



# Dementia Alliance International

Submission to the Australian Department of Health and Aged Care Consultation on the New Aged Care Act Exposure Draft

**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, whose mission is to provide support globally including in Australia for people with dementia, and local, national and global advocacy for timely and accurate diagnosis, improved post diagnostic support and services including access to rehabilitation, to ensure a higher quality of life and independence for longer. 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 in Australia, and globally.**

## Opening Remarks

### Language Conventions

Much progress has been made in understanding the power of language in influencing attitudes, beliefs and behaviours across the community. This power is magnified when the language comes from our government. Language presented in legislation and associated materials will have a strong influence on the wider community including older persons, families and the paid workforce in the age care context.

The Government have worked hard to ensure that older persons are the focus of funded age care services, however this concept and its associated language conventions may inadvertently continue to tacitly support outdated concepts of a passive older person and an active carer or supporter. The preponderance of such language conventions within the Exposure Draft (ED), indirectly perpetuates the ageist view that older persons are passive recipients of the attention and support of others – including service providers.

Separation and othering of older persons through the very naming convention of the Act further perpetuates ageist attitudes and beliefs. By singling out older persons from the wider community and identifying them as in need of ‘care’, ageism continues to be an accepted attitude in the wider context. Terms such as ‘sickness’ have no place in legislation as they are often clinically incorrect, misleading, upsetting, and imply that the condition of the older person requiring support is always ‘contagious’.

Many or most older persons that DAI support, are disappointed that the Government did not take the leadership opportunity to re name the Act in line with modern language conventions. Suggestions put forward by members include ‘*The New Universal Support Act for Older Persons*’, ‘*The National Ageing Support Act*’ “*Positive Ageing Support Act*” and the most popular ‘*National Life Course Support Act*”

Choosing language that will actively demonstrate the leadership role of the older person in the context of funded age care as much as possible in developing their individual support plans – including using the term ‘support’ as opposed to ‘care’ will progress the change of understanding and go far in addressing the power imbalance that older persons currently live with when engaging with the Age Care System.

Outdated terminology such as ‘Person Centred Care’ while not present in the ED provides an excellent example of terminology developed for us but not with us. While it may sound like an excellent model, it in fact disempowers and unpersons the older

person by implying that they are sitting passively in the centre of a group of well-meaning and helpful people all discussing and deciding what is best for them.

DAI suggests that terms that perpetuate the passive roles of other persons be replaced, in this case by ‘Person Led Support”, which does not affect the activities described, but provides an ACTIVE role for the older person in the support transaction.

Many DAI members have also expressed over time, the difficulties they face with literal interpretations of the word ‘care’. The implication is that ‘care’ will also include emotional connection, and this is a service that cannot be purchased or measured well. Certainly, training could be provided in how to demonstrate emotions, but it is not possible to train an individual to feel emotions associated with care. Thus, many older persons and service providers manage this dilemma with somewhat unsatisfactory results, as the older person may have unrealistic expectations from a service provider or other supporter, and the people providing the service become emotionally drained, demoralised and overwhelmed.

DAI advocates for a high-level discussion of language conventions used in the Age Care industry context, as we feel that this is an important pillar in changing attitudes towards a rights based, person led model of support into the future, that will combat some elements of ageism, support realistic expectations, and support the workforce and informal carers in moderating their emotional energy and resilience. Such an update on language conventions should also flow into service provider IT systems, Reports, Education and Training as well as advocacy.

Attention should be placed on dementia appropriate language, and of course this flows through to the assessment tools, reports, behaviour support plans, care plans case notes and other miscellaneous documentations. We draw attention to the Behaviour Resource Utilisation Assessment (BRUA) presently in use in the classification of residential age care funding. The language and concepts used in this tool are wildly inappropriate for older persons living with dementia. The language is demeaning and implies fault or nefarious intent of the older person when behaviour occurs that is unpalatable, irritating or inconvenient to others. While violence and assault are serious matters, they are poorly described in the tool, and it remains unclear to DAI if funding allocation to positively support older persons with changed behaviours is appropriate, as the statistics provided by the ACQSC do not seem to indicate any improvement in the levels of violence and sexual assault in residential age care – which to DAI is a better measure of success than measuring dollars calculated by the BRUA with the previous assessment model.

An outcomes-based review of the BRUA is desperately needed in order to adjust the current paradigm of “Behaviour Suppression Plans” which are clearly not effective to a more positive ‘Actively Positive Behaviour Support Plan” with appropriate funding to support an older person to manage and moderate changed behaviours.

DAI further recommends as noted in the body of the submission that deeper consultation with DAI, OPAN and Dementia Support Australia commence as soon as practicable in order to develop a truly co designed, accessible fair and safe process for management of behaviour changes in older persons, and how the older person can be involved through the mechanism of an ‘advance social directive’ to participate actively in the design of any “active positive behaviour support plan’ including advance directive for restrictive practice through the mechanism of an “Advanced Social Directive”

DAI note that locked wards, institutionalisation in general and Guardianship represent restrictive practice, and that further work must be done to uncover and minimise subtle and indirect restrictive practice such as use of opioids, removal of aids such as teeth, glasses and walkers, restricted continence changes, restricted access to food and drink and restricted access to the community.

### Statement of Rights

While a Rights Based Act is a great improvement for older persons, this alone again perpetuates the stigma that the older person is passive and sits quietly and enjoys their human rights at the expense of others. This is clearly not what is intended; however, this is the implication of the ED in its current form. We hope that deeper and more accessible and genuine co design is undertaken with the disability community in the formative stages of any drafting of human rights legislation in the future.

Statements of Rights and Principles that are not directly enforceable simply provide older persons with a false sense of security. It feels like we have been offered a screenshot of what rights could be but discovering that there is nothing behind the screenshot makes it inaccessible, particularly for those living with dementia, whose English is a second language, or who have other literacy challenges. DAI therefore strongly advocates the Department to consider adjusting the present model where older persons who have their rights breached are expected to already know that a code of conduct exists, where to find it, how to match their circumstance to the code of conduct, hope they get it right, then try and explain it all to someone.



## **This is not an accessible process for anyone in Australia.**

Either the rights and principles must be directly enforceable, or the rights must be clearly and unambiguously linked to the relevant enforceable section of the Act. Complaints around breaches of rights must be interpreted by the complaint recipient, and the burden of identification of the correct legislative section must rest with the complaint receiver and not with the older person themselves. In any case, it is vital that there is direct clarity for any older person around what their rights are and how to claim them.

DAI further advocate for a disclosure requirement to be placed on the Statement of Rights whereby older persons are provided with the Statement of Rights when signing any service agreement, Clear and Accessible complaint pathways and details of organisations who can support the older person in making a complaint – including anonymous complaints such as made to OPAN.

Furthermore, there is a lack of accountability of perpetrators of neglect, harm and all forms of abuse, or the protection of whistle-blowers of such harm. There is also a lack of transparency, reporting mechanisms, and a lack of adequate, indeed, if any redress and reparations for known harm.

Governments including departments such as the Aged Care Quality and Safety who clearly state they are “**...national regulator of aged care services, we protect the health, safety and wellbeing of older Australians**” and whom the Royal Commission provided evidence they do not meet this simple standard, as well as providers including their governing boards and managers, must much be made accountable.

DAI notes that in the government’s own 2023 publication, **Serious Incident Response Scheme (SIRS) Insights Series: Report 1 – 2023, Unreasonable use of force:** Notifications of resident to resident incidents, the numbers of unreasonable use of force is high.

They state that they chose to **‘focus this report on unreasonable use of force because it consistently accounts for 6 out of 10 of all serious incident reports notified to the Commission by residential aged care services – more than all the other incident types combined.’** This is deeply concerning, and as outlined in tables in Appendix A of this report, the numbers of incidents of SIRS in residential care in Australia are high.

**Accountability, transparency, redress and reparations, are critical for this to change.**

## Risk Management

DAI strongly advocate for the department to develop and consult on requirements for residential age care providers to have a detailed and robust pandemic plan as part of their operational risk management framework that is audited and publicly available.

## Communication, Transparency and Empowerment of the older person

Certain sections of the ED provide for mandated minimum timeframes for the provision of information to certain organisations such as the ANACC classification report, however no mention has been made of an equal timeframe for provision of such information directly to the older person.

All information, reports and assessments relating to the funded age care services must be freely available in a timely manner to the older person. It is difficult to feel empowered, to exercise autonomy, make choices or even complain if information is withheld. At a recent DOHAC meeting regarding this new act, it became apparent that the Department do not expect an older person to access their own ANACC assessments.

Provision has not been made to provide this information to the older person. This is not an acceptable part of the age care journey. Full, transparent and timely provision of all documentation created by either the DOHAC or funded service providers including assessors must be provided to the older person concerned within the same timeframe as any other organisation noted in the Act. Similarly, DAI expects to see care plans, behaviour support plans, clinical notes and other associated personal information to be freely available to the older person and their support persons and legal or informal representatives.

DAI are aware of many older persons living in residential age care who have been denied access to their care plans and behaviour support plans either through direct denial or through lengthy obfuscation.

DAI strongly advocates for equal access to all documentation created in relation funded age care services to be provided to the older person and their nominated representative simultaneously with any other listed organisation in the Act, as soon as it has been completed or upon request. Of course, free and transparent access must be available for registered supporters and representatives to assist them in properly supporting the older persons with their age care services.

## Advocacy – the missing link

For the objects of the Act to be successful in practice, advocacy services must be specifically referenced in the Act. There is substantial difference in quality of advocacy services provided under NACAP, and those provided by independent and individuals who call themselves advocates.

Specific legislation that links advocacy services to NACAP, potentially referencing the advocacy standards will provide comfort, consistency and security of quality of service to the older person.

Advocacy for or about people living with dementia continues the alarming '**about them, without them**' method of operating and acting.

Indeed, in their final report, the voice of people with dementia was missing from the Australian Royal Commission into Aged Care Quality and Safety (RCAC) Final Report, an absence which was notwithstanding because the RCAC was explicitly tasked to inquire into dementia care, and reported it included people with dementia in residential care. In reality, only three people with dementia provided witness statements, none of whom lived in residential care. All other accounts were provided by 'experts', advocacy organisations, care partners or family members.

DAI believes people living with dementia themselves, must be included at every stages.

### System Governor

The System Governor is often referred to in the ED, however the scope of responsibility and delegation of the System Governor remains unclear. We welcome further detail soon.

## Missing parts of the Act

**At present, it is difficult to make detailed commentary on the overall ED given the level of detail missing.**

Financial matters such as co-payments, deposits and fees directly impact an older person's quality of life and levels of stress and anxiety. Details that will be included in the forthcoming 'rules' are critical to us, and it is very concerning to us that such critical information is absent.

DAI strongly advocates for sufficient time to provide meaningful feedback on the omitted parts of the ED, along with published sections where there may overlap in feedback and implications.

## Part 2 – The Age Care Act Exposure Draft

### (5) (a) Objects of the Act

DAI are pleased to see consideration of the Convention of the Rights of Persons with a Disability (CRPD), and that the proposed Act will give effect to Australia's responsibilities under this treaty. We note however, that dementia as a disability has not been highlighted, and the word disability only occurs three times on the exposure draft. This is concerning, when the World Health Organisation have determined **'dementia is a leading cause of disability and dependence of older persons globally'** for more than 15 years

We further suggest that consideration be given to direct reference to all 7 conventions that Australia has committed to, and that direct reference also be included to the Madrid international Plan on Ageing which is a critical part of the human rights of older persons infrastructure in Australia.

### (5) (e) Regulatory Framework

While a risk based regulatory framework is ideal for ensuring continuity of service, it is of little value to the older person in addressing urgent compliance matters. Unlike the finance system, each incident directly affects the wellbeing and safety of our older persons. Along with our families, when we do find the mental fortitude to bring a formal complaint, it gives us little satisfaction of feeling of justice when the only outcome is a change in policy or procedure, that is often agreed upon between the regulator and the organisation with little transparency to the complainant. When things go wrong, older persons and our supporters want and need an independent compliance-based complaints mechanism to ensure that complaints are not only dealt with at the systemic level (with a view to keeping the industry working smoothly) but at the individual level which will facilitate pathways to not only redress and compensation, but restorative justice, a process that must continue past the death of the older person.

## Part 2 – Definitions and Key Concepts

### (8) Age Care Service List

At the time of writing, The Rules, the report of the Age Care Taskforce and the Age Care Service List have not been released for consultation. It is unclear to DAI whether any consultation will be offered at this stage, and this is a matter of concern. However, if these items are only related to the deferred Support at Home program, we eagerly await an opportunity to consult on these matters.

The concept of a service list is a difficult one, as Prima fascia it appears to be somewhat limited in scope and may further limit the choices of the individual. While a service list of basic items and services may facilitate faster organisational processing, it becomes problematic for older persons with more diverse needs.

A service list of commonly prescribed items that serves the purpose of expediting access to the older person, without the often ‘punitive’ requirements of paying for “professional prescriptions” this will be very welcome. A service list of low-cost low risk items and services that may be accessed directly will provide the older person with access to timely and cost-effective products and services.

Publication of a closed loop Service list without person-based flexibility would be extremely unacceptable.

DAI advocates for reasonable flexibility, an accessible process for an older person to appeal a decision and a streamlined process for additional items to be prescribed outside of the service list according to need and professional recommendations. Again, we look forward to more detail in due course.

### (9) Where funded services can be delivered

Limiting of location of service delivery in the Act may also prove somewhat problematic for many older persons. It is unclear if persons who are homeless or otherwise disadvantaged will be able to access services. DAI is also concerned about the exclusion of older persons who are incarcerated – whether in prison or in mental health facilities. We understand the challenges around providing services in these environments, however restrictions on location of service delivery may result in unintended gaps in coverage, and active exclusion of persons in prison or other non-prescribed circumstances.

DAI urges the department to consider older persons who are not in mainstream society, and work in consultation with stakeholders on pathways for our marginalised persons excluded from this definition to access funded services and supports, particularly our Forgotten Australians and our Stolen Generations.

(13) & (14)

We look forward to the Rules becoming available for consultation and discussion.

(15) Reportable incident

Again, more reference to the Rules, however DAI understands that the ambit of this legislation only covers incidents perpetrated in the course of funded service provision. In the absence of a Federal Adult Safeguarding Scheme, much elder abuse is observed and suspected by persons acting in their capacity under the Act, but they have inconsistent reporting pathways. DAI warmly invites the Department to consult with relevant State and Territories in the urgent development of a Federal Adult Safeguarding Scheme.

Further, DAI takes this opportunity to express concern around the lack of protections for older persons who are in the fortunate position to self fund all or some of their age care needs. While these services cannot be encompassed within this Act, we suggest that the Department develop a pro forma service agreement that will reflect the protections – in particular the rights of older persons – of the Act in a way that can be used to protect the older person under Consumer Law. This service would at least provide some comfort and certainty to the many older people for whom a level 4 age care package is insufficient to support them to stay at home, and who have access to self-funding additional support.

It is DAI's experience that most people living with dementia do not wish to leave their homes, and this wish is fully supported by our families, however in the absence of meaningful dementia specific support in the community, families do not have a full-time unemployed family member to undertake the support needed. At present, the only government funded support pathway is residential age care, which for many of us is upsetting and demoralising. We are further demoralised and indirectly discriminated against when we attempt to top up our home care packages privately, only to find that these privately funded services do not attract the favourable protections afforded to funded services.

This gap makes people with dementia more vulnerable to abuse and neglect from unscrupulous service providers who find us to be an 'easy target'.

DAI advocates for further consultation with stakeholders including consumer law specialists to develop a pro forma service agreement that will afford us similar protection from abuse and neglect from age care service providers.

(16)(17) Restrictive Practice

DAI looks forward to further information when the Rules become available, however we note that the term 'informed consent' is used frequently. While the concept of 'informed consent' is a good one, in the context of dementia, true informed consent to a restrictive practice is rare. In practice, most behaviour support plans (bsp's) are signed off by a representative, quite often without much background information as to the reasons for the restrictive practice, the proposed benefits and the alternatives that have been tried and documented.

It is DAI's opinion that there is a fundamental difference between 'informed consent' and 'Informed Authorisation' – neither of which seem to happen in practice. The Age Care industry use BSP's as a mechanism to moderate so called 'behaviours of concern'. Most BSP's are AI generated, often prior to admission to residential care. In practice, after reviewing a significant number of BSP's, it is apparent that they are in fact Behaviour Suppression Plans, almost always associated with persons living with dementia. The BSP's observed showed no reference to positive behaviour or reinforcement of positive behaviours, simply a description of behaviours deemed negative – aka – inconvenient, and the ways to suppress them. The BSP's observed through a research project without exception were signed off by a representative of the older person.

It is unclear what information was provided to the representative for them to base their decision on.

DAI advocates for new terminology that better describes the practical application of the consent process and differentiates between the **informed consent** of the older person, and the **informed authorisation** by a representative – with the focus being on documenting the information the decision was based on, and the supported decision-making process used.

Restrictive practice legislation must be carefully developed in close consultation with persons actually living with dementia, Dementia Support Australia, Public Advocates

and other disability advocates and must be developed in parallel with supported decision-making legislative requirements. These intersecting concepts are still in their infancy in terms of overall understanding in the age care context, and they must be brought to maturity throughout the development of this new age care act. DAI will welcome the opportunity for consultation in drafting forthcoming rules in relation to Restrictive Practice and Supported Decision Making.

(18) Significant failure and systemic pattern of conduct

DAI look forward to more detail and consultation in relation to the specific detail supporting a decision on the determinants of significant and systemic in practice.

(19) High Quality Care

(19)(a) Puts the person first – whilst this is an admirable concept, this wording continues to perpetrate the notion that the older person is passive in the activities.

In DAI's opinion while the older person should be predominant in any care or service transaction, this may be better expressed by giving the older person some power in the care and support dynamic.

The phrase putting the person first – gives all the decision-making power to the individual providing the service, and the 'person' gets to be intellectually prioritised.

In practice, older persons want, and have a legal and human right to a voice.

They wish to be able to lead care and services – consumer led care. Active phrasing of the role of the older person will go a long way to communicating the change of focus of the New Act from power sitting with the service provider to power sitting equally with the service recipient.

DAI suggests 'The Older Person has Control', 'the wishes of the older person are paramount' or 'The older person leads the care and support' or some variation of these. Reinforcing perceived passivity of the older person through older fashioned wording may not achieve the change of focus we are all trying to achieve.

While there are multiple points to (19), DAI strongly suggests that the concept of supporting the older person to make their own care and support decisions is included, as the current version assumes that their wishes have already been adequately communicated under (a), which is rarely the case.



(20) Statement of Rights

DAI welcomes the Statement of Rights; however we think it important that it is noted in legislation that the statement of rights do not supersede or invalidate our rights under other rights-based legislation and treaties.

Further, DAI advocates for the 'right to life' to be specifically included. While the statement of rights is currently indirectly enforceable, it appears that it is only enforceable against service providers. DAI provides a recent example of older persons in Residential Age Care who were not provided with the opportunity to vote in elections as part of the 'covid pandemic'. This was a frank breach of basic human rights, and while the restriction may have been executed in the 'public interest' or the 'best interest of the older person', this is frankly in breach of their human rights as they were not offered a choice to either vote by post or other means.

This alongside other horrific breaches of the human rights of older persons such as refusal of treatment, have had a significant impact on the older community. Older persons have now experienced ageism at its worst, and fear for the future, as there is little guarantee of equality of access to healthcare, access to civic participation or even access to fresh air and family life.

DAI members have expressed that during covid, persons incarcerated in jails had a vastly better experience of their rights being protected than those incarcerated in residential age care.

(2)(ii) Assessments are suitable and accessible for persons living with dementia and cognitive impairment

DAI look forward to further clarity around dementia specific support in the forthcoming support an 'at home' work plan.

It is curious that the assessment process should be accessible for persons living with dementia is specifically set out in the legislation, considering the disappointingly inappropriate inclusion of the BRUA in the residential care assessment tool. It is a matter of concern that persons living with dementia will be assessed using words like 'problem wandering' or 'manipulation' and 'attention seeking'.

The BRUA is inconsistent with the rest of the ANACC which is based on the costs of positive and active support, while the BRUA simply sets out the costs of behaviour suppression, thus perpetrating restrictive practice.

The trial of the BRUA that was considered successful simply matched the BRUA numbers with previous numbers that also costed suppression. This is not a positive outcome, and DAI look forward to urgent review of this extraordinarily important section of the ANACC.

It is also noteworthy that an accessible assessment process should also be transparent, with the older person having unfettered access to their own assessment information.

This is a fundamental human right for us; however the inclusion of the BRUA will make extremely demoralising reading for us. Certainly not consistent with (2)(i) Culturally appropriate and healing informed etc.....

While the statement of rights is comprehensive, the BRUA is inconsistent with many of those rights.

In DAI's experience, the statement of rights is important, but will only be effective if the older persons actually know about them. Access to communication is vital for older persons, not only for social and community participation, but in order to assume their role as leader in the care and support context.

For example it is difficult for an older person in a locked ward to make a complaint – even if they had the will or the capacity as there is often limited access to the internet or appropriate devices, as well as limited access to support to use such devices. We hope that access to communication will feature in the forthcoming Rules

21(3) Statement of Rights not enforceable

It is difficult for the dementia community to understand the point of an unenforceable statement of rights

(23)(13)(f) Effect of Statement of Principles

DAI looks forward to further information on how this will be enacted in practice. We hope to see formal employment of persons with contemporaneous living experience by the regulator as well as within the Department of health and age care – as well as other peak advocacy bodies as envisioned by the CRPD and various disability inclusion legislation for the inclusion of older persons living with disabilities to be included.

## (23)(3) Statement of Principles

Again nothing is enforceable – making it difficult to understand the point of including a statement of principles.

## Part 4 – Supporters and Representatives

### Division 1 – Actions and duties of supporters

#### Subdivision A – Action and Duties of Supporters

##### Overview

Broadly speaking, while much progress has been made in recognising the role of supporters and representatives in the age care context, the living experience of DAI members and others is that such supporters are in short supply. Many many older persons do not have access to a trustworthy adult who is freely available to provide support and representation not only within the ambit of age care, but in the broader guardianship and power of attorney context. Many older adults live alone with family members who live interstate or overseas. Even when supportive family members live geographically close, they have careers, volunteering, children, other family members and other responsibilities that limits the time and energy available to fully support an older person in the daily administration of support services.

DAI believe that it may be somewhat unrealistic to suppose that each family whether biological, family of choice or other arrangements has at least one member who can financially afford to take the time required from work to attend to these duties to the expected standard. Even fewer may have the appetite or indeed the skills to undertake training or to fully understand the requirements of the role of supporter or representative. A further impediment to provision of such support and representation is the broad lack of flexibility in employment law, which greatly impacts working persons from taking calls, attending appointments and making and supporting daily decisions for their older person.

The status of the carer payment/carer allowance which only caters to physical care presents a further barrier to providing administrative type support, which is time consuming to provide correctly. DAI recommends that the department of health and age care work alongside Centrelink and other relevant agencies to develop pathways to financially support persons who wish to provide timely and quality support to their older person without sacrificing their own employment, housing, food and energy security.

DAI further recommends the expansion of existing advocacy services to support the older person in their age care administration decisions where required.

While in 2024, the strong expectation from the government is that older persons must have a secondary person deeply involved in their lives, little thought has been given to our ability to plan for potential future decisions. Many older persons including those of us living with dementia have a strong desire to support our own decisions into the future, and that such advance directives are respected as being valid in real time.

DAI strongly advocates for a third pillar in the supported decision making/representative decision-making model – an Advance Social Directive.

Such a directive can inform future decisions when capacity is impaired, it can inform our supporters, and provide guidance on our social wishes to our future representative decision makers. Such a directive would enshrine the validity of our voice into the future, which under the current model is more or less missing, particularly in the later stages of life when representative decision making is in place.

An advance social directive is not an extension of an advance care directive or a will. It provides a picture of the person we are, provides decisions in advance and promotes our will and preferences into the future. As an example, many older persons living with dementia wish to remain sexually active with their life partners. At present, active consent is required – and rightly so. This can present a barrier in this case if the older person living with dementia cannot or does not communicate. An advance directive coupled with for example a ‘token’ gesture, would provide certainty for an intimate partner into the future.

Similarly, an older person living with dementia may wish to not be sexually active when they can no longer clearly articulate consent. Such an advance directive would support families, care staff and others to protect the older person from unwanted sexual advances and provide certainty that human rights to say no are being upheld and protected into the future.

Clearly such a model would need careful consideration, however it is a necessary part of maintaining our human right to autonomy into the future when decision making and communication capacity fluctuates, and the older person transitions from autonomous to supported to representative decision making.

## (24)(b) Actions of Supporters

While it is useful for supporters to be able to access information, the legislation as it stands does not set out methods for the supporter to validate that they are passing on the views of the older person or the consent of the older person. How will the information recipient be able to tell if the information provided was the instructions of the older person or whether the supporter is actually taking the role of representative?

DAI believes that further deeper work is required to develop a workable and safe system is developed that will not only enable supporters to assist us with our funded age care, but to protect us older persons and persons living with dementia from being 'taken over' inadvertently by well-meaning supporters who do not always understand the limits of their role.

Service providers also need a level of satisfaction that they are operating according to the wishes of the actual older person, and DAI don't have confidence that the legislation as it stands will provide such satisfaction or protection for service providers.

**DAI welcomes the opportunity to work on this into the future, alongside the Department and other stakeholders.**

## Chapter 2 – Entry to the Commonwealth Age Care System

### Division 3 – Age care needs assessments and reassessments

#### Part 3 – Classification

#### Division 1 – Classification assessments and decisions

### Overview

While great effort has been made to prioritise the wishes of the older person as noted in the statements of rights and principles, A system of assessment that places the result of an older person's assessment into a matrix of groups, associated service types, restrictions and conditions of approvals does not appear to be a particularly person centred approach. It does not provide any sense of transparency to the older person, and its complexity may well result in great dissatisfaction. Use of algorithms while useful for funding and data, are unhelpful in a human context, and while testing

may reflect similar financial outcomes – this is not necessarily a measure of success for the older person. For example, while the BRUA was tested, and the outcome was perceived as satisfactory due to the expected funding amounts being consistent with the prior assessment model. Anyone *placed* in a locked ward who is a victim of violence and/or sexual assault would strongly disagree. The statistics published by the ACQSC prove grim reading and must surely prompt an urgent review of both funding modelling and practice requirements for positive behaviour support in residential age care.

Further, recent data errors only highlight the vulnerability of all stakeholders to data error, internet and power outages, pandemics, floods and fires.

In addition, DAI continue to express concern at the modest consultation on the assessment and classification development with older persons. It is unclear how much impact their feedback had on the process of development of the support at home assessment tool, however the residential care assessment tool development completely excluded older persons and persons living with dementia from contributing.

DAI strongly urges the Department to consider the human impact of an inflexible classification matrix and look at additional human centred controls and alternative options.

#### (56)(b)(iii) Classification Assessment

It would appear that legislation will require the older person to be ‘in situ’ in residential age care prior to undertaking a specific res care classification assessment. DAI looks forward to further information on how this might work in practice, as in our experience, Res Care providers will undertake a preadmission classification assessment in order to anticipate funding levels. While this makes good business sense, DAI are concerned that older persons accessing residential age care who live with dementia may be subjected to the BRUA assessment twice. The assessment process is a necessary but exhausting, demoralising and depressing experience, and we are interested in minimising the levels of trauma which are already heightened during this difficult transition period for the older person.

DAI further looks forward to publication of the in-home support classification tool for consultation, and we reiterate our hopes for full transparency and uncomplicated access to all reports compiled about the older person.

## Part 4 Prioritisation & Part 5 Place Allocation

DAI looks forward to consultation on the proposed prioritisation process, including detail on proposed automation systems, oversight and monitoring.

## Chapter 3 – Registered providers, age care workers and age care digital platform operators

### PART 1. Division 2.

#### (66) (3) (a) Registration Category

DAI looks forward to publication of prescribed registration categories and their proposed functions

#### Division 2 – Registration Requirements

#### (68)(1)(c) Suitability of responsible persons

Further detail is required here – At a minimum we need fit and proper requirements amongst others

DAI looks forward to the forthcoming Rules which will set out the detail of registration requirements more fully

## Part 4 – Obligations of registered providers etc, and conditions on registration of registered providers

### Division 1 – conditions on provider registration

#### (101)(a) Quality Care Advisory Bodies

DAI are strong advocates for the rights of persons living with dementia to have a place in the system of governance of funded age care service providers – particularly when many of their clients live with dementia. While the concept of a consumer advisory body is interesting, in practice one of the defining symptoms of dementia is inertia. Therefore, while it may appear that we are disinterested or have nothing to

say, that is not in fact the case. The person living with dementia often has a great deal of input and ideas and are very often able to contribute fully if they are supported carefully and safely to do so. In our opinion it is insufficient to 'offer' the opportunity to create a consumer advisory body. The provider instead should **support** their clients and supporters to form and attend a consumer advisory body. Usage of the word 'support' as opposed to 'offer' again gives an important message in changing the power dynamic and making the process at least in some way accessible for users of funded age care services.

Furthermore, while a consumer advisory body may sound like co design or consultation, when persons living with dementia are expected to be present, this is not necessarily the case. A specifically developed lived experience framework will be required to support not only persons living with dementia, but also service providers/researchers/ advocacy bodies and the Government in safely and productively engaging with persons living with dementia.

DAI advocates for at least 2 places on the Quality Care Advisory Body to be active clients of the organisation – and/or supporter. Intellectual, cognitive and skill specific diversity will only add value to the group dynamic, will force accountability and give veracity to the process. This model will also ensure that at least 2 voices of living experience are brought to the table in the event of the failure of the 'offer' to create a consumer advisory body. This model should be extended to all government funded services specific to older persons and persons living with disability. DAI will be pleased to participate in this process.

#### (104) Wholly owned Subsidiaries

While this may not be the most appropriate section of the Act, and our feedback may sit better in Part 13, DAI recommends that provision be made to prohibit parent companies from transferring liabilities incurred in other subsidiaries into the subsidiary company associated with being the registered provider. In recent years, it has become well known that inappropriate transfer of liabilities incurred from poor practice have been transferred into subsidiary age care companies, thus providing the impression that the business is performing more poorly than it is, in order to support an argument for increased fees.

Ring Fencing registered providers from transfer of assets or liabilities will protect the public from flawed information and will provide true and proper business transparency to the taxpayer and potential clients.



(107) Ceasing to provide service

DAI looks forward to consultation around the rules for cessation of service.

## Part 5 Statutory Duty and Compensation

The introduction of individual and collective actions for people with dementia who experience violence, abuse and neglect in any setting, and including care partners and family members who are impacted by that harm.

This must be at all levels to improve the recognition of, and prevention of all forms of violence, abuse and neglect in residential aged care, respite, and community.

Governments will introduce improved reporting of violence, abuse and neglect in residential aged care, respite and community care, and for perpetrators of harm to be held accountable.

Governments will introduce improved complaint processes victims/survivors support schemes, and specialised services for older people and people with dementia who have experienced any form of violence, abuse or neglect, including or who are at risk of experiencing sexual assault, and

Individual and collective reparations that are accessible and affordable for people with dementia and older people who experience any form of harm, and others who are impacted by that harm such as care partners and family members.

## Division 3 Compensation Pathway

People living with dementia have been subject to significant harm including violence, abuse and neglect in aged care. Yet, this harm is rarely recognised and redressed. People living with dementia in aged care, as well as care partners and family members, encounter ineffective complaint and prosecutorial processes, including barriers to reporting harm to the police, and difficulty accessing justice through the courts. The systems that allow harm to occur remain unchanged and continue to perpetrate further harm.

People living with dementia and their care partners and family members await accountability, justice and change.

The new Aged Care Act must include accountability, and redress and reparations for harms to all people receiving community or residential care who are harmed or abused in any way.

## Chapter 4 Fees Payments and Subsidies

DAI looks forward to consultation on this fundamental section of the upcoming Act. It's omission greatly impacts the quality of feedback and consultation.

## Chapter 5 Governance of the aged care system

### Part 2- System Governor

#### (134) Register of Coroners Reports

DAI welcomes the Register of Coroners Reports; however, this will be incomplete without a designated policy whereby all unexpected death reports are provided to the System Governor regardless of autopsy status. Such unexpected deaths should be reported regardless of the location of death – residential care, hospital or in the wider community. Ideally autopsy would be required for any unexpected death in Australia regardless of residential status, as it is discriminatory practice to accept unexpected death in residential age care, but to investigate for the wider community. Older persons have equal value in our society regardless of where they live.

### Part 3 – Aged Care Quality and Safety Commission

## Division - Establishment and functions of the Commissioner

#### (143) Quality and Safety Commission

Section 143 sets out the additional roles of the commission including education, capacity building and consultation. To date while the commission has made good efforts to consult with the community, they are primarily online efforts, and the issue of technology discrimination has not been easy to address. Combined with language differences, cognitive ability, lack of technology access and 'othering' of older persons, the consultation efforts have resulted in modest uptake. DAI strongly advocates for the embedding of living experience into the body of the commission by way of living experience consultants, as well as a living experience advisory body to ensure that the commission hears the views of a diverse range of older persons, including persons living with dementia who sadly are so often the subject of the commission's work.

(144) Statutory independence of a complaints commissioner, facilitated by information and a shared database is the model supported by DAI. It is unclear whether the complaints commissioner will be delegated with enforcement powers, DAI will welcome clarity on the scope of the complaint's commissioners' powers.

It is vital that the complaints commissioner is operationally independent and separate from the Quality and Safety Commissioner. The fundamental basis of risk management is forward looking and is firmly based on systemic quality improvement. This is fundamental and necessary to the industry, but similar to the financial services prudential regulator, (APRA) we in the community need and expect a compliance-based regulator to examine matters that happened in the past and assist with complaint resolution at the individual level similar in nature to ASIC. The complaints commissioner would provide a gateway to restorative justice, mediation and compensation/redress when required.

This is a critical distinction.

It remains unclear if older persons and their supporters or representatives have a complaints pathway about the regulator themselves.

#### Division 6 Financial and Prudential Standards

##### (5) (3) (6) Prudential Standards

DAI looks forward to the publication of proposed prudential standards including liquidity, risk management and capital adequacy. In light of Chapter 4 not having been published, there remains a significant impediment to the consultation process.

#### Part 4 Age Care Quality and Safety Advisory Council (ACQSAC)

DAI looks forward to further clarity around the scope and function of the ACQSAC, however we believe that no advisory council will be able to act with veracity unless it comprises living experience.

This will not only show leadership from our government, but the intellectual and cognitive diversity in our older persons which is so often overlooked, will enhance the productivity and scope of the council as well as guarding from self-referencing behaviour and decision making.

## Part 5 – Complaints Commissioner

### Overview

As previously noted, DAI strongly advocates for separation of powers between the risk based prudential regulator and the complaints commissioner, to ensure both the veracity and independence of the actions of the complaint's commissioner from the ACQSC commissioner, and to provide individual one to one attention to the complaints of an older person, with a view to a satisfactory resolution for the older person. This is in direct contrast with the ACQSC brief which is to ensure satisfactory resolution and continuity of service which is not the same thing.

## Chapter 8 – Miscellaneous

### Part 4 Appointment of Supporters and Representatives

#### (374) (6) (376) (8) Appointment can be made verbally

DAI are keen to understand how verbal appointments can be validated and communicated. We look forward to further detail in this regard particularly in relation to the appointment of a representative who appears to have the power in this capacity to accede to the institutionalisation of an older person outside of any guardianship system.

#### (376) (6) (b) Appointment of Representative

While (376)(6)(b) states that consent of the older person is required for the system governor to appoint a representative, The note at the bottom of this section sets out the fact that 'consent' is not required for the appointment of a representative. DAI seek clarity over this important matter. Some providers spare little time in obtaining true informed consent and will always default to convenience and risk aversion.

#### (376) (7) Cancellation of supporter

DAI notes that this proposed model of supporters and representatives does not facilitate an older persons often fluctuating capacity and ability to make and communicate decisions. This further isolates the older person, particularly those of us living with dementia, essentially forcing us to nominate a representative while we still have the capacity to make decisions. Bringing forward the appointment of a

representative well before it becomes completely necessary is for all practical purposes a restrictive practice.

DAI will be pleased to discuss adjustments to this ‘supporter OR representative model” and the resulting limitation on persons living with dementia, and workable alternatives to provide a ‘transition phase’ where the ‘supporter’ *transitions* to ‘representative’ depending on the type of the decision, when it is being made, access to support and capacity – all of these factors impact the older persons decision making ability. Ignoring the often quite long ‘transition phase’ is simply contravening our human right to autonomy for the sake of administrative expediency as well as a frank breach of the CRPD.

DAI urges the DOHAC to further explore the nature of supported decision making in the context of age care, and the potential unintended consequences of the section as it stands. DAI will be pleased to consult on this extraordinarily important section, and advocate for supporters and representative functions to have a specific section in the Act.

#### Part 7 Use of computer programs to make decisions

DAI wishes to express concern in relation to the use of AI to make such life altering decisions for older persons, many of whom still live with the traumatic memories of robodebt.

Classification and prioritisation decisions intimately affect the quality of life, health and well-being of older persons, and while it may appear logical for these decisions to be automated, we must keep in mind the potential for harm should the algorithm fail (recent failures in data reporting), should the internet go down (recent Optus outage), should the power fail (too many times to mention – climate change).

DAI further note that the use of AI in such important life affecting decisions forces monitoring and compliance of the veracity of such decisions onto the older person. At this time it remains unclear how the older person can even access the results of their ANACC assessments and Classifications, so it will be important for such transparency to be highlighted to us. How can we challenge a decision based on information that we cannot see about ourselves, and decisions made by invisible algorithms. **This approach is not putting the older person first.**

DAI further requests that a manual oversight system be in place, where AI decisions are regularly reviewed for consistency.

While DAI do not explicitly object to the use of AI, we ask that in light of historical failure of such initiatives in the context of our oldest and most vulnerable persons, that additional clauses be inserted referencing an operational risk plan, very timely review processes and contingency planning.

While the department will most likely already have this in place, after experiencing how covid was managed in the age care system, there is little faith in the community around operational risk management and contingency planning across the industry, and we in the community seek some certainty around new processes with a disappointing track record.

#### Part 10 Sect 412 Review of the Act

In light of the magnitude of changes, and the staged implementation of the new Act, DAI strongly advocate for a 2-year review period. Consultation opportunities for the exposure draft of the Act have been significantly limited – exacerbated by the gaps in the ED, Age care task force review and publication of the ‘rules’ that will affect our day-to-day life so significantly. It is important to take stock of what has been implemented to assess what may need to change prior to implementation of the support at home program in 2025. DAI also request that the annual report on the operation of the Act be publicly available in a timely and accessible manner.

Further – the current uncertainty for older persons living with disability, and the perceived exclusion of meaningful disability support in the Exposure Draft leads us to believe that either Disability supports for older persons will be distinct and separate to age related age care, or that disability will be supported through the age care system through a vastly different support at home program.

DAI remain confused and uncertain as to why dementia appears to be somewhat nebulous in the existing scheme. Residential Age Care simply cannot be the final destination of life for a person living with dementia in Australia. Dementia is an accepted disability in its own right, and attracts all of the protections of the CRPD, yet it appears to be wrapped in with ‘sickness’ in the ED, and that is simply unacceptable.

DAI look forward to further clarity around dementia and disability support for older persons who do not wish to be institutionalised and stand ready to consult at any time in this important and vital work.

## Part 11 Critical Failures Powers

DAI looks forward to extensive consultation on Part 11 in relation to critical failures.

## Part 14 – Recoverable amounts

While it is important that unexpected debts or errors are resolved correctly, it is equally important that an older person is not placed in poverty due to age care debt. DAI strongly advocates for a humane approach to debt recovery, and that maximum limits be set for repayments as a percentage of income to protect older persons from housing, food and energy insecurity, and that these maximum limited be enshrined in legislation. It is also necessary to protect older persons who have received compensation – for example our Stolen Generations from having their compensation payments assessed both in relation to co-payments and/or Commonwealth age care debt.

## Chapter 7 Information Management

### Overview

As technology solutions progress to support active living for older persons, so also do the risks of breaches of privacy. Discussions ensue as to the palatability of video monitoring services, GPS locators and other devices. These can be a valuable tool in maintaining the physical safety of an older person, however such devices must only be used with the genuine and informed consent of the older person or with the genuine and informed authorisation by a representative. When consent has been provided, extreme care must be taken in protecting the privacy of the older person. Balancing the risks and benefits of video recording, GPS tracking and sound recording must be negotiated between the service provider and the older person. Privacy policies and procedures must be robust, and regularly reviewed. Such policies should comprise an essential part of the operational risk management systems of the service providers, and specific penalties for breach of privacy included in the Act.

### Division 2 Section 323(4) & 342 Prohibition on recording

It is unclear what penalties or actions will result when the staff of registered providers inappropriately share private information. As a vignette, a past legal case notes that a staff member took intimate photographs of an older person in their care. The staff member circulated these pictures as a source of merriment. The family of

the older person took the staff member to court with a charge of sexual assault; however the magistrate considered the offence to be simply a matter of excessive fun.

DAI are committed to the dignity and human rights of all older persons, and we look forward to clarity on the consequences of funded age care staff who breach the privacy and dignity of older persons through the inappropriate sharing of images and recordings.

Throughout the section on the sharing of recording, a notable gap is the informed consent of the older person. DAI looks forward to an updated version that reflects the importance of consent or at least informed authorisation for such sharing. Furthermore, it is important to include a mechanism for the older person to access their own 'protected' recordings.

In respect of section 342, DAI further note that we feel it an extremely inappropriate overreach for the system governor to reserve power to circulate private protected information to researchers, particularly without our express and informed consent, and we object in the strongest terms to this section. We also find it difficult to understand why protected information would enhance the quality of the pricing authority or star ratings – or any other program or entity where deidentified information would be sufficient. It is DAI's opinion that any protected information being disclosed without specific informed consent for reasons other than criminal activity by the older person must only be shared with the specific authorisation of the system governor based on a set of pre agreed criteria,

## In conclusion

The road to a diagnosis of dementia can be a long, stressful, and beset by unrealistic expectations, fears based on myths and stigma, unfounded hopes and certain confusion.

We must change the approach of treating people with dementia as having lost capacity from the moment they are diagnosed.

Instead, it needs to be acknowledged that some people with dementia are now living 20 or more years beyond diagnosis and striving to live positively, not the life expectancy of 7-10 years as the current data – and post diagnostic experiences reflect.



People with dementia are not invisible; not children, and we will not be ignored, trivialised, patronised, or shunted aside.

Australia has international obligations to take appropriate legislative, administrative and other measures to promote the human rights of People with disability including caused by dementia, to protect people with disability from all forms of exploitation, violence and abuse under the Convention on the Rights of Persons with Disabilities, and are obligated to provide adequate, timely and equal health and social care, and support for cognitive and other disabilities acquired due to their diagnosis of dementia.

We ask that your recommendations give effect to those obligations and broader responsibilities to all Australians, all Australian Governments provide funding and services for people with dementia, with laws implemented to protect and enhance the independence, wellbeing, health and quality of life of people with dementia.

## Recommendations

This submission seeks the inclusion of the following recommendations:

1. Dementia is adequately defined not only as a medical condition, but also as a condition causing disabilities.
2. People with dementia are part of the Australian and global neurodiverse community.
3. Employment Rights, including access to the Disability Discrimination Act, are central to the new Act.
4. Human Rights are central to the new Act.
5. Disability Rights including access to the CRPD are central to the new Act.
6. Deinstitutionalisation and desegregation for all people with dementia, as recommended by the United Nations Deinstitutionalization Guidelines are included in your recommendations. Multiple formal enquires and the Royal Commission into Quality and Safety in Aged Care has proven the institutionalisation of older people and people with dementia causes harm and abuse. Residential Aged Care is also coercive, due to the lack of alternative and accessible, dementia-enabling options, and the lack of appropriate environmental design which to enables community living allows people to stay at home for longer.

7. That the CRPD is acknowledged in the current Exposure draft, highlights the longer term need for the closing of all institutional style residential care facilities, as reflected in multiple Articles on the CRPD, but I particular we highlight **UNCRPD Article 19: the right to live independently and be included in the community. Article 19 reinforces government' duties to provide everyone with support to live independently.**
8. Governments to provide improved access to independent supported decision making, including mandatory training and accountability for substitute decision makers, which is auditable, transparent, and outside of the ambit of current guardianship arrangements (to ensure that guardians or substitute decision makers do not block access due to real or perceived conflicts of interest). Furthermore, a pathway should be developed for people living with dementia to make an Advance Social Directive, whereby they have a voice into the future, should capacity become compromised, particularly in relation to living and social arrangements, visitors and family of choice relationships and including sexual activity.
9. Disability workers and organisations providing disability services and supports through the National Disability Insurance Scheme (NDIS) to people with young onset dementia must be educated in all forms of dementia. This should include, at a minimum, the freely available University of Tasmania Wicking Institute 9-week 'Understanding Dementia' Massive Open Online Course (MOOC)<sup>vii</sup>, or an alternative free course in dementia.
10. Dementia education must be provided and must include dementia as a condition causing acquired disabilities, with appropriate training on supporting cognitive and other disabilities specific to the many types or causes of dementia.
11. The introduction of individual and collective actions for people with dementia who experience violence, abuse and neglect in any setting, and including care partners and family members who are impacted by that harm.
12. We recommend other strategies are developed, and that the Dementia Friendly Communities and other Dementia Friendly Initiatives are not the only strategies being targeted and funded for awareness raising, or to reduce stigma and discrimination. An inclusive community, that
  - a) does not define people by their condition or disability, and
  - b) is accessible for everyone, is critical.
13. We also note people with dementia and dementia specific organisations such as DAI have not been involved in the reforms to the NDIS or the NDIS review,

Government needs to fund a DPO of people with dementia as part of the funded DPO's National Disability Representative Organisations in the Department of Social Services. In the absence of an Australian based DPO, DAI should be included.

14. We recommend that **all people with disabilities due to dementia have access to the NDIS, as it currently discriminates against people with dementia the age of 65 and older.** This is especially significant, due to the time to get a diagnosis often being delayed and prolonged, due to multiple factors, including the pervasive and harmful stigma, and a lack of education of medical and other health care professionals about dementia.
15. DAI is included in all future consultations, and not represented by other organisations, for these reasons;
  - a) Other organisations are partially or wholly funded by government, hence cannot be devoid of conflicts of interest,
  - b) DAI is the only organisation which is autonomously and exclusively representing people with dementia in Australia, and globally,

It is important that people with dementia are central to processes that inform best practice decision-making on what all Australian Governments and others can do to ensure adequate health and social care is provided, in such a way that no human rights are being violated.

We therefore ask you take our submission and recommendations seriously, to ensure you do not leave people with dementia behind.

People with dementia are being left behind in the 2030 Sustainable Development Goals and the pandemic has significantly increased isolation and the violation of multiple rights of all persons with dementia.

Thank you,

Ms Theresa Flavin  
Human Rights Advisor and Member  
Dementia Alliance International  
Prepared and submitted on behalf of the Board of Directors and Members

Contact: Theresa Flavin  
Email: [theresa@infodai.org](mailto:theresa@infodai.org)