



## **Dementia Alliance International**

**Submission to the Open-ended Working Group on Ageing**

**Ensuring the inclusion of people with dementia in the Older Persons' Convention**

**Submission from:** Dementia Alliance International (DAI)

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

**Submitted on:** 24 November 2023

---

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

All rights reserved. Subject to the Copyright Act 1968, no part of this document may be reproduced, stored in a retrieval system, or transmitted in any form, or by any means, electronic, mechanical, photocopying, printed, recording or otherwise, without the prior written permission of Dementia Alliance International Please contact us at [info@infodai.org](mailto:info@infodai.org) to request permission. As a US Corporation with 501(c)(3) status, donations to Dementia Alliance International by US citizens are fully tax deductible.

## Part 1

**About DAI:** Dementia Alliance International is a registered 501(c)(3) charity registered in the State of Texas USA, with ECOSOC status as a Disability Persons Organisation (DPO) at the UN. Our mission is to provide support globally for people with dementia, and to advocate for services, improved quality of life and the human rights of all people living with dementia, in the community and in residential care (nursing homes). Our 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 globally, and 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 therefore the only organisation exclusively representing people living with dementia and the only global independent voice of people diagnosed with dementia.

The former United Nations Special Rapporteur on the rights of persons with disabilities, Catalina Devandas-Aguilar, in her report on the rights of older persons with disabilities (which includes dementia), observes that many human rights violations experienced by older people with disabilities “are frequently regarded as normal and rendered invisible to Governments, deepening the circle of discrimination and exclusion of older persons with disabilities. It is with this in mind, we make this submission.

On 7 October 2021, the Human Rights Council (HRC) of the United Nations adopted resolution (A/HRC/RES/48/3) by consensus. Governments committed to consider and act on the resolution, which calls upon States to prohibit all forms of discrimination against older persons and to take measures against ageism and age-based discrimination. It calls upon all stakeholders to eliminate ageism and age discrimination in all its forms.

It calls upon all stakeholders, including States, the entities of the UN system, civil society, national human rights institutions, and the private sector to adopt a human-rights based approach in all programmes, campaigns and activities relating to ageing and older persons.

The OHCHR report (A/HRC/49/70) was made available in early 2022 and the multi-stakeholder meeting on the human rights of older persons was held on 29-30 August 2022 (summary report at A/HRC/52/49).

There are two quotes from the summary report of the multi-stakeholder meeting which we argue highlight that the rights pertinent to older people and the gaps in their implementation have already been identified and that, rather than further discussion of whether gaps exist, there is a pressing need to take action delivering a convention on the rights of older people:

“The Independent Expert on the enjoyment of all human rights by older persons, Claudia Mahler, stated that the global discussion on the protection gaps and solutions had been extensive. Many reports, including the 2021 update by OHCHR to the 2012 Analytical Outcome Study on the normative standards in international human rights law in relation to older persons and various reports of the Independent Expert, had identified the problems and how to address the challenges that prevented the full implementation and enjoyment of the human rights of older persons. More than 800 documents had been submitted to the Open-ended Working Group on Ageing since its inception and yet a legally binding instrument had still not been drafted. The lack of a comprehensive international instrument had significant negative impacts on the lives of older persons. A binding human rights instrument would provide guidance to States on addressing demographic change.” (para 6) and,

“Human rights in older age must be grounded in the principles of dignity, equality and non-discrimination, autonomy, independence and meaningful participation. The instrument should enable older persons’ independent living, full inclusion and participation in society, including in the digital sphere, and affordable and accessible care and support services. Lifelong learning, education and skills-building without discrimination were crucial for autonomous and independent living. Older persons must also be able to live their lives free from all forms of violence, abuse, ableism, exploitation and neglect. The convention should pay particular attention to older persons’ rights to access to justice, housing, privacy and a clean and healthy environment”. (para 10)

A/HRC/52/49: Summary of the multi-stakeholder meeting on the human rights of older persons - Report of the Office of the United Nations High Commissioner for Human Rights, 27 December 2022, <https://www.ohchr.org/en/documents/thematic-reports/ahrc5249-summary-multi-stakeholder-meeting-human-rights-older-persons>

#### **a) Equality and non-discrimination**

As has been noted repeatedly, there is no specific reference in most of the international non-discrimination guarantees to older age as a ground of prohibited discrimination; nor does the term “ageism” appear in the UN human rights treaties. There is no explicit general treaty obligation requiring States to take steps to eliminate ageism or age discrimination that is

comparable to the obligations under conventions relating to discrimination against women, and the rights of persons with disabilities to eliminate sexism and ableism. This gap means that there is no clear external stimulus to take such action at the national level. Australia, for example, has no national plan to eliminate ageism, while it has many national plans in other areas.

The last four Alzheimer's Disease International World Alzheimer's Reports confirmed that attitudes and stigma have not improved<sup>1</sup>, enabling environmental design is inadequate<sup>2</sup>, and people are being left behind in terms of diagnosis and post diagnostic support<sup>34</sup> including being denied equal access to health care, rehabilitation, an adequately educated health care sector, and denial of disability access and disability rights under the CRPD. People with dementia are being denied equal access to health care, to employment, and to equitable inclusion in their communities.

Throughout the active Covid 19 pandemic, older people were detained in residential care facilities and access to family, advocates and services was denied. Despite these human rights violations in the name of 'public health', the numbers of older persons who died alone in residential age care is disproportionate with the wider population. Australia's banking and financial system is regulated by a prudential regulator and a compliance regulator. Banks, insurance companies and pension funds must meet a very high standard of risk management in order to retain a license to operate. Sophisticated risk management plans consistent with ISO31000 are in place, monitored and reviewed on a regular basis. Australian financial institutions fared well in the pandemic, as they had specific plans in place for example pandemic plans, disaster recovery plans in the event of low personnel etc etc. No such high level and sophisticated risk management frameworks are in place for the care of our older persons. Risk management requirements are limited to the financial operations of the sector. No effective pandemic plans were evident, and the older people paid the price for this. In Australia it is clear that we value our financial capital more than our human capital, as despite drafting a new Age Care Act, there are no signs of lifting the requirements for risk management to a similar level of sophistication with our financial sector, and we live with

---

<sup>1</sup> Alzheimer's Disease International. 2019. *World Alzheimer Report 2019: Attitudes to dementia*. London: Alzheimer's Disease International.

<sup>2</sup> Alzheimer's Disease International, 2021, *World Alzheimer's Report 2020*, <https://www.alzint.org/resource/world-alzheimer-report-2020/>

<sup>3</sup> Alzheimer's Disease International, 2021, *World Alzheimer's Report 2021*, <https://www.alzint.org/resource/world-alzheimer-report-2021/>

<sup>4</sup> Alzheimer's Disease International & McGill University, 2022. *World Alzheimer's Report: Life after diagnosis: Navigating treatment, care and support*, <https://www.alzint.org/resource/world-alzheimer-report-2022/>

compliance based backward looking legislation being regulated by a forward looking risk based regulator. Older people have nowhere meaningful to turn when things go wrong. While moves are afoot to place human rights into the new Age Care Act, it is notable that these human rights will only extend to the services provided and are not applicable to life outside the scope of active care. Further to this, these human rights only extend to care that is government funded, thus further excluding a large population. Culturally and Linguistically Diverse as well as Indigenous Australians traditionally access government funded age care services at a much lower rate than the wider population, thus further excluding this cohort from any taste of human rights in their older age.

A specific Convention on the human rights of ALL older persons would clarify the right of older people to equality and to be free from discrimination, especially the experience of ageism. This will include States' obligations arising from that human right and how it is to be implemented in practice. It would, for example, clarify that older persons have a right to equality and non-discrimination and to be free from ageism, that this right applies in public and private spheres, and that States<sup>1</sup> have an obligation to take preventive measures.

## **b) Violence, neglect and abuse**

In recent times, significant attention has been paid to the prevalence of abuse of older persons, including the Age Care Royal Commission into abuse and neglect which exposed grievous abuse across all sectors of the age care system, and to a lesser extent the Disability Royal Commission which interestingly largely ignored older persons living with a disability including dementia.

At the Federal (or Commonwealth) level, the government committed funds to establish Elder Abuse Action Australia (EAAA), and the Australian Law Reform Commission conducted an Inquiry and delivered a Report on a national legal response to elder abuse. Importantly, following the 5th National Elder Abuse Conference (2018) the Commonwealth Attorney General, the Hon Christian Porter MP, announced funding for a national plan to address the problem of abuse of older people. The National Plan to Respond to the Abuse of Older Australians (Elder Abuse) 2019–2023 was adopted in 2019: it contained no explicit reference to “human rights” or to any international treaty. The document is currently being reviewed and consultation is occurring for a new National Plan.

Currently in Australia, over 50 sexual assaults occur in residential age care every week. Despite all the above enquiries, plans and resources, the number of sexual and violent assaults including murder continue unabated, including the violent taser of an 86 year old woman

living with dementia in residential care by a police officer, and the violent murder of a 67 year old woman in her bed in a residential care facility. It remains unclear how many sexual assaults, violence abuse and neglect cases occur within the community, as data is not collected, and there is no consistent Australia wide plan to escalate actual or suspected cases of violence abuse and neglect of older persons.

Until older people including people living with dementia have access to the protection of an international treaty, we will continue to endure under reported under acknowledged and under actioned violence abuse and neglect with little access to relief, justice or redress.

As pointed out in the 2023 report to the Human Rights Council by the UN Independent Expert on the enjoyment of all human rights by older persons, the current international human rights framework lacks specific provisions addressing violence against and abuse and neglect of older persons. While violence neglect and abuses occur daily, Australia has little data on the true prevalence both within the institutional sector and the community at large. At present, no data is collected to tell us how many older persons currently live in 'locked dementia wards'. No data is collected in relation to sexual assault of older persons, particularly those in the community living with dementia. Anecdotally, doctors and practice nurses observe the signs both physical and emotional in their daily practice, however as the perpetrator is usually their formal guardian, and also in attendance, and without an adult safeguarding mechanism, the older woman is treated and sent home to the same circumstances.

A specific Convention on the rights of older persons would clarify the rights of older people to be free from violence, abuse and neglect in older age and, States' obligations arising from that human right and how it is to be implemented in practice. It would, for example, clarify that the right applies in public and private spheres, and that States have an obligation to take preventive measures and that older persons have a right to support services, as well as access to remedies and redress. If there had been a convention on the human rights of older persons containing provisions of this sort, it would have helped to drive law and policy reform at all levels in Australia – and we would not have seen a national plan on elder abuse that made no explicit reference to human rights.

### c) Long-term care and palliative care

We note the United Nations Deinstitutionalisation Guidelines, which should apply equally to older persons,<sup>5</sup> and the growing recognition in United Nations and international human rights systems of the need for equal access to justice and remedies for people with disability and older people.<sup>6</sup> Currently in Australia, persons age over 65 have no access to any government funded disability specific supports as this is perceived to comprise part of the ‘age care’ system. As in home support is limited to around 20 hours per week, and only ‘age related’ supports are provided, the only truly funded support for older persons living with complex healthcare needs and/or disability/dementia is institutionalised residential age care. Privately funded disability or age care supports attract only the protection of consumer law and the onus is on the older person to develop and monitor a service contract that reflects age care legislation and pursue injustice through consumer law.

Presently in Australia, 50% of persons over age 65 live with disability and it would be expected that at least this cohort would enjoy the protection of the CRPD, however this is not the case, as the veil of ageism truly makes us invisible to policymakers and the sector at large. The recent Disability Royal Commission recommended that group homes should be abolished over the coming years for NDIS recipients (age under 65), however the recommendation did not extend to older persons.

Until older people including people living with dementia have access to the protection of an international treaty, we will continue to endure under reported under acknowledged and under actioned violence abuse and neglect with little access to relief, justice or redress.

---

<sup>5</sup> Pia Kontos et al, ‘Separate and Unequal: A Time to Reimagine Dementia’ (2021) 80(4) *Journal of Alzheimer’s Disease* 1395; Rachel Herron, Christine Kelly, and Katie Aubrecht, ‘A Conversation About Ageism: Time to Deinstitutionalize Long-term Care?’ (2021) 90(2) *University of Toronto Quarterly* 183. In relation to public debate, see Sara Luterman, ‘It’s Time to Abolish Nursing Homes’, *Nation* (11 August 2020) <<https://www.thenation.com/article/society/abolish-nursing-homes/>>; Gerard Quinn and Ann Campbell, ‘Nursing Homes Must be Made a Thing of the Past’, *Irish Times* (20 May 2020) <<https://www.irishtimes.com/opinion/nursing-homes-must-be-made-a-thing-of-the-past-1.4257422>>.

<sup>6</sup> See eg Committee on the Rights of Persons with Disabilities, *Guidelines on Deinstitutionalization, Including in Emergencies*, UN Doc CRPD/C/5 (10 October 2022); Catalina Devandas-Aguilar, *International Principles and Guidelines on Access to Justice for Persons with Disabilities* (Special Rapporteur on the Rights of Persons with Disabilities, August 2020); Catalina Devandas-Aguilar, *Report of the Special Rapporteur on the Rights of Persons with Disabilities*, UN Doc A/74/186 (17 July 2019); Claudia Mahler, *Older Persons Deprived of Liberty: Report of the Independent Expert on the Enjoyment of all Human Rights by Older Persons*, Claudia Mahler, 13 September 2022, UN Doc A/HRC/51/27; Gerard Quinn and Israel Doron, *Active Social Citizenship for Older Persons: The Current Use and Future Potential of the European Social Charter* (Council of Europe, August 2021) <<https://edoc.coe.int/en/european-social-charter/10958-against-ageism-and-towards-active-social-citizenship-for-older-persons-the-current-use-and-future-potential-of-the-european-social-charter.html>>.

We note that a right to long-term care and support and a right to access palliative care services are two distinct concepts. Neither of these rights is explicitly guaranteed by the United Nations human rights treaties; this represents a significant gap in the international human rights framework that would be filled by a new convention.

As pointed out in the 2023 report to the Human Rights Council by the UN Independent Expert on the enjoyment of all human rights by older persons, the current international human rights framework lacks specific provisions addressing violence against and abuse and neglect of older persons.

For persons living with dementia, unlike a younger person with a life limiting illness, palliative care or palliative principles of support do not feature in dementia until the very late stages of the disease. If palliative care could be accessed throughout the disease course, people living with dementia, their families and wider community would be supported carefully and holistically, however presently this style of supportive care is reserved primarily for persons under 65 or in the final days of life.

Restrictive practices, which include the use of chemical, physical and environmental restraints, are predominantly used on older people living in institutional aged care. Their use involves violations of the rights to freedom from torture or cruel, inhuman or degrading treatment, liberty of movement, the right to health, the right to a remedy for violations of rights and other rights.

Noting that the CRPD specifies that restrictive practices cannot be used this is only in relation to people living with disability. Though the CRPD also applies to people living with dementia it is not applied in the same way, but technically it should be because all people with dementia, of all ages, are deemed people with disabilities<sup>7</sup>.

Recent changes to legislation on the use of restraints in Australia has improved protections for older people, but not to the full extent of the protections under our National Disability Insurance Scheme, which operates under the CRPD, and the current regulation still falls short of full compliance with human rights standards.

A specific Convention on the rights of older persons would clarify the right of older people to be free from restraint in older age, including States' obligations arising from that human right and how it is to be implemented in practice. It would, for example, clarify that the right applies

---

<sup>7</sup> World Health Organisation, Dementia Key Facts, <https://www.who.int/news-room/fact-sheets/detail/dementia>, retrieved 22 November 2023



in public and private spheres, and that States have an obligation to remove the use of restraints and that older persons have a right to be free from restraint as well as to have access to remedies and redress if this right is breached.

Further, a specific Convention on the rights of older persons would clarify the rights of older people to be free from violence, abuse and neglect in older age and States' obligations arising from that human right and how it is to be implemented in practice. It would, for example, clarify that the right applies in public and private spheres, and that States have an obligation to take preventive measures and that older persons have a right to support services, as well as access to remedies and redress. If there had been a convention on the human rights of older persons containing provisions of this sort, it would have helped to drive law and policy reform at all levels in Australia – and we would not have seen a national plan on elder abuse that made no explicit reference to human rights.

#### **d) Autonomy and independence**

Most adults in Australia exercise self-determination, have their personhood acknowledged, their competency assumed in every-day life, and their capacity under the law assumed. However, these assumptions are not extended to all adults, particularly to some people with disability, and often, to people of advanced age.

Ageism is one of the “causes of systemic failures”, leading to substandard care, mistreatment, and even abuse. Ageism involves the withdrawal of the underlying assumptions of capacity and competency, the failure to uphold the rights of ‘older’ adults and eventually, the loss of their self-determination.

Article 12 of the CRPD, which covers equal recognition before the law, stipulates that “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life”. The CRPD’s definition of legal capacity is two-pronged, defined as the capacity to be both: a holder of rights which entitles persons to full protection of their rights by the legal system; and recognition that a person is an agent with the power to engage in transactions and create, modify or end legal relationships. Substitute decision making is contrary to this important safeguard against abuse, and in fact comprises a more subtle expression of restrictive practice.

The right to Supported Decision Making, to enable autonomy and independence is a key right that must be applied to older people. As with all adults, older people have the right to make decisions about the care and services they receive, their day-to-day life and community

connection, their relationships and the risks they are willing to take. The presumption must always be that older people have the ability to make decisions. Decision-making ability is complex, fluctuating and difficult to assess. Decision-making ability depends on many complex and inter-related factors, including but not limited to the quality of information provided, the supports available to make a decision, the person's confidence and the person's communication methods and preferred language.

The presumption of decision-making ability should only be diverged from when the complex nature of decision-making ability has been fully considered and all possible options to support a person to make their own decisions have been exhausted or are impossible (e.g. if the person is in a coma). However, too easily agencies and services default to substitute decision makers, who act in the "best interests" of the older person rather than adhering to their "wishes and preferences".

While there are moves to incorporate the concept of supported decision making into the Age Care Act, these protections will only cover persons receiving government funded age care services. Older people who self-fund their supports, and older people who have the good fortune of family support will not enjoy the rights outlined in the Act. They will continue to be subject the goodwill of the persons around them indefinitely without significant change.

A specific Convention on the rights of older persons would clarify the right of older people to have autonomy and independence and the right to supported decision making. It would outline States' obligations arising from that human right and how it is to be implemented in practice. It would, for example, clarify that the right applies in public and private spheres, and that States have an obligation to remove barriers to accessing supported decision making and access to remedies and redress if this right is breached.

#### **e) Education training lifelong learning and capacity building**

While there is ample evidence to show that education and lifelong learning are a risk modifier for dementia, including as part of a specialised reablement program for people living with dementia, access to formal programs remains limited for older people. The Australian context heavily focusses support for lifelong learning and capacity building for persons under 65 through a number of Commonwealth, State and Disability specific programs, however these are heavily targeted to people under age 65 with a view to supporting people to enter and remain in the workplace.

Significant bodies of research demonstrate capacity within the dementia trajectory to show that cognitive maintenance and reablement have a positive impact on quality of life and activities of daily living, but access to these supports is scarce.

#### **f) Right to work and access to the labour market.**

Ageist attitudes, perceptions of increased risk, lower productivity and systemic taxation and social security structures which penalise older persons heavily for attempting to improve their quality of life and financial circumstances combine to create an almost impenetrable barrier for older persons to remain or re-enter the workforce. This is further exacerbated in the Australian context in that, 50% of older persons live with disability, and in the absence of disability specific support, these people are effectively excluded from mainstream life including the ability to work and earn a living. Persons under the age of 65 living with disability can access NDIS funding to support them with entering or re-entering the workforce. Again, as previously noted, 50% of persons over age 65 in Australians live with disability and are largely unsupported outside of the modest age care and age related supports which do not cater for right to work or access to learning as it is designed to support physically frail older persons to remain safely at home, or 'safely' locked in an institution.

#### **g) Access to Justice**

There is a significant and longstanding problem of multiple harms to people living with dementia receiving care, and a failure to recognise, redress and repair the harm and hold people accountable for this harm. In 2019, there were an estimated 57.4 million people living with dementia globally, and it is estimated this will increase to 152.8 million in 2050.<sup>8</sup> Research tells us people in aged care can suffer harm arising from such experiences as lack of access to medical and dental care and rehabilitation, neglect in personal care, malnutrition, social isolation, verbal abuse, and physical and sexual assault (although quality of care and support can vary between aged care facilities and countries and can depend on individuals' socioeconomic and other circumstances). People with dementia in community, respite and aged care can additionally suffer harm from substituted decision-making, use of restrictive practices such as chemical restraint, forced mental health treatment, segregation in separate dementia units, and non-consensual confinement in aged care (all of which are often lawful or clinically and socially authorized by reason of disability). These experiences can cause harms that include mental distress; deterioration in physical health, cognitive ability, and physical mobility; and sometimes even premature death. The pain, resistance, and distress that people

---

<sup>8</sup> Emma Nichols, 'Estimation of the Global Prevalence of Dementia in 2019 and Forecasted Prevalence in 2050: An Analysis for the Global Burden of Disease Study 2019' (2022) 7 *Lancet Public Health* e105.

express in response to harms they have suffered might be disbelieved or dismissed by aged care staff and police, and, for people with dementia, their responses to harm can be pathologized as part of their dementia (sometimes even resulting in further use of restrictive practices and forced treatment).

While serious incidents that occur in the residential age care settings are reported to the regulator, and moves are in place for home care incidents to also be reported, again it is notable that this reporting scheme only covers the government funded age care sector. Access to justice is limited to the regulator, where consequences usually take the form of increased monitoring, or an update to the institutions policies. There is no avenue of recourse or redress outside of the criminal justice system, which is simply inaccessible to many older people, including those living with dementia. In fact the Royal Commission into violence and neglect in age care reported that of the 50 sexual assaults per week that occur in age care, in 58% of those reported cases, the facility staff reported that there were no negative effects of the sexual assault on the victim. People living with dementia are perceived to be protected from rape and sexual assault due to their age, however this is not the case. They are rarely believed and less often offered appropriate support. Their evidence is considered unreliable and they are left to live and die with the trauma, as are their families who remain powerless.

We further note also that all institutional residential care facilities, and secure dementia units are locked, therefore qualify as places of detention, and must be subjected to OPCAT monitoring, however access has not so far been facilitated in Australia. In fact we are not even sure how many people are currently living in these conditions or the locations as that data has not been considered important enough to collect.

These are gross examples of non-equality and discrimination.

## **h) Right to Health and Access to Health Services**

Whilst the World Health Organisation defines dementia as a major cause of disability and dependence of older persons globally, people with dementia are not being adequately recognised or supported in post diagnostic pathways and care as people with acquired disabilities. This therefore denies them equitable disability support, and health care including rehabilitation. The coronavirus pandemic has highlighted the gross multiple violations of our human rights, and disability rights, also highlighting to those who do not have a diagnosis of dementia, what it is like to live with stigma, discrimination, isolation and loneliness, as they are experienced by people with dementia from the time of their diagnosis.



The last four Alzheimer's Disease International World Alzheimer's Reports confirmed that attitudes and stigma have not improved<sup>9</sup>, enabling environmental design is inadequate<sup>10</sup>, and people are being left behind in terms of diagnosis and post diagnostic support<sup>1112</sup> including being denied equal access to health care, rehabilitation, an adequately educated health care sector, and denial of disability access and disability rights under the CRPD. People with dementia are being denied equal access to health care, to employment, and to equitable inclusion in their communities.

COVID-19 impacted on all of us but especially on older people. The perceived increased susceptibility to the virus of older persons led to targeted responses designed to protect those cohorts. Unfortunately, these responses led to a greater level of stigma and discrimination within the broader community. This was exacerbated by media, with their simplified messages of "older people more likely to die" and coverage of the situations in other countries, where overwhelmed health resources were being rationed, with reports that older people were more likely to be the ones who were denied interventions.

Every day we heard the public debate about "competition for ventilators" and "older people taking up beds" as though their lives were negotiable and expendable. DAI reports from our member advocates, that some older people were deciding not to seek treatment for general illnesses or for existing chronic conditions. They did not want to be a "burden" on the health system or, "use up" resources that younger people could need, or they considered themselves as not worthy of care. This is the result of ageism, stereotyping, prejudice, and discrimination against older people on the basis of their age, which became dominant in these debates. This is not to say that an older person cannot choose not to receive care as this is within their rights to autonomy, choice and control, but DAI is concerned that there were now external factors pressuring older people to make these decisions.

All older people have a right to receive quality healthcare treatment when and if they need it, whether for existing health care needs, chronic conditions and other illnesses. Health care must be age-friendly, responsive to older people's needs and take "into account the diversity

---

<sup>9</sup> Alzheimer's Disease International. 2019. *World Alzheimer Report 2019: Attitudes to dementia*. London: Alzheimer's Disease International.

<sup>10</sup> Alzheimer's Disease International, 2021, *World Alzheimer's Report 2020*, <https://www.alzint.org/resource/world-alzheimer-report-2020/>

<sup>11</sup> Alzheimer's Disease International, 2021, *World Alzheimer's Report 2021*, <https://www.alzint.org/resource/world-alzheimer-report-2021/>

<sup>12</sup> Alzheimer's Disease International & McGill University, 2022. *World Alzheimer's Report: Life after diagnosis: Navigating treatment, care and support*, <https://www.alzint.org/resource/world-alzheimer-report-2022/>

---

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

All rights reserved. Subject to the Copyright Act 1968, no part of this document may be reproduced, stored in a retrieval system, or transmitted in any form, or by any means, electronic, mechanical, photocopying, printed, recording or otherwise, without the prior written permission of Dementia Alliance International Please contact us at [info@infodai.org](mailto:info@infodai.org) to request permission. As a US Corporation with 501(c)(3) status, donations to Dementia Alliance International by US citizens are fully tax deductible.

of older people, as they are not a homogeneous group but face varying health risks and circumstances”.<sup>1</sup> Recognising the right to health, as a specific right for older people, also highlights the needs and issues of more marginalised and vulnerable older people such as lesbian, gay, bisexual, trans and intersex people (LGBTI), Aboriginal and Torres Strait Islander people, Forgotten Australians, people with disability, people who are homeless or at risk of homelessness, people from culturally and linguistically diverse backgrounds and people from low socio-economic backgrounds.

It is a basic human right and that all older people even those living with dementia have the right to access and receive quality healthcare without the discrimination, often intersectional, that is often in evidence. The delivery of health care, especially for marginalised and vulnerable older people, must be non-discriminatory and health resource allocation decisions must be based within an ethical framework and not be based solely on a person’s age.

Currently in Australia, persons diagnosed with dementia are ineligible for Voluntary Assisted Dying. The popular opinion amongst clinicians is that capacity at the time of death is the determining factor. In DAI’s opinion, as this is largely impossible in the context of dementia and other neurodegenerative conditions, the person living with dementia has the human right to make their own decisions, and that we must work together with clinicians to make the process safe and humane. We are currently permitted to starve ourselves to death if the fear and despair become overwhelming. Surely we can be supported to make our own choices and give voice into the future in a safe and respectful manner.

A further complication to accessible VAD is the age care provider’s position. Many residential care providers are fundamentally opposed to VAD, and this may limit the access and choices of the older person at the end of life.

A specific Convention on the rights of older persons would clarify the right of older people to have the right to health and health care services including palliative care and VAD without discrimination on the basis of age, including States’ obligations arising from that human right and how it is to be implemented in practice. It would, for example, clarify that the right applies in public and private spheres, and that States have an obligation to take ensure equitable access and outcomes and that older persons have a right to health services, as well as access to remedies and redress if their right to health care is not upheld.

## **i) Social Inclusion**

It is difficult to put into words the gap between the ideal of social inclusion for persons living with dementia and the actual situation of mass institutionalisation where entry is often coerced by desperate family members and the systemic coercion of the health and age care system. Daily occurrence of restrictive practice, locked dementia wards, violence, neglect, social isolation, loneliness, confusion, grief and pain that comprise the lived experience of dementia in 2023. In fact it is difficult to express how wide that gap has become between policies of mass systemic and legal institutionalisation and the idea of social inclusion. Social inclusion is not possible in a locked ward in a large institution – also locked, often built on a highway or far from local communities with severely limited access to the outside world. ‘Residents’ often require ‘permission’ to go on family outings. Permission not only from the facility but often from their adult children or other substitute decision makers. This is of course compounded for people who do not have close family and rely on the ‘public trustee’ to make decisions for them.

Institutionalised risk aversion and lack of understanding of the concept of ‘dignity of risk’ as well as flawed assumptions and erosion of personhood of the older person all contribute to the social physical and emotional exclusion of the older person ‘in their best interests’. Protestations from the person living with dementia are labelled as ‘behaviours of concern’, and inability or unwillingness to accept their life in carceration, is further labelled and often results in further restriction of the older persons freedoms.

An international convention on the rights of older persons would raise the social currency and visibility of older people, and provide a platform of equality, thus promoting their voice in the design of communities and supports that are appropriate to their needs. The adoption of specific protections for older persons to guarantee their right to full social inclusion would provide an accessible and consistent framework for bringing these rights to life in Australia

## **j) Accessibility, infrastructure and habitat (transport, housing and access)**

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD Article 19) - Living Independently and Being Included In The Community requires that State Parties to the current Convention recognize the equal right of all persons with disabilities to live in the community, with equal autonomy as all others. This means they must enjoy choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by

persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

1. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
2. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
3. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Currently if an older person acquires a disability that requires complex care such as dementia or stroke past the age of 65, as previously explained their only realistic option is Residential Age Care. The transition from community to institutional care has become systemically embedded in the Australian consciousness, and it is often considered to be a rational and natural part of the life course. This of course is not the case with many or most older people moving to residential age care under protest or through coercion. Most older persons leave the community not through choice, but through a complete absence of a realistic and safe alternative. of Absence of disability specific government funded support to remain in the community essentially underwrites the residential age care system by guaranteeing a steady supply of older persons who can no longer live in their homes with only 20 hours a week of paid support workers. Particularly in the current economic crunch where families are struggling to work as much as they can to maintain themselves, and there is little time to actively contribute freely to the support of their older loved ones. This is a cruel and unjust system of coerced incarceration of older persons. Institutionalisation of our Aboriginal people has been a feature of the Australian landscape through the 'Stolen Generation' and the 500,000 'forgotten Australians' who were removed from their families. These people are now approaching the Age Care system and live in fear of being institutionalised by the same actors as in their childhood and early years.

DAI considers the withholding of disability support to older Australians in the community to be a breach of CRPD, however our human rights institutions are unable to take action on behalf of the 50% of older Australians living with disability who face a choice less future in an institution. This is particularly challenging for our First Nations people who have faced forced institutionalisation in their childhoods as part of the 'Stolen Generation' and the 'Forgotten Australians'. These people live in fear that their lives will end in the same manner of forced



carceration as it began, and by the same protagonists. Further, as Australia is a nation with migrants from many communities where institutionalisation is associated with torture, fear and loss, only they can communicate the pain they live with both for themselves as older persons, and the pain of their adult families who have no economically feasible way to support and care for their elders in the community.

DAI looks forward to a specific reference to the rights of older persons to access justice in a fair and accessible way. The '*International principles and guidelines on Access to Justice for Persons with Disabilities*' (Geneva 2020) may form a useful basis to set out States obligations in relation to 'access to justice' and how it would be implemented in practice. Further clarifying that the right extends across all aspects of life including the area of Guardianship, redress, recourse for breaches and extending past government funded services to whole of community.

#### **k) Participation in the public life and in decision-making processes**

Currently there are few strategies in place to support the older person to participate fully in public life, however there are many barriers and impediments that can be systemically addressed that are covered in the preceding subjects such as access to transport, supported decision making etc. The most egregious breach of the human rights of older persons in Australia concerned the recent federal elections that occurred during the active stage of the Covid pandemic. Older people in institutional care were not provided with the opportunity to vote, either through an election official visiting the institution or through the mechanism of postal votes. Despite Article 29 A (1), no facility was made for even the persons living with disability living in residential age care to participate in the voting process. They were effectively excluded from the democratic process due to their institutionalisation. The current Australian human Rights Commission is only enabled to receive individual complaints, and there is no mechanism for a systemic complaint. The human rights complaints system is largely online and very much out of reach of the vast majority of older Australians living in institutional care. Further, the matter of intersectionality of human rights breaches is not accommodated in the current complaint model, and in the absence of a specific convention for the older person, were they to have the will, means and courage to report human rights breaches, they would have to try and find one that best fits their circumstances, despite the fact that multiple covenants were breached by the same action.

In the disability, mental health, indigenous and women's sectors of advocacy in Australia, there has been slow but strong progress in the inclusion of living experience into the governance system and operations of advocacy organisations. This is not the case for older persons or persons living with disability or dementia. Many millions of dollars fund our peak

bodies; however the older person remains at arm's length from the core of the organisation. Placed on satellite 'advisory committees' and 'interest groups' their voice is still seen as an optional extra, a box to tick to demonstrate the optics of inclusion and a gesture of goodwill and compassion. While lived experience frameworks have been developed to support this organisational inclusion which set out consistent expectations, older persons and persons living with dementia are treated on a best-efforts basis which is inconsistent and often physically and emotionally unsafe. While the wider community are remunerated for their considerable time in the advocacy and advisory space, persons living with dementia remain a resource for such organisations and are relegated to the occasional low value and inaccessible 'gift card' as a token of recognition of their time and expertise.

A truly inclusive and human rights-based system of inclusion in public life would value the voice of the lived experience through recognition, remuneration, safety and employment as opposed to being organisational collateral. This must include direct representation from people diagnosed with dementia.

A specific Convention that upholds the rights of older persons to participate fully participate in public life without the existing barriers would go a long way to reducing the fear and apprehension that accompanies ageing at present. Such a treaty would effectively guarantee the whole of life approach to human rights which as previously noted begin to erode at age 65, age 55 for our Indigenous people. Older persons would have a pathway to regaining equality, visibility, respect and full engagement with public and social life alongside the wider community.

## **Part II. Options on how best to address the gaps**

Please state how your Government/organisation has engaged with international and regional human rights mechanisms:

Dementia Alliance International is a registered 501(c)(3) charity registered in the State of Texas USA, with ECOSOC status as a Disability Persons Organisation (DPO) at the UN. Our mission is to provide support globally for people with dementia, and to advocate for services, improved quality of life and the human rights of all people living with dementia, in the community and in residential care (nursing homes). Our vision is a world where all people are valued and included.

---

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

All rights reserved. Subject to the Copyright Act 1968, no part of this document may be reproduced, stored in a retrieval system, or transmitted in any form, or by any means, electronic, mechanical, photocopying, printed, recording or otherwise, without the prior written permission of Dementia Alliance International Please contact us at [info@infodai.org](mailto:info@infodai.org) to request permission. As a US Corporation with 501(c)(3) status, donations to Dementia Alliance International by US citizens are fully tax deductible.



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 globally, 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 therefore the only organisation exclusively representing people living with dementia and the only global independent voice of people diagnosed with dementia.

DAI has engaged substantially with the Open Ended Working group on Ageing, and partly supported our Human Rights Advisor (living with dementia) to attend the OWEGA 2022 to give voice to the people of the world living with dementia, who are so often excluded from such discussion. Nationally, DAI has joined the Rights of Older Persons Australia network, to further advocate and lobby for a Convention on the Rights of Older Persons.

DAI has advocated through consultation opportunities at the National level in the development of the new Age Care Act in Australia as well as other developments in an effort to promote the importance of the human rights and dignity of older persons by referencing existing treaties including the Madrid International Plan on Ageing.

The absence of an existing convention has greatly complicated the development of a rights-based age care act, as there are few norms to anchor the act to. Further to this is the limitation of coverage of a new rights-based act to older persons in receipt of government funded age care services, as this implies that all older persons will need and want this type of support.

Have those engagements resulted in positive impact in strengthening the protection of the human rights of older persons? Please elaborate.

It is difficult to know if DAI engagement has had any effect at all, as there is no feedback mechanism for efficacy of advocacy in this space.

However, in the Australian context, the draft Dementia Action plan 2023 that was released for consultation did not make reference to human rights at all. The recommendation of the Age Care Royal Commission to fully fund disability specific support in the community for persons over age 65 has not been actioned despite extensive efforts, and in fact the guidance for support at home that has been released has become even more restrictive in the supports that can be accessed by the older person, and specifically repeats that only 'age related' supports can be accessed through the support at home package. This essentially excludes any

---

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

All rights reserved. Subject to the Copyright Act 1968, no part of this document may be reproduced, stored in a retrieval system, or transmitted in any form, or by any means, electronic, mechanical, photocopying, printed, recording or otherwise, without the prior written permission of Dementia Alliance International Please contact us at [info@infodai.org](mailto:info@infodai.org) to request permission. As a US Corporation with 501(c)(3) status, donations to Dementia Alliance International by US citizens are fully tax deductible.



disability and consequently dementia specific supports, again with the only available funded option being residential/institutionalisation.

Unfortunately to date, despite extensive consultation, human rights for older persons will be ring fenced within the government funded age care system, with the perceived expectation that older persons will spend their lives under this system, with no other interests, activities or responsibilities. Alternatively, we could speculate that older persons are perceived by our government not to need specific human rights in our daily lives

Compounding the lack of progress in human rights for older persons, despite extensive advocacy efforts is the extravagant discrepancy in government funded support for persons who live with disability under age 65, and those who acquire disability after age 65.

The absence of a convention of the rights of older persons results in weak and segmented policy and legislation. Inconsistency of practice across states, territories and member States, and a feeling for the older person that human rights are only deserved by the under 65 population, further isolating and excluding us and embedding that perception of helplessness, incapacity and general lack of utility and contribution.

What other options can be considered to strengthen the protection of older persons? Please elaborate

DAI and its international membership of persons living with dementia, including their families and care partners firmly believe that an international convention on the human rights of older persons is absolutely essential to take us into the future on an equal footing with the rest of the human race.

As addressed above, the practical implications of living as an older person, and in particular an older person living with dementia in the absence of an international convention can be serious and significant. Piecemeal and scattergun approaches, plugging holes on an ad hoc basis nationally and internationally will further deepen the gaps and silos of poor practice. Older persons simply wish to live their lives with the same rights and freedoms of everyone else in the world. However, the increasingly pervasive spectre of ageism often compounded by ableism impedes any consistent expectation or hope of equality throughout the life course.

The OEWGA and the Independent Experts have provided substantial and powerful reports that support the absolute need for a Convention, and this is further supported in our communities, however that support often remains silent and unheard. The OEWG have been

---

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

All rights reserved. Subject to the Copyright Act 1968, no part of this document may be reproduced, stored in a retrieval system, or transmitted in any form, or by any means, electronic, mechanical, photocopying, printed, recording or otherwise, without the prior written permission of Dementia Alliance International Please contact us at [info@infodai.org](mailto:info@infodai.org) to request permission. As a US Corporation with 501(c)(3) status, donations to Dementia Alliance International by US citizens are fully tax deductible.



thinking on the matter for nearly 14 years, although conventions for other marginalised cohorts have been completed in a timelier fashion, further compounding the global sense of the unimportance of older persons and lack of urgency in action. From the perspective of DAI, and all older persons who have their human rights violated in every way every day, this is unacceptable and we demand action. We do not want to be locked up, physically and chemically restrained, have our capacity questioned by anyone with an interest, left to live in poverty, abused physically financially emotionally and sexually without recourse to justice or redress, or simply discounted according to someone else's assessment of our utility to the wider community.

All of these injustices are compounded by intersection with disability, gender, sexual identity or indigenous status. It is time to Act, and we implore you to support and empower ALL older persons to take their equal place in our world without reservation.

---

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

All rights reserved. Subject to the Copyright Act 1968, no part of this document may be reproduced, stored in a retrieval system, or transmitted in any form, or by any means, electronic, mechanical, photocopying, printed, recording or otherwise, without the prior written permission of Dementia Alliance International Please contact us at [info@infodai.org](mailto:info@infodai.org) to request permission. As a US Corporation with 501(c)(3) status, donations to Dementia Alliance International by US citizens are fully tax deductible.