Dementia Alliance International

Submission to the Office of the Chief Psychiatrist in relation to the 2005 Review of the SA Mental Health Act 2009.

Submission from: Dementia Alliance International (DAI)

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

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About Dementia Alliance International

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

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

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

Preamble

Historically, and in other areas of the world, dementia is considered to be a mental illness, and is therefore included in mental health legislation. It is heartening to see change in South Australia, where conditions that may 'show the outward characteristics' of a mental health crisis are in fact caused by neurodegeneration, and require specific and particular types of support.

DAI look forward to the opportunity to contribute to further work in the development of improved human rights based legislation, practice, support and safeguarding of people living with dementia who are experiencing acute distress.

1. Prevention of Harm Principle

DAI welcomes the proposed Prevention of Harm Principle, and its proposed benefits. Inclusion of a mandatory 'risk standard' is very important in order to provide an element of safety for the person, the public and the treating professional. A risk assessment however is not enough. A specific risk management plan must be developed and incorporated into treatment plans to inform treating professionals. The risk management plan must be quickly available to first responders and potentially others. This may well overlap and inform existing behaviour support plans and care plans, which also need to be circulated to care and support staff and others who may be the subject of risk of harm or responsible for preventing individual self harm.

Recommendation 1:

DAI suggests that a well recognised risk assessment tool be trialled for the Australian context, to assist with consistency of application and review of efficacy.
https://pubmed.ncbi.nlm.nih.gov/30663614/?dopt=Abstract
https://www.bcmhsus.ca/health-professionals/clinical-resources/risk-assessment-start-manuals

Recommendation 2

Risk Assessment must be accompanied by a Risk Management Plan which is integrated with any Behaviour Support Plans in place. This must be freely available to first responders, and others who have a duty of care to the individual, or are at risk of harm from the individual. The risk Management Plan must be consistent across SA to ensure measurability of efficacy and implementation.

2. Suicide Prevention Principle

DAI support a Suicide Prevention Principle and development of a Suicide Prevention Standard. This is a worthwhile aim, however it is unclear if SA currently has the structures and resources to implement the standard as described at this time. DAI look forward to reviewing progress in the matching of service provision to community need, and eventually a lower rate of suicide in SA.

DAI acknowledge that people living with dementia, and many older people across SA and the rest of the country struggle significantly with suicidal ideation. From a living experience perspective, this is often driven by a lack of safe options for the older person to live and thrive. Mass institutionalisation of older people, where the risk of harm is significantly higher than that of living in the community, coupled with fear of vulnerability and isolation further drives the despair. The urgent cries for 'Voluntary Assisted Dying" can be directly tied with fear of institutionalisation, most particularly and sadly for those of us who are 'care leavers'. When one is in the position of being older, vulnerable to abuse and institutionalisation, potentially with cognitive decline, it is easy to see why so many older people feel there is no 'off ramp' for their suffering. As a community, it is our responsibility to ensure that our older people can live well and safely with support in our community, however poverty, loneliness, physical and cognitive decline coupled with very low support at home results in many of our older people living in fear and misery. We are routinely marginalised, homogenised, collateralised and institutionalised. Older people living with disability are doubly impacted by this antiquated and fragmented support network, which suppresses our older humans into invisibility and perceived irrelevance.

Any suicide prevention activities for older people (i havent seen any yet) must first acknowledge that the situation many older people live within is indeed grim, and potentially find ways to help the older person live alongside that knowledge and maximise their services.

Recommendation 3

DAI recommends that suicide prevention programs be co designed, co developed and co delivered to all Older People who need them, including specialised services for people living with Dementia

Principle 3: Severe Mental Conditions Principle

DAI welcomes establishment of a principle that acknowledges people who live with high mental health support needs. Current policy and planning - from the perspective of the community, appear to focus on the widest area of low level need through outreach telephone services provided by various government funded NGOs. Crisis lines are a fundamental component of the public health approach to suicide prevention. Efficacy of these crisis lines in suicide prevention is not yet fully established, https://pmc.ncbi.nlm.nih.gov/articles/PMC6978712/ however availability of a service to respond in a timely manner to a crisis is perhaps more important. Understaffed and under resourced call centres, where an individual in crisis is advised to call themselves an ambulance while they await a call back in 48 hours is not exactly supportive, and is perhaps more likely to cement the sense of 'unimportantness' of the caller. DAI further points out that inertia is a significant factor for people living with (Mild Cognitive Impairment) MCI and Dementia - not to mention depression. It may be quite unlikely that a person living with these conditions will be in a position to navigate complex telephone menus, and we become further discouraged when we are asked to provide information like date of birth etc - which we often don't remember. Better integration of community in person services with the mental health system, soft referral systems and inter agency co-operation including Adult Safeguarding services could go a long way to providing better coverage for older people's mental health.

It is also worth mentioning that ‘active neglect’ is often seen as an ‘off ramp’ for people living with support needs that are not being adequately or effectively met - whether in the community or an institution. It is a human right to refuse support and medical/clinical care. While it is important that support and care is offered and is of good quality, respectful of the individual and freely available, unless there is significant risk to others, older people using mental health services must have their right to self determination respected. Lack of will to live in an unfriendly and unsafe environment is not necessarily a mental health matter, and this reality needs to be balanced carefully with the duty of care, dignity of risk and the right to self determination.

Recommendation 4:

DAI recommends that further work be considered in providing adequate mental health support to the older community, whose needs are somewhat different to the wider community.

Recommendation 5

DAI strongly recommend that dementia specific mental health and suicide prevention measures be developed and trialled both in the community and in the institutional setting, that acknowledges that the circumstances and goals of an older person may differ greatly from younger people.

Recommendation 6

DAI recommends that suicide prevention programs including those targeted for older people, and people living with dementia are embedded into the support systems of South Australia, with outreach, Adult Safeguarding Services, Social and Support Services, Age Care Services and NDIS, with a system of warm referrals and in person services.

4. Mental Health and Substance Use Principle

DAI welcomes a principle that recognises and affirms the relationship between substance use and mental health, and that treatment and support plans acknowledge both matters holistically. However this principle assumes that services are actually available for people in the community. There is grave potential for an 'over servicing' in the assessment phase, and 'under servicing' in the treatment phase. It may be counter productive to mandate a treatment or care plan that cannot in fact be operationalised by the individual. This may have the unintended consequence of reinforcing the sense of isolation and unworthiness of the individual.

Recommendation 7:

DAI recommends that careful consideration be given to the potential limitations of the current service landscape in drafting the principle and any associated standard, to avoid unintended worsening of the individual's symptomatology.

5. Neurodevelopmental Disorder Comorbidity Principle

DAI welcomes the acknowledgement of comorbidity of mental health and neurodevelopmental disorders, and fully supports a principle that promotes access and inclusion for people living with neurodevelopmental disability. We further point out that people living with dementia and cognitive impairment also live with mental illness, which presents for similar reasons and in similar ways to the neurodevelopmental disability community. https://pmc.ncbi.nlm.nih.gov/articles/PMC6978712/

People living with dementia are surely entitled to similar accessibility provisions in the mental health system.

Recommendation 8

DAI strongly recommends that neurodevelopmental disorder and neurodegenerative disorder be included in a single principle, as while it is not appropriate to use mental health legislation as a basis for institutionalisation or removal from the community, it is absolutely appropriate and necessary to provide accessible mental health services to both of our communities too.

6. Compassionate Care Principle

DAI warmly welcomes a principle to deliver compassionate care in the mental health space. Certainly in the institutional mental health space, there is considerable lack of compassionate care, with coercion, bullying and threats being part of daily institutional life. This olde worlde mechanism of control of a person through intimidation has no place in our mental health system. Any principle for compassionate care must be embedded into the KPI of any service provider, with 360 degree feedback from service users to form part of any reporting to the Chief Psychiatrist.

Recommendation 9

DAI recommends that the compassionate care principle be reinforced with a specific standard that must be reported appropriately as a condition of funding. A star ratings system that rates a provider on their 'compassionate care' similar to that in the age care system, would greatly empower service users.

Recommendation 10

DAI recommends that a robust and accessible complaints system be established for reporting not only human rights and practice breaches, but when services are provided that are lacking in compassion and do not adequately provide for the wellbeing of the individual receiving the service.

Recommendation 11

DAI suggests that consideration be given to mandating access to a community advocate for anyone receiving mental health services, in particular those in secure institutions.

Part B - Proposals to facilitate emergency mental health responses

DAI supports the change of wording proposal to clarify the scope of S56 to ensure an assessment in a timely manner. DAI interprets the current system in terms of crisis intervention to mean that the initial S56 covers transportation, restraint and assessment, quickly followed by a formal order for involuntary care (Mental Health Order) to facilitate involuntary treatment. It is unclear how reporting of the timeliness of assessment will impact access to actual treatment, as it appears that the point of tension between the two systems is the transition from the assessment and restraint phase to the treatment phase.

It is unclear why S56 could not be amended to include access to urgent treatment based on the assessment.

DAI acknowledges the difficulty of balancing a S56 power with the limitations on access to human rights, and a Mental Health Order which may affect an individual's right to work or right to travel.

Recommendation 11

DAI recommends that consideration be given to extending S56 to include access to treatment.

Recommendation 12

DAI suggests further research be conducted to determine ways to better protect the human rights of people covered by S56, potentially through a human rights act and access to advocacy.

8. Provisions to support psychiatric review of people who are on involuntary treatment orders prior to inter hospital transfer

DAI supports telehealth review of people placed on an ITO, both in rural and non rural settings. Access to urgent psychiatric assessment is equally limited in regional and city locations, although for different reasons. It is difficult to understand the upside of reserving access to telehealth psychiatric review to certain areas of the country, when timeliness is such an important factor, and the ability to move to a treatment phase is improved.

Recommendation 13

DAI recommends that consideration be given to facilitating telehealth urgent review for all people placed on an ITO who cannot access a 'timely' in person review.

Part C. Other Proposals

9. A Requirement to consult family members when a decision is made about involuntary care.

DAI are cautiously supportive of a consultation requirement for family and carers in relation to involuntary treatment. Our main concern sits around the privacy rights of the individual. While it is certainly a commonsense approach both to gather background information that could benefit the individual, and potentially improve the individuals access to family support, there are innumerable instances where mandatory consultation with family may result in significant breach of the trust 'contract' between the individual and the practitioner, and a decreased sense of the agency of the individual. We note in the NZ example provided in the consultation document, that the treating professional has decision making authority on whether consultation is in the *'best interests'* of the individual, however we point out that the *'best interests'* model of care has been long superseded in recognition of the human right to autonomy and self determination. It is also difficult to understand from the community perspective, exactly what information a practitioner could base this decision on, if there are no pre existing records of preference or clinical mental health records. It is assumed that the practitioner would take at least some guidance from the individual themselves in how to proceed. It is imperative that any such legislative mandate to ‘consult’ must be balanced with a specified ‘supported decision making’ framework to be used as a first line of approach.

Recommendation 14

DAI Strongly recommends that further work be undertaken to protect the privacy and autonomy of individuals in relation to family consultation. Supported Decision Making processes must be directly referenced in the Act, when obtaining ‘consent’ to consult with any ‘interested party’. Any reference to ‘best interests’ have no place in modern Australian legislation.

Recommendation 15

Should a practitioner ‘decide’ to consult with family or others outside of a direct consent model, they must document a specific ‘consultation risk plan’ that sets out the proposed risks, mitigating factors, benefits and consent/refusal of the individual, to build a case for why the individual's right to privacy should be overridden. A supported decision making approach can open pathways for communication between the individual and their inferred support networks including family, that are consistent with the wishes of the individual - a staged approach for example, where the family can be advised the individual is safe, but not provide further details as to their circumstances.

11. Enshrining in legislation a ‘duty to warn’ other people at risk

DAI broadly supports enhancement of the ‘duty to warn’ provisions of the Act, to change from permissive to mandatory. This however must be balanced and accompanied by a mandated consistent risk assessment (see recommendation 1) and a (potentially co designed with consent) disclosure plan.

DAI makes the community based assumption that the ‘duty to warn’ provision would only apply to matters that would sit within the existing criminal justice system, and apply only to threats of physical harm or significant property damage. It would not be appropriate to wrap crimes relating to matters such as potential for arms length verbal abuse, social media hate posts etc, as there are already sufficient mechanisms in place to manage non violent harm.

Specific Exclusion of the duty to warn, due to an individual being in hospital doesn't seem to be particularly robust, as hospitals in general are not seen to be ‘secure’ in the manner intended by the legislation, and hospitalisation is simply not an appropriate risk mitigator in a high risk situation unless specific additional incarceration and security measures are in place - which should of course comprise part of the Risk Management Plan.

Recommendation 16

DAI suggests that further consultation be undertaken in respect of the ‘duty to warn’ provision, to ensure that there is consistency in its application across practitioners.

Recommendation 17

DAI suggests that the 'duty to warn' provision be limited to significant threat of harm, and that definitions be developed concerning the limits of what can be considered 'significant'.

Recommendation 18

DAI suggests that consideration be given to development of a specific risk assessment and risk management and disclosure plan while the individual is still in a safe environment, and that this plan be co designed with the individual if at all possible.

Part D: Additional proposal regarding a statutory Mental Health Human Rights Committee and Coercion Reduction Committee

DAI wholeheartedly and unreservedly welcome the proposal for this committee to become a statutory committee.

Recommendation 18

DAI recommends that the proposed statutory committee comprise equal representation of direct living experience and 'experts', and that the committee runs on the principles of a 'lived experience framework'.

Part E: Further areas of work

13 Development of non mental health act powers for the detention and restraint of people who require acute care due to a delirium dementia and/or intoxication

DAI welcomes acknowledgement that the Mental Health Act is not a suitable or appropriate mechanism for involuntary incarceration and/or treatment for non mental health conditions. However there is work to be done to ensure that any new legislative mechanism attracts equal human rights protections for all individuals. This is extraordinarily important for people living with dementia, who are often subjected to restrictive practice routinely, and outside of the area of 'crisis'.

The present difficulty for us living with dementia in the community, is not the specific legislation that facilitates involuntary transportation, assessment and treatment, it is the absolute lack of alternatives in terms of services.

For example, in a crisis situation, an older woman reaches out to police because her partner living with frontotemporal dementia (FTD) is chasing their dog with a hammer. She fears for her safety and her partner and dogs safety. The police arrive, and if they are very well trained, they will secure the premises, make the people safe, de-escalate the situation with the individual, contact an ambulance where the gentleman would be taken to hospital for assessment and treatment of both underlying conditions

(potentially delirium, uti) and distress (mental health and behaviour support practitioner).
The older gentleman feels better, feels safe and returns home, the family are provided with dementia specific behaviour support in the home, they are provided with contact details for emergencies and offered a severe behaviour response team referral and/or referral for specialist behaviour support respite.

However, in the real world, the older gent would be hospitalised, fearful, medicated and considered to 'lack capacity'. A social worker would insist that the older gent is 'placed' in residential aged care, as he is a risk to himself and others. The older man does not want to leave his family home, his partner and family want him to stay at home, however there is no meaningful pathway to access sufficient support to help this family care for their older man. The whole family is wracked with guilt, they feel railroaded. the older man feels coerced, he is moved into residential care and passes away within 4 months of entry.

This is the experience of many DAI members, and the experience of many Dementia Australia advocates that DAI interact with regularly.

As noted in recommendation 8, bundling of dementia and intoxication is a poor fit. While there may certainly be instances of overlap, in the vast majority of cases, delirium and other dementia associated matters are more aligned with those of the Neurodivergent community.

Recommendation 19

If time and resources are allocated to a change in how people living with dementia are supported through ‘crisis’, a number of things need to happen. Specialist behaviour support practitioners must be available - perhaps in a similar telehealth manner to facilitate the new equivalent of urgent S56 reviews.

Recommendation 20

First Responders MUST be trained to de-escalate, and understand that people living with dementia - particularly those experiencing crisis - do not have the ability to process ‘commands’. We are often vision and hearing impaired. Shouting causes fear, as we sense the urgency of the command, but if our auditory processing center has been eaten by dementia, louder just means louder, and may result in defensive based aggression. This training must be co designed and co delivered by people living with dementia. DAI would be pleased to participate in any such work going forward.

Recommendation 21

Short term respite specifically designed for people living with dementia who require behaviour support must be more freely available, to people living in the community. Currently specialist behaviour support units are extraordinarily difficult to access, and most referrals come from a hospital setting, however hospitals would of course be avoided if the service could be accessed by people living in the community. Many older people who experience and communicate their fear and frustration at their situation are transferred into a ‘secure unit’ of a residential institution, which is most certainly not a specialist behaviour support unit. Others are referred to specialist dementia care units outside of their own residential care placement.

DAI note that as it is a frank breach of human rights to ‘place’ any older person in permanent institutional care against their will - even if it is called ‘age care’.

Recommendation 22

Restrictive practice legislation must be consistent with the CRPD, and must be applied equally to all individuals across South Australia, regardless of their age or disability status. It is unacceptable to carve a whole segment of the population out of the human rights landscape based on age alone.

Recommendation 23

Older people, including people living with dementia and their care partners must have unrestricted access to a professional impartial advocacy service when they are subject to any involuntary treatment order under any circumstances.

Recommendation 24

The national plan to end elder abuse, the national dementia action plan must be mapped to existing support services, both within and external to the mental health support landscape to ensure that all older people can access the services they need prior to escalation and institutionalisation

14. Development of limited powers to require people who have co morbid drug and alcohol conditions to mental illness to receive involuntary treatment.

DAI do not support any use of involuntary treatment of any person, even as a last resort option. While the notion of involuntary treatment has appeal, it is based on the 'best interests' model of care , and is not consistent with any modern day human rights approach. It is absolutely positive to make such treatments accessible and available, but treatment should never be imposed on an individual without active and informed and if necessary process consent. Better implementation of the 'compassionate care' principle over time, may contribute towards improved uptake of drug and alcohol programs as trust is rebuilt between the community and practitioners.

Court mandated drug and alcohol programs are used as a means to offer a pathway back to community life for an affected individual, whereby activities that attract community expectations of safety such as driving and employment can become available again. Compliance with these schemes is of course voluntary, with the consequences of being unable to fully participate in society being seen as the ‘punishment’.

This type of coercive style mandated drug and alcohol treatment program does not seem to be particularly attractive, and in fact further excludes and isolates the individual from community participation. That being said, community expectations of safety are valid and important. As with involuntary treatment of any other matter that society deems unsatisfactory (such as dementia).

14. Proposal for further work in seeking to address a gap in legislation coverage related to the involuntary care of people who have a neurodevelopmental disorder when the mental health act does not apply

DAI supports and welcomes the proposal for further work in relation to this gap in coverage in the Act, however we draw your attention to the similarities both in need and presentation between neurodevelopmental disorders and dementia. The same considerations apply in relation to human rights protections and tensions between understanding ‘behaviour disturbance’ and isolating the driver of the discomfort. From the community perspective, there seems to be little value in developing separate legislative pathways for these conditions. Of course, many people living with dementia are also neurodiverse, and this overlap will most certainly increase in line with the increasing prevalence of both autism and dementia.

Recommendation 25

DAI recommends that the OCP consider the same legislative provisions and treatments for people who have a neurodevelopmental disorder and people who live with dementia and other neurodegenerative conditions. Aside from age discrimination, it is difficult to see an upside to making separate and different arrangements for different disabilities with common presentations.

Conclusion

DAI would like to thank the OCP and staff for giving consideration to the voices of people living with dementia. We welcome comments, questions and clarification, and reiterate our offer to give our time freely to inform the development of future legislation policy and services that impact the quality of life, human rights and dignity of all older people including people living with dementia.

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

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