



## Dementia Alliance International

DAI UN Status: ECOSOC

Submission to the 54th session of the Human Rights Council  
Submitted on 1 March 2023

### ***“Violence, abuse and neglect of older persons.”***

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, 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.**

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

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 annually<sup>i</sup>. The Alzheimer’s Disease International (ADI) 2021 World Alzheimer’s Report (WAR)<sup>ii</sup> estimated 42 million people with dementia do not have a formal diagnosis. A study in The Lancet Public Health<sup>iii</sup> estimated the number of people with dementia would increase from 57.4 million cases globally in 2019 to 152.8 million cases in 2050. They must not be left behind.

More than 90% of people with dementia are older persons over the age of 65, and the goal of this submission is to ensure they are not left behind on the Ageing and Rights agendas.

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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>iv</sup>, enabling environmental design is inadequate<sup>v</sup>, and people are being left behind in terms of diagnosis and post diagnostic support<sup>viii</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.

For this submission, we highlight the novel research undertaken and led by Associate Professor Linda Steele in collaboration with Associate Investigator Kate Swaffer (also the author of this submission, on behalf of Dementia Alliance International), **The Dementia Redress Project**<sup>viii</sup> supported by two organisational partners, Dementia Alliance International and People with Disability Australia. The project operated July 2021-March 2023 and was funded by a Dementia Centre for Research Collaboration, Dementia Australia Research Foundation Pilot Grant.

Dementia Alliance International is a project partner for the Dementia Redress Project and advocates for this submission to be considered for the proposed report and the 54<sup>th</sup> Session of the Human Rights Council, including those who live in residential aged care and/or are people living with dementia. We have also asked the Open-Ended Working Group on Ageing consider the publications on reparations and human rights that are relevant to the Open-Ended Working Group on human rights for older persons. People with dementia must not be left behind.

**About the Dementia Redress Project:** Using Australia as a case study, the project researchers developed a set of 'Dementia Reparations Principles'. These principles were informed by international human rights norms, design and lived experiences of other Australian specialised redress schemes, and empirical data from focus groups with people living with dementia, care partners and family members of people with dementia who have been harmed in aged care, and advocates and lawyers.

The Project Report draws on the empirical data to provide rich detail of individuals' experiences of harm and its impacts, and their perspectives on reparations and redress. See 'Reparations for Harms Experienced in Residential Aged Care'<sup>ix</sup>.



The Dementia Redress Project found through empirical research that people living with dementia want reparations, redress and justice which is inclusive, accessible and advances their human rights. In response to this finding and to guide future work on reparations and redress, the Dementia Reparations Principles have been developed.

**These principles provide an evidence-based framework for the need for a focus by the Open-Ended Working Group on access to justice and reparations, including domestic jurisdictions reforming existing options for redress in court systems and specialised redress schemes, and design and operation of new redress and reparations schemes.**

While the Dementia Redress Project used Australia as a case study, its **exploration of the international human rights basis for reparations has broader application to other domestic jurisdictions and the UN human rights system.** The Project Report and other publications are to be launched on 13 March 2023<sup>xxi</sup>.

It is important that people with dementia are central to processes that inform decision-making on what all Member States and others can do to ensure no human rights are being violated, in any setting including community and institutional care.

We therefore ask you take our submission seriously, to ensure people with dementia are not left behind in the SDG2030 Agenda.

If required, we are available to discuss our submission with you at your convenience.

Thank you.

Kate Swaffer  
On behalf of Dementia Alliance International

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- <sup>i</sup> World Health Organisation, 2022, *Dementia*, <https://www.who.int/health-topics/dementia/>
- <sup>ii</sup> Alzheimer's Disease International, 2021, *World Alzheimer's Report 2021*, <https://www.alzint.org/resource/world-alzheimer-report-2021/>
- <sup>iii</sup> Steinmetz, et al., 2019, 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, *The Lancet Public health*, [https://doi.org/10.1016/S2468-2667\(21\)00249-8](https://doi.org/10.1016/S2468-2667(21)00249-8)
- <sup>iv</sup> Alzheimer's Disease International. 2019. *World Alzheimer Report 2019: Attitudes to dementia*. London: Alzheimer's Disease International.
- <sup>v</sup> Alzheimer's Disease International, 2021, *World Alzheimer's Report 2020*, <https://www.alzint.org/resource/world-alzheimer-report-2020/>
- <sup>vi</sup> Alzheimer's Disease International, 2021, *World Alzheimer's Report 2021*, <https://www.alzint.org/resource/world-alzheimer-report-2021/>
- <sup>vii</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/>
- <sup>viii</sup> Dementia Redress Project **website and blog**: [www.dementiajustice.org](http://www.dementiajustice.org)
- <sup>ix</sup> Linda Steele and Kate Swaffer, 'Reparations for Harms Experienced in Residential Aged Care' (2022) 24(2) *Health and Human Rights: An International Journal* 71.
- <sup>x</sup> Launch of Reparations Report and Principles, <https://www.dementiajustice.org/post/launch-of-dementia-reparations-principles>
- <sup>xi</sup> Linda Steele and Kate Swaffer, *Reparations for Harm to People Living with Dementia in Residential Aged Care – Project Report* (University of Technology, Sydney, 2023); Linda Steele and Kate Swaffer, *Reparations for Harm to People Living with Dementia in Residential Aged Care – Dementia Reparations Principles* (University of Technology, Sydney, 2023).