



## Dementia Alliance International

DAI Status: ECOSOC

Submission to the 13<sup>th</sup> Session of the Open-Ended Working Group on Ageing

Submitted on 1 March 2023

### ***“Strengthening the protections of the human rights 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 the only organisation representing people living with dementia exclusively globally and is the only independent voice of people diagnosed with dementia globally.**

Despite decades of costly and time-consuming advocacy by local, national and international 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.

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

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.

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 all persons with disabilities as close as possible to their own communities, including in high income, and LMIC's, and in regional, rural and remote communities.

Dementia Alliance International advocates for the following to be addressed and included at the 13<sup>th</sup> Session of the OEWSGA:

#### **This submission seeks the inclusion of the following recommendations:**

1. Dementia is defined as a condition causing multiple disabilities, including cognitive disabilities, and people with dementia globally are a global neurodivergent community.
2. Employment Rights, including access to the Disability Discrimination Act.
3. Human Rights.
4. Social inclusion.
5. Disability Rights including access to the CRPD.
6. Recognition and monitoring of people with dementia and older persons living in residential care facilities to OPCAT.
7. 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.

8. Member States to provide improved access to independent supported decision making, including mandatory training and accountability for substitute decision makers, which is auditable, transparent, and outside of the ambit of current guardianship arrangements (to ensure that guardians or substitute decision makers do not block access due to real or perceived conflicts of interest). Furthermore, a pathway should be developed for people living with dementia to make an Advance Social Directive, whereby they have a voice into the future, should capacity become compromised, particularly in relation to living and social arrangements, visitors and family of choice relationships and including sexual activity.
9. All health care workers educated in dementia and disability; and all disability workers educated in disability care and support specific to the disabilities caused by dementia, and disability rights. This includes, if a worker is supporting someone with dementia, adequate education about dementia, and the disabilities the different types of dementia can cause. This would include, at a minimum, the freely available University of Tasmania Wicking Institute 9-week 'Understanding Dementia' Massive Open Online Course (MOOC)<sup>vii</sup>, or an alternative course in dementia.
10. The introduction by Member States of individual and collective reparations and actions<sup>viii</sup> available for people with dementia who experience violence, abuse and neglect in any setting, including their care partners and family members who are impacted by that harm.

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 adequate health and social care is provided, and social inclusion, 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.

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**Submitted on:** 1 March 2023  
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- <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> 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); Linda Steele and Kate Swaffer, 'Reparations for Harms Experienced in Residential Aged Care' (2022) 24(2) *Health and Human Rights: An International Journal* 71.