Dementia Alliance International

Submission to The NSW Department of Communities and Justice in relation to A legislative framework to regulate restrictive practices.

Submission from: Dementia Alliance International (DAI)

Dementia Alliance International. C/- 6575 West Loop S, Ste 400, Bellaire, TX 77401-3512, USA

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

Submitted on: March 4 2025

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Submission to NSW Department of Communities and Justice In Response to the December 2024 Consultation paper on a legislative framework to regulate restrictive practices

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).

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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

While dementia is invariably associated with older age, awareness is increasing around the impact of dementia on people under age 65 including children living with childhood dementia. Most of these people access support through the NDIS, and are the subject of varying degrees of behaviour support including restrictive practice. It was not possible to find any data in the public domain which clarifies the number of people living with dementia outside of the age care system who might be subject to behaviour support and restrictive practice, and that is a gap that should be addressed going forward. People living with dementia are anecdotally over represented in the restrictive practice space, and are still subject to a binary 'capacity based' model of substitute authorisation of such practice, even outside of crisis situations. Much of this restrictive practice sits in the community, and is not necessarily subject to the same level of oversight as that in the wider disability sector.

For the purposes of this submission, DAI interprets the phrase 'NDIS participants' to also include those who will in the future be accessing state funded 'foundational supports'.

While it is disappointing that NSW have actively chosen to isolate people over age 65 (differing ages for different cohorts) from the protection afforded by the proposed principles, DAI will offer practical recommendations to support people living with dementia and other neurodegenerative and neurodivergent conditions who are NDIS and Foundational Support participants. To this end, we have attached a separate section to provide the direct voice of older people living with dementia to the NSW government appealing for equality, dignity and human rights protections to the same

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level as the wider population. DAI takes this opportunity to thank you for taking the time to review our submission and consider our recommendations. We are available to answer any questions or provide further clarification around operationalisation of any of our recommendations, and look forward to a fruitful collaboration with the NSW government in respecting and upholding the human rights of all people living with dementia in NSW.

Section 3 - Scope of the framework

DAI agrees with the DCJ proposal that the legislation is targeted at the service level, with individual settings where the service is delivered being a secondary consideration. This however does not take into account the many many people who are also supported by non government funded individuals such as unpaid carers, parents and other family members. Currently the focus of training and regulation is on paid providers which is appropriate, but there is a significant gap of understanding of both development, consent and implementation of BSP's in the wider community setting.
In respect of proposal 2, it is unclear if the government agencies listed are the only agencies being considered for reporting. For example it would seem that there would be benefit in extending reporting requirements to agencies that deal with children, First Nations people and the human rights agencies.

DAI supports coverage of both registered and unregistered providers.

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In relation to the current regulation outlined in section 3.2.5, it is apparent that the existing 'consent' landscape is not serving people living with disability in any meaningful way. It is operationalised in the superseded binary model of substitute decision making and best interests. This presents a grave concern for the human rights of the people subject to restrictive practice of any kind in NSW.

It is unclear why non government schools are not included in the 'settings' for restrictive practice, as our NSW disabled children are well represented in this sector, and deserve equal protection.

DAI notes that law enforcement is not part of the justice setting and is out of scope for this consultation. Law enforcement are unfortunately the first port of call in many crisis situations, and while it may not be appropriate to wrap that particular public service into these principles, First Responders are often in the difficult position of having to apply some sort of restraint outside of a Behaviour Support Plan (BSP) to protect the public or the individual from harm in a crisis situation. The gaps of understanding of matters such as de escalation, disability such as cognitive impairment, hearing loss etc have resulted in the avoidable death of Clare Nowland. It is clear that first responders have an important role in interacting with the disability community, yet they are ill prepared to do so safely and effectively, thus placing not only the person with a disability at risk, but the wellbeing, freedom and access to employment of the first responder themselves.

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Recommendation 1

DAI recommends that DCJ consider a policy position that supports accessible and meaningful training and upskilling of the unpaid caring community in the safe and appropriate implementation of behaviour support and restrictive practice. Improved handover, access to daily case notes (with consent) and improved communication between formal and informal carers will provide greater consistency of practice, and provide the individual with continuity of care and expectations.

Recommendation 2

DAI recommends that DCJ consider the value of a living experience panel at the individual service provider level. This could be designed with provider level peer support being facilitated for individuals and carers to share knowledge of best practice, and raise issues within the service.

Recommendation 3

DAI supports annual reporting to the Senior Practitioner on compliance with the principles, and strongly recommends that this report be publicly accessible. Compliance reporting should also be made available by individual service providers to participants, as it is a very important quality indicator for many of us, and since we are in a market based care economy, transparency and equality of important information is required for us to make an active and informed choice in selecting our service providers. This may sit better in a 'disclosure and equity of information' principle.

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Recommendation 4

DAI recommends that the legislation does not rest upon the setting, but rests upon the service delivery itself, whether that be an administrative service that works with the individual to construct the Behaviour Support Plans, or at the operational level, where a government funded service provider of any type implements the actual restrictive practice regardless of the physical location. For example, it is not uncommon to observe various forms of active and passive restraint of people living with disability across the wider community setting, such as libraries, shopping centres, playgrounds etc by 'support workers', who wish to have free time to look into their mobile telephone.

Recommendation 5

DAI recommends that an additional principle of equitable access to material information be considered

Recommendation 6

DAI strongly recommends review of the NSW Restrictive Practices Authorisation Policy and the NSW Restrictive Practices Authorisation Procedural Guide in collaboration with people living with disability and our peak body representatives, including human rights advocates. This must be supported by a strong policy position

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of supported decision making, audit of BSP's to ensure they are co designed with the individual, zero tolerance for inappropriate 'authorisations' and greatly improved access to community resources and advocacy for supported decision making, including a Carers NSW and Carer Gateway campaign to support formal and informal carers on their journey from substitute decision making default, to a more human rights based supported decision making risk based approach to restrictive practice. DAI note that active informed consent is not interchangeable with authorisation from our perspective. We are human beings, and while we may not communicate to the satisfaction of the wider world, that is not commensurate without not having an opinion or a human right to be supported to express it.

Recommendation 7

DAI recommends that NSW Trustee and Guardian develop improved processes for the transition to and communication of supported decision making principles going forward, and provide accessible resources to all clients advising them of their rights, and how to access independent support to co design their own BSP, and give active and informed consent to its implementation.

Recommendation 8

DAI recommend that exploration of novel ways to bring the non government school system into compliance with the principles, potentially through MOU or other means to ensure equal protection for all NSW children who live with a BSP.

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Recommendation 9

DAI strongly recommends that DCJ work alongside the disability community directly, in developing training and resources to support NSW First Responders in interacting with people who do not necessarily have criminal intent, and who are inherently unable to respond to traditional methods of authority. Again we reinforce that such training should be delivered by people with living experience in order to provide direct opportunities not only for employment, but for deep learning, opportunities for questions and mutual understanding of how to best communicate.

Recommendation 10

DAI recommends that DCJ consider the disability communication training provided by Scope Australia as an adjunct for first responders in NSW

Section 4 Fundamentals of the proposed legislative framework

Proposal 1 - Principles governing use of restrictive practice

DAI supports the proposal that legislation is linked to principles recommended by the DRC 6.35(b) noting our recommendations on scope in section 3.

Proposal 2 - legislation requiring an annual report to the Senior Practitioner on compliance with the principles.

DAI supports this proposal. Compliance reporting is vital not only for compliance monitoring, but forms an important data set for progress or lack of progress in the move to elimination of restrictive practices.

Recommendation 11

While reporting to the senior practitioner is important, the individuals and their supporters who are the subject of restrictive practice are equally entitled to full understanding of the level of compliance of their individual service provider. DAI recommends that star ratings be developed and applied to service providers in a similar manner to age care providers. Choice is only meaningful when there is equality and parity of essential information. Compliance with these principles represents more than simply quality of care, it represents the value of human dignity and the right to be free from torture. It is absolutely essential that compliance is publicly reported at the service provider level.

4.4 Prohibited Restrictive practices

Many restrictive practices can be considered 'passive', such as removal of AT such as walkers dentures and hearing aids. In other settings, inappropriate and prolonged use of blood pressure cuffs, princess chairs and dignity suits are often considered 'business as usual', and are not considered to be restrictive practice, although of course the free movement of the individual is clearly restricted. Limiting of food and drink can also be considered restrictive.

It is worth noting that any secure unit represents restrictive practice.

Research has shown that sensory deprivation impacts the mental health of an individual within hours, with extended deprivation resulting in the complete mental breakdown of the human being. Drab monotone environments with no personal interaction, no access to colour, pleasurable sound, smells and touch such as institutions, represent a sensory deprivation environment and may be one of the most detrimental and harmful forms of passive restrictive practice.

Psychological Restrictive Practice is also often overlooked. Scolding, shaming, embarrassing and humiliating treatment is an obsolete way of controlling a human being. It makes the individual feel 'small and powerless', and the results are never positive for us. Inappropriate forms of communication, inaccessible communication and deprivation of communication are all forms of passive restrictive practice.

Recommendation 12

DAI recommends that further work be done to understand the scope and depth of passive restrictive practice, including the built environment

Recommendation 13

DAI recommends that providers ensure that all staff have appropriate communication skills - the SCOPE Australia training is particularly good.

4.5 Defining Restrictive practices

As noted above, there are many subtle restrictive practices that may fall within the proposed framework, but are often overlooked. These include denial of privacy, ignoring call bells, inappropriate use of pain or other hypnotic medication, premises that are out of town with no access to transportation, limited or no access to the community and refusal of access to doctor of choice and family/family of choice

Recommendation 14

As above, DAI recommends further research into the passive restraint of people living with disability across all settings.

4.5.3 Senior Practitioner has power to issue guidelines

Recommendation 15

DAI strongly recommends that guidelines are developed by the Senior Practitioner in consultation with a lived experience panel.

5. The Senior Practitioner and the disability service provision setting

5.2.2 improving the quality of behaviour support plans

DAI agrees that the quality of BSP's is low, and has no meaningful effect on the level of restraint imposed on the individual. While there are existing consultation requirements, community feedback tells us that the consultation is not meaningful, and the views of the individual are rarely represented in the plans or their implementation. They may in fact be being used as a shield for inappropriate and poorly informed responsive practice by the service provider. Behaviour support plans that do not have the genuine buy in from the individual are simply another oppressive framework to facilitate control. The individual has no clear pathway to complain or update their own BSP if it does not fit their individual needs. There is a sense in the community of limited access to intervention and advocacy in this space, as resistance to any aspect of an authorised BSP is deemed as a 'behaviour' in itself. People living with a disability under a BSP need an accessible 'off ramp'. Anecdotally, the very existence of a BSP is often used as a threat to control behaviour, and a tool to shame the individual. The threat of enlivening a BSP, or making public that a person lives under a 'BSP' is real, and troubling.

Recommendation 16

DAI recommends that NSW moves from 'consultation' to 'co design' of BSP's. This is consistent with the human rights obligations of the CRPD, and is simply the right thing to do.

Recommendation 17

DAI recommends that NSW provide free and accessible access to an independent advocate in the BSP co design process at the request of the individual or the individual's nominated representative.

Recommendation 18

DAI recommends that an accessible pathway be developed for the individual or their nominated representative to request a formal review and uplift of an existing BSP.

Recommendation 19

DAI recommends that consent to a co designed BSP be mandated unless there are extraordinary short term circumstances requiring the specific authorisation by the Senior Practitioner

Recommendation 20

DAI recommends that Carers NSW receive both the SCOPE communication training and uplifted behaviour support and human rights training to support the carers of individuals who are unable or unwilling to participate in the BSP co design and consent process.

5.3 Authorisation Models

From a human rights perspective, it is chilling to see a section in this paper devoted to the authorisation of restrictive practice that does not refer in any way to the informed consent of the individual concerned. We may be misunderstanding the intent of the term 'authorisation', in which case perhaps the term 'approval' may be helpful.

DAI are operating on the understanding that this section of the document deals with the 'approval' of BSP's that have a restrictive practice component, based on the meeting of prescribed requirements, prior to implementation. We will base our recommendations on this understanding, as it is unthinkable to us to consider that the term 'authorisation' equates to 'permission' to implement restrictive practice in any BSP without the informed consent of the individual or their nominated representative.

Recommendation 21

Again assuming that the authorisation processes described in 5.3 represent approval of specified restrictive practice contained in a BSP, DAI very strongly recommend that any APO mechanism be decoupled from providers, and are either State employed or

independent practitioners. There is an inherent conflict of interest in associating any APO with the provider who will be responsible for implementation.

5.4 Duration of authorisation

DAI supports the maximum 12 month period of 'approval' of a BSP with components of restrictive practice as set out in proposal 6. The emergency process as described in proposal 7 is more problematic, as the individual is likely in crisis and not in a position to self advocate. The existing interim process is clearly unsatisfactory, however it is quite unclear whether the 'person in charge of the provider' has the skills required to authorise emergency restrictive practice. There is also the lack of clarity as to whether the support worker on the ground has the skills to determine the restrictive practice appropriate to the individual or the situation.

While DAI appreciates the need for personal safety of all disability support workers, and the inconvenient fact that sometimes situations arise when action must be taken to preserve safety, we believe that this can be done better and more safely.

Recommendation 22

DAI recommends that behaviour response units staffed by experienced and qualified behaviour support practitioners be developed in NSW. This could be similar in nature to the service provided by Dementia Support Australia in responding to changed behaviour involving risk to the safety of individuals and those around them. This service could involve teleconference where the support worker could get appropriate and

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timely advice from a qualified practitioner. A behaviour response unit staffed with an APO could provide the appropriate 'approvals' of an emergency BSP, and assist with first responder referral and/or other specialised respite services. This would greatly reduce the number of 'off the cuff' 'responsive' restrictive practices designed and implemented by unqualified and vulnerable support workers in the field. Of course there will be situations where there is no time or safe space for a teleconference, however these instances would be a first responder situation in any case.

Power to cancel authorisation

DAI noted that circumstances for cancellation do not include the request or initiation by the individual.

Recommendation 23

DAI strongly recommends that a pathway for review or cancellation of restrictive practice be made available to individuals and their advocates

5.5 Individual Review Rights

The discussion proposes a process for an individual or concerned person to request review of an approved BSP containing restrictive practice. DAI considers it a human right to request review of any assessment or plan related to the individual. Likewise,

any provider responsible for the care and safety of the individual and their staff has the right to intervene in a process that they do not feel safe participating in.

If BSP's were genuinely co designed, and if active and informed consent was a requirement, DAI believes that the instances of review requests would be lowered. DAI further believe that availability of an independent advocate to participate in the co design process to support the individual would further improve the quality and palatability of BSP's more broadly.

Recommendation 24

DAI reinforces its recommendation for robust co design and informed active consent of all BSP's particularly those involving restrictive practice.

Recommendation 25

DAI also reiterate its recommendation that independent advocates be made available to individuals to support their genuine and active participation in the development of their own BSP, including the active and informed consent to its approval by the Senior Practitioner/Independent APO

Recommendation 26

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DAI strongly recommend that the individual has the right to BSP review at any time, however in the rare instance of nuisance review requests, the provider/Independent APO can also involve an advocate and an independent reassessment and redevelopment of a new BSP (a second opinion clause)

5.6 Complaints Handling and Investigation

DAI warmly supports the Senior Practitioner having powers to investigate on the basis of complaints, and at its own discretion.

DAI further supports the Senior Practitioner having powers to respond to the misuse of restrictive practice. We note the difficult circumstances of living under an inappropriate restrictive environment, and the impact this would have on the ability and appetite of the individual to engage in multiple complaints processes. An accessible system must be built which shares information across relevant parties to avoid duplication of effort from the individual.

Recommendation 27

DAI recommends that all complaints made to the senior practitioner be copied into the NDIS complaints framework automatically and vice versa.

Recommendation 28

DAI recommends that all complainants be offered an independent advocate to walk the journey with them and provide support

5.7 Reporting

DAI notes that the Senior Practitioner is proposed to receive information to provide visibility of the use of restrictive practices, however all sources of information come from providers, and nothing seems to come from the individuals concerned. This is somewhat unbalanced, and the inherent conflict of interest in 'self reporting' can potentially screen out much of the 'passive restraint' discussed earlier in our submission

Recommendation 29

DAI very strongly recommends that a quality assurance program be developed as noted in section 4 of our submission. This is a critical gap in the existing framework as the living experience of living under restrictive practice remains ignored.

Recommendation 30

DAI very strongly recommends again per section 4 of our submission that compliance with the principles is publicly available at the service provider level to the public, in order for individuals and our representatives to make informed choices regarding our safety and quality of life.

5.8 Education and Guidance Functions

DAI warmly welcomes the proposal that the Senior Practitioner (having access to a wide range of operational information unavailable to the public or educational/advocacy organisations) develop information education and advice to the individuals and wider community.
DAI further welcomes the proposal to develop guidelines and standards.

Recommendation 31

DAI reiterates its recommendation that the Senior Practitioner engage a living experience expert panel to support development of standards and guidelines.

Recommendation 32

DAI recommends that the Senior Practitioner develops a dedicated research project examining the quality and compliance of BSP's with restrictive practice components, which includes the views of the impacted individuals and service providers. Such research would give a baseline for measurement of potential improvement in the living experience of individuals living under restrictive practice in NSW, and potentially highlight further areas for improvement.

5.9 Liability

DAI suggests that from the perspective of the individual, sanctions are an important component of healing from unjust restrictive practice, and provide an element of assurance to the community that the provider /individual involved is no longer active in the disability space. However, numerous pathways to sanctions can be overwhelming, resulting in the individual just 'giving up'

Recommendation 33

DAI recommends that however NSW choose to manage the scope of the Senior Practitioner and Sanctions, that the process be seamless from the perspective of the affected individual. Close cooperation, including real time interactive communication with the individual, their representative and their advocate is vital to keep everyone informed on an equal basis. A single complaint pathway that diverges across both NSW Senior Practitioner, NDIS Complaints Framework and the criminal justice system should be fully facilitated and supported in the back office, and place no additional administrative burden on the impacted individual.

Recommendation 34

DAI recommends that in certain urgent situations, the Senior Practitioner has the power to directly intervene with a provider to bring immediate safety to the individual, whether through emergency respite, intervention from a proposed behaviour support

unit, and engagement of another service provider outside of existing contractual service agreements.

Recommendation 35

DAI recommends that the Senior Practitioner mandates full transparency in any investigation of poor practice, whereby the impacted individual is provided with all relevant communications, reports, decisions and referrals that are in relation to themselves, including case notes.

5.9.2 Immunity

DAI absolutely refutes immunity from liability on the part of any provider. Immunity is unnecessary if practice is authentic and in good faith. The very existence of immunity undermines the personhood and human rights of an individual. DAI recognises the difficulties encountered with the 'good faith' doctrine. It is simply not good enough - our lives deserve better than hope, and unspoken and unacknowledged reliance on a service provider not becoming' resentful or simply fed up'.

Good quality risk management processes, including documentation of BSP implementation in case notes, that must be signed off by the individual/representative at the end of a shift would more or less address the risk of inappropriate litigation, as the risk is spread between provider and the individual.

Legislated immunity is an obsolete, clumsy and provider centric approach to support services in difficult circumstances.

Recommendation 36

DAI recommends that the Senior Practitioner consider a provider requirement for a specific risk management plan for restrictive practice across the service, which includes documented case notes that are provided to the individual/representative for sign off on a daily basis. Individuals can opt out of this risk/control mechanism at will.

Recommendation 37

DAI recommend that the legislation move away from 'good faith' and into more contemporary risk management practice language, which promotes proactive planning from service providers, and places less reliance on the internal thinking processes of the individual support worker, and gives the individual concerned a more consistent and safe experience, with documentation and data available for quality assurance.

Part 2 Exclusion of older people from the protections of the 'principles'

DAI would like to take the opportunity to acknowledge that while older people are inexplicably out of scope for the purposes of this specific consultation, that the NSW government has begun the process of gathering submissions, inviting commentary on the matter.

Older People acquire disabilities too

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While Australia has been a signatory to the CRPD since July 2008, the practical application is significantly limited by the interpretative declaration relevant to Article 12 - Equal Recognition before the law which essentially permits ongoing substitute decision making arrangements across Australia.
The disability advocacy movement in Australia is strong and vocal, and tremendous change is ongoing in the under 65 disability landscape with active emphasis on supported decision making baked into the structure of the NDIS.

People age over 65 (50 for some cohorts) are at greatly increased risk of being placed under substitute decision making regimes both formal and informal. This interpretative declaration was an important signal to the Australian community that older people are not equal before the law. This indirectly facilitated the age caps on the NDIS excluding people considered to be 'aged'.

Older people living with disability were supported through a modest Disability Support for Older Australians scheme - which was something of a mechanism to comply with the CRPD, however this was phased out and the individuals were moved over to the generalised 'age care' system and out of the 'disability support system'. The then minister stated that all Australians with a disability were appropriately supported as those under age 65 were all on the NDIS Scheme, and those over 65 would not be kicked off the NDIS. Unfortunately the minister 'forgot' that most disability affecting older people is acquired over the age of 65 such as dementia - the leading cause of death and disability for women, second leading cause for men.

AIHW statistics clearly show that acquired disability increases proportionally with age. Approximately 80% of the over 80 year old cohort live with disability and so forth.

The very fact that Australia has singled out older people as being in need of their own specific system of support through the ageist structure of an 'aged care act', which implies that the 'aged' need 'care' is simply the leading edge of the inherent and systemic ageism that our governments promulgate.

There are few good reasons to be found to exclude older people from any system or service across Australia - aside from expediency.

The routine institutionalisation of older people, withholding and capping of in-home support services which simply underwrites the institutional market is unjust and cynical.

The National Plan to end Elder Abuse notes that inappropriate restraint is core business in institutional settings. 50 sexual assaults per week on average of older people, predominantly older women, frail with thinning skin, often living with dementia is considered 'business as usual'. SIRS reports of 'unexpected death' go uninvestigated, older people live in institutions with no access to meaningful or pleasurable sensory input, and malnutrition is rife.

Active and passive restrictive practice occurs on a daily basis, and represents the last dirty corner of systematic institutionalisation in Australia, where there is limited

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oversight, and no access at all to help or assistance for the individuals 'placed' into locked wards.

Behaviour support planning and implementation is scattergun and ad hoc. The quality and consistency of practice simply isn't there, even amongst the best quality providers.

DAI could quote numerous human rights treaties and clauses, hundreds of examples of abuse and neglect of older people, however we believe the NSW government already are aware of these statistics, and have taken an active choice based on expediency to exclude older people from improved behaviour support practices and regulation. This is of course disappointing as we had hoped for leadership in this space in NSW, where we have one of the best collections of public brains in the country. DAI invites the NSW Government to work with us in looking at alternative 'soft' ways to uplift the quality of behaviour support for older people in NSW through education, best practice models and incentivising improved risk management processes particularly in institutional settings.

Thank you,
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Prepared and submitted on behalf of the Board of Directors and Members

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