



Dementia Alliance International

Submission to the Australian Department of Health and Aged Care Consultation on the National Dementia Action Plan

Reframing dementia as a condition causing disabilities to enact the human rights of all people living with dementia in Australia

Submission from: Dementia Alliance International (DAI)

Submitted by: Ms. Kate Swaffer, Co-founder, Board Member and Human Rights Advisor, on behalf of the Board of Directors and 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. DAI is the global voice of people with dementia, and 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 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 voice of people diagnosed with dementia in Australia, and globally.

Discussion on the Consultation paper on the National Dementia Plan.

DAI commends you on this in depth consultation, noting most of your feedback from people with the lived experience will have been received from dementia advocates via Dementia Australia.

The draft objectives:

1. Tackling stigma and discrimination
2. Minimising risk, delaying onset and progression
3. Improving dementia diagnosis and post-diagnostic care and support
4. Improving treatment, coordination and support along the dementia journey
5. Supporting people caring for those living with dementia
6. Building dementia capability in the workforce
7. Improving dementia data and maximising the impact of dementia research and innovation

Whilst we support your draft objectives, specific details of how you plan to achieve them is lacking in some areas. Furthermore, in objective 1, the focus on awareness raising which we expect is likely to be through the Dementia Friendly Initiatives (DFIs), is inadequate and must also including the kinds of justice-based strategies that have been utilised for decades to address discrimination against other marginalised groups such as women and racial minorities. The foundation for tackling stigma and discrimination is to ensure the strategies for realising this outcome are no less than what would be done in relation to all others in society.

We are also extremely concerned your *National Dementia Action Plan Consultation Paper* makes **no mention** of 'dementia being a condition causing disabilities', or the terms 'justice', 'rights', 'human rights', 'discrimination', 'disability rights', 'law', 'redress', 'reparations', and 'employment'.

The National Dementia Action Plan must be framed by international human rights, including the UN CRPD, OPCAT and the Disability Discrimination Act. International human rights are universal and are not limited because of dementia, age or disability.



The National Dementia Plan Consultation paper omits important issues.

We list a number of issues to be addressed and ask you to include them in the National Dementia Plan, and to provide us with details of how you intend to address them.

1. Dementia is not defined or listed as a condition causing disabilities
 - a. That you now allow people with young onset dementia to apply for services and support through the NDIS, provides evidence the government is aware dementia causes disabilities
2. Disability Rights (hence access to rehabilitation and reablement is critical)
3. Human Rights
4. Employment Rights
 - a. With early disability assessment and disability interventions, many people with dementia could be supported to continue to do paid work,
 - b. This plan makes no mention of the rights of people with dementia to reasonable adjustments by employers, or the Discrimination Act, to support remaining employed
5. Redress and Reparations for current and future harms, including violence, abuse, neglect, and assault, inclusion sexual assault in community and residential care.
6. Access to the NDIS for people with dementia aged 65 and over, who are also people with disabilities

It is critical the Consultation on the National Dementia Plan in Australia includes the independent views of people with dementia, through further consultation with Dementia Alliance International.

Despite decades of costly and time-consuming advocacy by local, national and even international dementia charities, and decades of costly research, people with dementia are still being left behind in the 2030 Sustainable Development Goals.

DAI is available for further consultation on these issues, and on our recommendations listed on pages 11-14, and we look forward to hearing from you.



Dementia prevalence

The World Health Organisation (WHO) states dementia is a major cause of disability and dependence globally, and in 2019, there were an estimated 55 million people and nearly 10 million new cases of dementia annuallyⁱ. The Alzheimer's Disease International (ADI) 2021 World Alzheimer's Report (WAR)ⁱⁱ estimated 42 million people with dementia do not have a formal diagnosis.

The Australian statistics on dementia highlighted by Dementia Australia in 2022ⁱⁱⁱ note:

- Dementia is the **second leading cause of death** of Australians.
- Dementia is the **leading cause of death** for women.
- In 2022, there are **up to 487,500 Australians** living with dementia. Without a medical breakthrough, the number of people with dementia is expected to **increase to almost 1.1 million by 2058**.
- In 2022, there are an **estimated 28,800 people** with younger onset dementia, expected to rise to **29,350 people by 2028** and **41,250 people by 2058**. This can include people in their 30s, 40s and 50s.
- In 2022, it is estimated that **almost 1.6 million** people in Australia are involved in the care of someone living with dementia.
- Approximately **65% of people with dementia** live in the community.

Whilst the World Health Organisation notes that dementia is a major cause of disability and dependence 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.

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 (ADI) World Alzheimer's Reports confirmed there has been little positive change over many decades:

1. Attitudes towards people with dementia have remained negative, and stigma and discrimination have not improved^{iv}
 - a. This is despite more than a decade of high levels of government and other funding being invested into the Dementia Friendly Community Initiatives (DFIs), and
 - b. The failure of the DFI's promises to improve awareness and reduce stigma.
2. Enabling environmental design, including the design of buildings and housing is inadequate^v
 - a. This causes earlier entry into residential care settings than would be required if environmental design principles were implemented,
 - b. Inaccessible communities for our neurodiverse community, and
 - c. Unnecessary earlier dependence on families, and then governments.
3. People living with dementia do not receive the same health and social care or disability support as all others. They **do not receive**
 - a. a timely and accurate diagnosis,
 - b. adequate post diagnostic support including being denied disability assessment and proactive disability support, or
 - c. rehabilitation to allow them to live more positively, maintain independence for longer, and to avoid or delay the need for institutional care^{vii}.

People living with dementia must not be left behind in this Australian Consultation on the National Dementia Plan, as they currently continue to be in the Sustainable Development Goals 2030 Agenda.



Dementia and Disability

We note the only mention of disability in your consultation paper refers to people with other causes of disabilities, who may also get a diagnosis of dementia, and the many additional issues they may face such as being at a higher risk of getting dementia.

This ignores the fact that dementia is a condition causing cognitive and multiple other disabilities.

The World Health Organisation, in its Global Action Plan for a Public Health Response to Dementia adopted in 2017 highlighted dementia as a condition causing disabilities and placed the human rights of people with dementia at the core, including implementation of rights through the Convention on the Rights of Persons with Disabilities (CRPD) with empowerment, inclusion and accountability as three of its seven cross-cutting principles.

These reflect the core elements of CRPD and all other Human Rights Treaties deriving from the United Nations (UN) Universal Declaration of Human Rights ratified in 1948. This approach to human rights and the CRPD reflects the standard being advocated for globally, and there in Australia, by Dementia Alliance International.

Hence, this submission, and our organisation is aligned to the Terms Of Reference from the Disability Royal Commission, and note that people with dementia must be RECOGNISED as people with disability and are therefore equal citizens with the right to the full and equal enjoyment of all human rights and fundamental freedoms, including respect for their inherent dignity and individual autonomy.

People with disability caused by dementia have the same rights as all other members of Australian society to live and participate in safe, enabling and accessible environments that enable and promote independence and well-being, and which are free from violence, abuse, neglect and exploitation.

People with disability caused by dementia must also be provided with equal access to high quality health care, from health care professionals with a high level of education about dementia, and on supporting people with acquired disabilities.



Human Rights, Disability Rights, Australia's Obligations

The COVID-19 pandemic has highlighted past injustices for the more than 55 million people living with dementia, through increasing the spotlight on the isolation, stigma, discrimination, and lack of equal access to Universal Health Coverage and post diagnostic care or support. Many Articles of the CRPD highlight further how people with dementia are being left behind.

The pandemic has created a human and social crisis of unparalleled scale, and the outbreak and its multidimensional influences have disproportionately affected persons with dementia and other causes of disability, and especially those with pre-existing health conditions, people from low socio-economic backgrounds, those in regional and remote communities, and those living in institutional settings such as residential aged care. Enforced segregation and institutionalization continues, and many other breaches of human rights have been under the spotlight as never before.

People without dementia don't talk about their 'right to live independently and to be included in the community', because their rights are not being denied.

The CRPD, OPCAT and other Conventions and Treaties are meant to be instruments to ensure the rights of people with disabilities including those caused by dementia. Despite the CRPD, many persons with disabilities experience discrimination and many other barriers and challenges on a daily basis without being able to enjoy these rights and freedoms. These have not only been highlighted by, but they have been worsened by the COVID-19 pandemic.

The following UN CRPD Articles highlight our rights to improved access to health and social care including rehabilitation, to disability support, to inclusion and to being supported to live independently in the community. Living independently and being included in the community are essential to quality of life and well-being of all, including of persons with disabilities.

Article 12 – Equal access to justice

Article 19 - Living independently and being included in the community

19a. 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.



19b. ...access to 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.

Article 25 - Health

25d. Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent.

25e. Prohibit discrimination against persons with disabilities in the provision of health insurance and life insurance...

25f. Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Article 26 - Habilitation and rehabilitation

26.b. Support participation and inclusion in the community

All aspects of society are voluntary and must be available to persons with disabilities as close as possible to their own communities, including in regional, rural and remote communities.

The road to a diagnosis of dementia can be a long, stressful, beset by unrealistic expectations, fears based on myth, 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 years and more beyond diagnosis and striving to live positively, not the life expectancy of 7 years as the current data reflects. We are not invisible; we are not children, and we will not be ignored 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 13 recommendations:

1. Dementia is defined as a condition causing multiple disabilities, including cognitive disabilities, and people with dementia are part of the Australian and global neurodiverse community.
2. Employment Rights, including access to the Disability Discrimination Act.
3. Human Rights.
4. Disability Rights including access to the CRPD (therefore, access to rehabilitation and reablement).
5. 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.
6. 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.
7. All disability workers must be educated in disability care and support specific to the disabilities caused by dementia, and disability rights, to ensure people with dementia in their care are provided with appropriate care and support. This includes, if a worker is supporting someone with dementia, adequate education about dementia, and the disabilities the different types of dementia can cause.

8. 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)^{vii}, or an alternative free course in dementia.
9. 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.
10. 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.
 - a) 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.
 - b) 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.
 - c) 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
 - d) 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.
11. We recommend other strategies are developed, and that the Dementia Friendly Communities and other Dementia Friendly Initiatives are not the only or strategies being targeted and funded for awareness raising, or to reduce stigma and discrimination.
12. 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^{viii} in the Department of Social Services. In the absence of an Australian based DPO, DAI should be included.



13. Finally, 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.

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.

We believe your draft vision within the consultation paper that 'Australians understand dementia - people living with dementia and their carers have the best quality of life possible and no one walks the dementia journey alone' will never be realised, without the inclusion of our recommendations.

It is our right – whether at home, on a bus, at a concert, a sports event, a restaurant, a doctor's office to be treated with dignity and respect.

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.

We need much more a National Dementia Plan. We need action, and we need it now.

Thank you,

Kate Swaffer
On behalf of Dementia Alliance International
Co-founder, Human Rights Advisor and Board Member

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- ⁱ World Health Organisation, 2022, *Dementia*, <https://www.who.int/health-topics/dementia/>
- ⁱⁱ Alzheimer's Disease International, 2021, *World Alzheimer's Report 2021*, <https://www.alzint.org/resource/world-alzheimer-report-2021/>
- ⁱⁱⁱ <https://www.dementia.org.au/statistics>
- ^{iv} Alzheimer's Disease International. 2019. *World Alzheimer Report 2019: Attitudes to dementia*. London: Alzheimer's Disease International.
- ^v Alzheimer's Disease International, 2021, *World Alzheimer's Report 2020*, <https://www.alzint.org/resource/world-alzheimer-report-2020/>
- ^{vi} Alzheimer's Disease International, 2021, *World Alzheimer's Report 2021*, <https://www.alzint.org/resource/world-alzheimer-report-2021/>
- ^{vii} 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/>
- ^{viii} <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/consultation-and-advocacy/national-disability-peak-bodies>