complicates the proposed written nomination process for the individual.

Recommendation 5

DAI recommends opening this provision to verbal instructions, and adding a clause that 'capacity' is presumed unless otherwise indicated. In which case supported decision making must be offered. The same access to quality capacity assessment must be provided as noted above.

6-20 Meaning of *restrictive practices substitute decision maker*

Again, we note that the terminology of 'substitute decision maker' is incompatible with the supported decision making provisions of the Act. We reinforce the notion that DAI expect leadership from our government in changing the context of age and disability care to a person led, rights based language in the Act.

Recommendation 6

DAI recommends that the obsolete term ‘substitute decision maker’ be replaced with ‘authorisation partner’ throughout the Rules

6-20 (2) Table

This table appears to provide a ‘hierarchy’ of potential people who can authorise restrictive practice for an individual. The fact that such a table has been brought forward is deeply disturbing to people living with dementia. It reflects the ‘desperation’ of providers to find ‘someone’ who will sign off on restrictive practice on the individual. It is deeply demeaning and demoralising to live with dementia, knowing that we can be restricted and restrained in residential care, based on the authorisation of just about anyone in the community at large who can demonstrate some interest in us, and confirm their own capacity. Column 2 (b) is extra demoralising, as it preferences the oldest ‘relative or friend’, with no particular reasoning other than chronological age. It is unclear from this table if the individual is protected in any way from ‘authorisation shopping’ where a provider can just keep contacting random people in our lives until they receive the answer they want to hear. Aside from the medical treatment authority provisions, this table is a perfect example of exactly how little agency a person living with dementia has when they enter an institution. The focus on whether a potential RP-SDM has a paid role in an individual’s life attempts to acknowledge that there is potential for some sort of harm, however it is difficult to understand the increased risks to the individual if permission for restraint is provided by a paid or an unpaid person, as the risks in this particular context from the restraint or restrictive practice are borne by the older person by way of increased falls risk, poor mental health etc, presumably with a cumulative effect of early death.

Recommendation 7

DAI strongly recommends that this ‘hierarchy of potential approvers’ of restrictive practice be reviewed in its entirety. It promotes the ability of providers to self select ‘authorisation partners’ without any apparent input from the individual, and short circuits any access to supported decision making principles.

Division 2 - Requirements relating to the use of restrictive practices

162-15 Requirements for the use of any restrictive practice

162-15(1)(c)

It is heartening to see that documentation of alternative strategies that have been considered or used must be documented, as this removes the need for a ‘good faith’ defence of poor practices. However this documentation may be better housed in a separate file or document, as a behaviour support plan (BSP) is a living document, that is often needed in a hurry, and may not be optimal if it contains historical information

Recommendation 8

DAI recommends that documentation of strategies used prior to the restrictive practice be housed elsewhere in the clients documentation file.

162-15(1)(d)

The restrictive practice must be proportional to the risk of harm to the individual or other persons. This is an admirable sentiment, however without a working definition of harm in the rules, it becomes subjective. In practice, vocalisation, walking, crying can all be interpreted as having the risk of harm to others sharing the space who have to live alongside these expressions of pain. This of course is a legitimate concern for those who have to live alongside people who are still in a position to express themselves in this way, however whether it comprises 'harm' as expressed in the rules is debatable. The terrible example of Clare Nowland, the very old lady on a walker with a knife can certainly be viewed as posing a 'risk of harm', however this situation was more complex than just a human with a knife.

A frail elderly person with very limited mobility poses a great deal less risk to herself and others than a very fit, strong and motivated person with full mobility with a knife. The single term 'harm' is insufficient to base a risk analysis for restrictive practice authorisation.

Recommendation 9

DAI strongly recommends that further guidance be included in the rules as to what exactly 'risk of harm' comprises. DAI further recommends that specific risk management training be developed for providers so that they can perform a quality risk assessment in a timely manner, with output that can be properly communicated to both the individual, and whoever will be responsible for providing 'authorisation' of any required restrictive practice or restraint.

162-15(1)(f)(ii)

In relation to the 'informed consent' from a substitute decision maker - we wonder what sort of information the government expects to be provided to the decision maker to ensure they are 'informed'.

Recommendation 10

DAI strongly recommend that at a minimum, the substitute decision maker be provided with situational context, details of any capacity assessment performed, details of the risk assessment performed, details of the alternative strategies used, details of whether the individual refused or accepted any intervention and specific details of the exact type or restraint, or restrictive practice being authorised, and for exactly how long. In addition, the substitute decision maker should be apprised of any support to the individual in consenting/declining the restrictive practice.

Anything less than this is not ‘informed’

162-15(2) Emergency Provisions

It is most troubling to see that the modest controls around restrictive practice can be completely overridden in an ‘emergency’ when no definition of what comprises an ‘emergency’ has been provided. We have no insight as to who ‘calls’ the emergency situation, or what qualifications might be required to assess what is an ‘emergency’ and what is not. This is absolutely unacceptable, and inconsistent not only with the statement of rights, and quality standards, but inconsistent with good quality care.

Recommendation 11

DAI strongly suggests that ‘exceptional circumstances’ be defined, with reference to the ‘risk assessment’ and minimum qualifications of the person who has the power to declare an ‘emergency’. DAI notes that inconvenience does not comprise an emergency.

162-20 Additional requirements for the use of restrictive practices other than chemical restraint

DAI welcomes the requirement for an ‘approved practitioner’ to make a risk assessment, however as noted above, definitions of ‘harm’ and formal documented risk assessments must also be used. 162-20(1)(b) notes that prior to the restraint, that the risk assessment, descriptions of engagement in relation to the assessment and description of external support services must be documented in the behaviour support plan (BSP). DAI notes that Dementia Support Australia typically do not provide input to the restrictive practice section of a behaviour support plan outside of their specialist residential services.

Recommendation 12

DAI recommends that specialised assessment services provided by a geriatrician, geriatric psychiatrist or other specialised practitioner be a requirement if restrictive practice is to be included in a behaviour support plan. Alternatively Dementia Support Australia could uplift their service to include restrictive practice recommendations.

Recommendation 13

DAI further recommends shorter review periods for restrictive practice that is ongoing such as secure unit placement. Presently most people who are located in a secure unit are never released back into the general population, and usually their move is permanent until very ill health necessitates a move to a high care unit for palliative care.

Recommendation 14

DAI also recommends that attention be paid to low key and passive restraint techniques such as sensory deprivation. The impact of sensory deprivation on the human psyche and mental health is well known and happens very quickly. Lack of pleasurable visible, tactile, and compassionate interaction comprises such passive restraint. It is actually possible to live in 'solitary confinement' even in a space where there are many people, who just don't really see or acknowledge you as a human being, just as something next in line for a wash.

162-25 Additional Requirements for Chemical Restraint

162-25(1)(a)(iv)

It is good to see that informed consent from the individual for the prescribing of chemical restraint medication is required, however there is quite a difference between consenting to a prescription being written up by a medical professional and consenting to actually taking the medication. The additional requirements are a welcome uplift to existing practice and represent a system of control that will hopefully greatly moderate the amount of chemical restraint in residential aged care facilities. We do however bring attention back to the 'emergency' provisions, which appear to be taking the place of previous 'immunity clauses'.

162-30 Requirements while restrictive practice being used

DAI welcomes the enhanced monitoring provisions while restrictive practice is on foot. We expect this to result in greatly improved quality of care in secure units where the individual is living under environmental restraint in many cases with a significant level of sensory deprivation. 162-30(b) notes the necessity for restrictive practice to be regularly reviewed and monitored, but without specifying exactly what is expected in terms of 'regular review', many older people for example will languish in secure units that do not need to be there.

Recommendation 15

DAI recommends that review periods be prescribed in the Rules - compatible with the nature of the restraint. For example chemical restraint would require review every 15-30 minutes due to the clinical risks of additional medication that may suppress respiratory system or contribute to falls and impaired balance/confusion/delirium. Environmental restraint such as a secure unit or locked ward must be re evaluated weekly, with absolutely no older person being excluded in a locked environment for the rest of their lives.

162-35 Requirements following emergency use of restrictive practice

DAI welcomes and supports the enhanced documentation requirements of restrictive practice outside of the individual consent/authorisation/supported decision making frameworks.

Recommendation 16

While the above documentation requirements are extremely useful, there is no reference to the safety or comfort of the individual after the 'emergency' has passed. It is almost as though the legislation deals with the situation, but ignores the person concerned.

Recommendation 17

DAI recommend that reference be made in this section to quality care standards, and person centred care. Some sort of restorative care and compassion to ensure the individual recovers from the emergency (and other residents/care staff if the incident involved others) deserve consideration.

162-40(1) Preventing coercion and duress in nominating restrictive practice nominee

While it is good that the rules acknowledge that there is a risk of coercion and duress both in the nomination process and the acceptance of a nomination process, this section appears somewhat incompatible with the 'table of potential authorisers' noted in 6-20(2).

Recommendation 18

DAI suggests that supported decision making has a place in the restrictive practice landscape, and that 'capacity' is not binary. We recommend that individuals be entitled to and actively offered independent advocacy to support their decision to appoint a RP nominee or RP SDM, and that independent advocacy services be offered to nominees in deciding whether to accept such a nomination.

Authorisation of restrictive practice and restraint on a loved one is painful and traumatic, often as painful and traumatic as it is for the individual in pain being restrained (although in a different way).

Recommendation 19

DAI further suggests that providers are obliged to offer independent advocacy to any individual with restrictive practice in their BSP, and such individuals are offered a referral to Relationships Australia for assistance in coming to terms with living under a control framework where they have little agency.

Similarly, anyone who is in the difficult position of being asked to authorise a restrictive practice on a loved one should be offered independent advocacy, support with decision making, and support to come to terms with the fact that their loved one is institutionalised, and if their loved one behaves in a way that is incompatible with institutional life, that they will be called upon to authorise restrictive arrangements.

Thank you,

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

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