



## Dementia Alliance International

Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability:

## Re-framing Dementia as a Disability

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

**Submitted by:** Ms. Kate Swaffer, Co-founder, Board Member, Human Rights Advisor

**Submitted on:** 31 December 2022

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## Introduction

In our submission to the to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission), we provide background information on our organisation, which to our knowledge, is the only one that exclusively represents people with disabilities due to dementia in Australia, or globally.

We provide a list of 17 suggested recommendations which we believe are crucial to preventing all forms of violence, abuse, neglect and exploitation of people with disabilities due to dementia, and for inclusion in the Commission's Final Report and Final Recommendations.

Our submission then provides a detailed rationale for the suggested recommendations, and for the inclusion of people with dementia as people with disabilities in the recommendations of the Disability Royal Commission.

We highlight relevant data, and provide detailed explanations of dementia as a disability, the relevance of equal access to the CRPD, and the significant impact of dementia women and girls compared to men.

We ask for improved education of dementia and disability, as well as the need for reparations for past and future experiences of experience any form of violence, torture, abuse, neglect, and exploitation, including sexual assault, and others who are impacted by that harm such as care partners and family members.

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## About Dementia Alliance International

Dementia Alliance International<sup>1</sup> (DAI) is a registered international charity, specifically being a Disability Persons Organisation (DPO) representing people with disabilities due to a diagnosis of any type or cause of dementia. Our mission is to provide support globally for people with dementia, and local, national and global advocacy for challenges we face including including timely and accurate diagnosis, improved post diagnostic support and services including access to rehabilitation. We do this to ensure a higher quality of life and independence for longer. DAI campaigns for the human rights of all people living with dementia, in the community and in respite and residential aged care (nursing homes), and for equitable inclusion in the community. DAI is the global voice of dementia.

Notably, for this submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission), we believe Dementia Alliance International is the only organisation in Australia who is exclusively representing people diagnosed with disabilities due to dementia in the Disability Royal Commission. We believe it critical the Disability Royal Commission includes people with dementia in their consultations and includes recommendations specific to disabilities caused by dementia.

Our vision is a world where all people are valued and included .

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

Dementia Alliance International, and our individual members are part of the broader Australian community of persons with disabilities, and an emerging global community advocating for human and disability rights and inclusion, for all people with dementia.

This is because every person with dementia, of any age, has equal rights to Social Inclusion, Disability and Human Rights, in the same way every other person with and without disabilities has.

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Our submission asks for inclusion of the following recommendations in the Commission's Final Report and Recommendations:

- 1) Governments at all levels will recognise, and advocate for people with dementia to be supported as people with acquired disabilities, including in all new research funding, and in health and social care.
- 2) Governments at all levels will introduce individual and collective actions for people with disability, including those living with dementia who experience violence, abuse, torture and neglect in residential, respite or community care settings, and care partners and family members who are impacted by that harm.
- 3) Governments at all levels will improve the recognition of, and prevention of all forms of violence, abuse, torture and neglect in residential, respite, and community care for people with disability, including people living with dementia, who experience harms, including care partners and family members impacted by that harm.
- 4) Governments will introduce improved reporting of violence, abuse, torture and neglect in residential aged care, respite and community care.
- 5) Deinstitutionalisation and desegregation<sup>iii</sup> for all people with disabilities, including people with dementia, as recommended by the United Nations Deinstitutionalization Guidelines. It has been proven institutionalisation of older people and people with dementia causes multiple violations, harm, assault, torture and abuse. Institutionalisation is also coercive, due to the lack of alternative and accessible, dementia-enabling environmental design, the lack of support to enable community living that allows people to stay at home for longer, and the lack of small group home style accommodation when assisted living is seen as the only option.
- 6) We urgently need new models of care<sup>iv</sup> and accessible, environmentally designed enabling housing<sup>vi</sup> that increases independence and allows people to live at home, potentially through to the end of life.
- 7) Governments at all levels will introduce individual and collective actions for people with disability, including those living with dementia who experience sexual assault

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and abuse, and others including care partners and family members who are impacted by that harm.

- a) Note, we highlight sexual assault separately, due to the current attitudes or ignorance within service providers, police and other organisations providing advocacy or care, many who do not believe it occurs, impacting reporting and access to legal processes.
- 8) Governments at all levels will improve the recognition of, and prevention of sexual assault in residential aged and community care for people with disability (including people living with dementia) who experience sexual assault and abuse, and others including care partners and family members who are impacted by that harm.
- 9) Governments will introduce improved reporting of sexual assaults in residential and community care, including mandatory acknowledgement, information, and support when assault is suspected or observed outside of the ambit of the Serious Incident Response Scheme, with a pathway to referral if the victim or their care partner or family member wishes to proceed.
- 10) Governments will introduce improved complaint processes victims/survivors support schemes, and specialised services for older people and people with dementia who have experienced or are at risk of experiencing sexual assault.
- 11) Governments to introduce individual and collective reparations that are accessible and affordable for people with disability, including people living with dementia and older people who experience any form of violence, abuse, neglect, and exploitation, including sexual assault, and others who are impacted by that harm such as care partners and family members.
- 12) Funding to be provided for third party advocates and organisations, to provide access to reparations, legal services, as well as counselling and support. For example, but not limited to, Victims/Survivors and their care partners and families that may require funded legal assistance, assistance with documentation and may not have access to the internet (many forms are online).

- 13) Governments to provide improved access to independent supported decision making, including mandatory training and accountability for substitute decision makers. This must be 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 sexual activity.
- 14) 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.
- 15) 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)<sup>vii</sup>, or an alternative free course in dementia.
- 16) 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.
- 17) Finally, we recommend that all people with disabilities due to dementia have access to the NDIS, as it currently discriminates against people with dementia, therefore people with disabilities, from 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 stigma, and a lack of education of medical and other health care professionals about dementia.



## How our submission relates to the terms of reference

Our submission is relevant to the Disability Royal Commission because Aged Care Royal Commission has also confirmed the extent of past, ongoing, and potentially future violence, abuse, neglect and exploitation, including physical and chemical restraints, of people with dementia, who are people with acquired disabilities. How we build a more inclusive society for people with disability, and prevent future harms is critical to our submission. As such, the supporting documentation is relevant to the following Terms of Reference:

The Commission's specific Terms of Reference therefore apply to all forms of violence, abuse, neglect and exploitation, including sexual assault experienced by people with disability, which automatically includes people of all ages with any type of dementia, in all settings and in all contexts.

Unlike the Aged Care Royal Commission, where action to implement any of the 148 recommendations made in the Final Report has not come to fruition, people with disabilities, including those due to dementia, demand action now. Inaction will unjustly and unfairly further discriminate against and isolate this cohort of vulnerable people who are living with a range of disabilities due to a diagnosis of dementia, and further perpetuate ageist, paternalistic beliefs and prejudices.

People with dementia are systematically excluded from rights based and equitable inclusion; the barriers are far more than dementia.





## Dementia and Disability: Global and Australian Perspectives

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 globally, and nearly 10 million new cases of dementia annually<sup>viii</sup>. The Alzheimer's Disease International (ADI) 2021 World Alzheimer's Report (WAR)<sup>ix</sup> estimated 42 million people with dementia do not have a formal diagnosis. A study in *The Lancet Public Health*<sup>x</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. Whilst prevalence data may vary, dementia is a significant global challenge, and we must not be left behind through the denial of disability support and services, and equal access to health and social care, including rehabilitation.

In Australia, there are an estimated 487,500 Australians living with dementia<sup>xi</sup>, and 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<sup>xii</sup>.

1 in 6 people in Australia are estimated to have disability, including people with dementia. Disturbingly, 24% of adults with disability experience very good or excellent health, compared with 65% without disability. 48% of working-age (aged 15–64) people with disability are employed, compared with 80% without disability<sup>xiii</sup>.

In 2022, it is also estimated that almost 1.6 million people in Australia are involved in the care of someone living with dementia<sup>xiv</sup>, approximately 65% of people with dementia live in the community<sup>xv</sup> and more than two-thirds (68.1%) of aged care residents have moderate to severe cognitive impairment<sup>xvi</sup>.

People with young onset dementia are eligible for services through the National Disability Insurance Scheme (NDIS), but there is significant anecdotal evidence from our members who report significant barriers to this access.



People with older onset dementia, who are also people with acquired disabilities due to their diagnosis of dementia, are therefore being discriminated against by the NDIS.

Whilst the World Health Organisation notes that dementia is a major cause of disability and dependence of older persons globally, people with dementia in Australia (and globally) are not being adequately recognised or supported as persons with disabilities in post diagnostic pathways and care as people with acquired disabilities, and instead are primarily only managed as people with a terminal chronic health condition.

Worse, the therapeutic nihilism, paternalism, stigma, discrimination and ageism further denies them access to disability assessment and proactive disability support, or even equitable access to health and social care.

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

The World Health Organisation, in its Global Action Plan for a Public Health Response to Dementia<sup>xxi</sup> adopted in 2017 which also highlighted dementia as a condition causing disabilities, 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 UN Universal Declaration of Human Rights adopted in 1948. This approach to human rights and the CRPD reflects the standard being advocated for at a global level by Dementia Alliance International and Alzheimer's Disease International.



Hence, this submission, and our organisation is aligned to your Terms of Reference and note that people with dementia must not only 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. They also have the right to be free from all forms of torture, abuse, violence and neglect, and free from restrictive practices such as institutional care, segregation and all others forms of restraint including chemical and physical restraints.

People with disability caused by dementia have the same rights as other members of Australian society to live and participate in safe and enabling and accessible environments free from violence, abuse, neglect and exploitation.

All forms of violence against, and abuse, neglect and exploitation of, people with disability of any kind are abhorrent, and unlawful. People with dementia must not be excluded from the recognition of past and current harms, as reported in the Interim Report<sup>xxii</sup>, which was titled Neglect, and is no longer available, and Final Report from the Royal Commission into Aged Care Quality and Safety (ACRC), and multiple previous taxpayers funded formal enquiries also reporting abuse and harm in residential and community care over two decades. To date, not one of the 148 recommendations<sup>xxiii</sup> from the Final Report have been implemented adequately, if at all.

Australia has international obligations to take appropriate legislative, administrative and other measures to promote the human rights of People with disability caused by dementia, including to protect people with disability from all forms of exploitation, violence and abuse under the Convention on the Rights of Persons with Disabilities.

That dementia is a major cause of disability and is the second cause of death of men and women in Australia<sup>xxiv</sup>, and the leading cause of death of women in Australia<sup>xxv</sup>, it is critical our submission to the Disability Royal Commission is genuinely reviewed, but also acted on.

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## Why it is critical to include people with dementia in this inquiry

1. People living with dementia are people with disability because the symptoms of dementia are recognised as a major cause of disability and dependence.
2. Many older people living with other chronic health conditions are also deemed people living with disability.
3. The majority of people living in residential aged care have a disability.
4. Residential aged care is a closed, institutional setting, hence many of the types of harms experienced in residential aged care are similar to those experienced by people with other causes of disability in locked, institutional settings such as residential aged care, group homes or mental health facilities. People with dementia are further harmed through segregation secure dementia units.
5. The international human rights foundations apply to all people with disability, including people with dementia. With the adoption of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006, the right to independent living and being included in the community was given legal recognition in the international normative frameworks as an essential part of the individual's autonomy and freedom. The CRPD advanced a human rights-based approach to the disability inclusion in many spheres of life, and recognizes the right of all persons, with or without disabilities, to live independently and be included in the community, with the freedom to choose and control their own lives, and to be free from all forms of violence and torture.
6. The Royal Commission into Aged Care Quality and Safety<sup>xxvi</sup> was not grounded in a human rights framework, did not consider the existing lack of access to justice, nor future access to justice and redress, or reparative justice, hence has not adequately addressed the issue of preventing all forms of harm and abuse for people living with dementia receiving care. It is therefore critical that the Disability Royal Commission Final Report includes recommendations for access to justice for all people with disabilities.



Many older people and people living with dementia can't or do not feel free or willing to advocate for themselves, especially if they are neurodiverse and or living alone and without family and funded professional advocacy services need to ensure they are reaching out to people who don't have capacity to self-advocate. In residential, respite care, this is partly due to potential retribution or receiving worse care from staff and care providers. People with dementia and older people deserve the same access to justice as all others.

We must also acknowledge the increasing digital divide, causing further discrimination of people living with dementia for whom online services remain out of reach. Digital information hubs and inbound call centres are inaccessible for most people living with dementia who are wholly reliant on face to face and non-verbal communication, particularly when language skills are impaired, compounded by lack of interpreter services. We advocate for a new approach in advocacy services from representative organisations from a self-service approach to an outreach, community embedded approach co-led by lived experience.

We also request you consider that coercive control of people with disabilities due to dementia is common, denying people agency and power over their own lives. This further and negatively impacts the ability of a person with dementia to overcome the inherent inertia and apathy, and depression which is more often caused by a lack of support to live well after a diagnosis of dementia, and the denial of dementia being managed as a disability, hindering people's willingness to seek help.

It is urgent and vital that the Disability Royal Commission fully explores and makes comprehensive recommendations in relation to recognition of, and prevention of sexual assault in community in-home care and in residential aged care. Locked residential care facilities, including secure dementia units that inhumanely segregate people based on disability, must also be subject to all United Nations Conventions and Treaties, including the Convention on the Rights of Persons with Disabilities (CRPD), and the Optional Protocol to the Prevention Against Torture, and other Cruel Inhuman

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or Degrading Treatment or Punishment (OPCAT). We also find it deeply concerning that the Disability Royal Commission has not yet released an issues paper nor held a Public Hearing on the documented 50 sexual assaults per week of people with dementia in Australian residential aged care facilities, as was reported in the Royal Commission into Quality and Safety in Aged Care Final Report.

Victims/survivors and their care partners and families must be able to access an independent third party advocacy and support with decision making, outside of the ambit of the guardianship arrangements. The creation of opportunities for partnerships with independent victims of crime organisations, as they do not adequately provide equitable justice to this particular cohort of disabled persons. Education about dementia for the police and service providers is paramount, as they are currently not adequately serving people with dementia and older persons who experience other forms of violence, torture, abuse or neglect, including sexual assault, or financial and emotional coercion or abuse.

We must see changes to criminal laws, as they are currently not adequately serving people with dementia and older persons who experience other forms of violence, torture, abuse or neglect, including all forms of sexual assault. Legislative reform is critical, to ensure equal access to justice for people with dementia and older persons who experience other forms of violence, torture, abuse or neglect, including all forms of sexual assault.

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## Woman, Girls and Dementia

We also wish highlight that women and girls are disproportionately impacted by dementia, as people diagnosed with dementia or caring for someone with dementia. More women than men live with the condition, and they provide most of the care support, hence women face the greatest stigma.

Women make up 2/3 of dementia care supporters and take on the roles of unpaid carers compared to males and are more often unemployed due to their unpaid role; girls who are carers often miss out on education.

Everyone impacted by dementia also receive little if any health care, including a lack of access to a diagnosis, or support to live with dementia if diagnosed.

Older women, especially widows, can be exposed to what has been termed a '**triple jeopardy**' discriminated against because of their age, sex and condition (care partner or person diagnosed with dementia).

The stigma surrounding dementia exists universally, with women more likely to be stigmatised in this way. Extreme forms of discrimination can lead to women with the condition facing abuse, violence and even death.

Governments and civil society must get behind this challenge and unite for a world where no woman is left behind because of her dementia, or because she is caring for someone with dementia. Gendered barriers to mobility and accessing justice leads to isolation and exclusion.

The need to disaggregate data by disability, sex and age to understand the situation of women with disabilities, especially in regional and remote communities, and informing policies to ensure their effective inclusion and the full realization of their human rights. Such data is too limited at the moment.

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Understanding intersecting forms of gender- and disability-based violence, exploitation and abuse against women with disabilities including forced medical and psychiatric interventions.

Many of the 'behavioural symptoms' of dementia have been misjudged as neuropsychiatric symptoms, and we labelled as the Behavioural and Psychological Symptoms of Dementia<sup>xxvii</sup> (BPSD), rather than normal human responses to a difficult diagnosis, and the multiple violations of rights. This has resulted in multiple forms of harm, and the excessive use of physical and chemical restrictive practices, and the Covid pandemic has basically proven BPSD does not exist<sup>xxviii</sup>. Whilst some types of dementia have specific neuropsychiatric symptoms, such as hallucinations, the majority of the behavioural responses can easily be supported, if the person with dementia is provided with rights based care and support; because nonpharmacological approaches work, this inherently also suggests BPSD is a fallacy. That we now have deprescribing protocols for reducing the use of anti-psychotics similarly indicates the overuse of chemical restraints, and the harm it causes, as well as there being a Black Box warning<sup>xxix</sup> (in other countries!) against the use of many antipsychotics for people with dementia.

Women with disabilities experience this type of abuse at disproportionately higher rates than others, and in unique forms owing to ingrained discrimination and stigmatization. It is estimated that women with disabilities are 1.5 to 10 times more likely to be physically or sexually abused by a family member or caregiver than other women.

Women with disabilities are often excluded from national laws and policies and remain marginal to global discussions and agreements relevant to their empowerment. The global women's agenda seldom takes into consideration the issues and concerns of women with disabilities.

In addition, women with disabilities are also neglected within the disability movement and the mainstream women's movement. Stand-alone policies on women with

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disabilities remain limited; they are often excluded in policymaking and decision-making processes.

Women and girls also face additional barriers to their cultural and socioeconomic participation, and the denial of disability, social and healthcare compared to men – with and without disabilities. This results in significant employment gaps and high exposure to gender based violence, compounded when living with disabilities due to dementia.

Laws largely fail to protect the rights of women and girls with disabilities to non-discrimination, respect for family life, labour market inclusion, and a life free from violence, abuse or neglect. Gender based stereotypes and discrimination further negatively impact women and girls.

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## The COVID-19 pandemic highlights past and current injustices

The COVID-19 pandemic has highlighted past injustices for the more than 58 million people living with dementia globally, and the estimated 487,000 people with dementia in Australia.

It has done this through increasing the spotlight on the isolation, exclusion, restrictive practices, stigma, discrimination, and lack of equal access to Universal Health Coverage and post diagnostic care and support. Dementia is a major cause of disability and dependence globally, yet people with dementia are still being Prescribed Disengagement®<sup>xxx</sup> (advised to go home and prepare to die, via aged care), rather than provided the appropriate disability assessment or support afforded others with disabilities. Many Articles of the CRPD highlight further how people with dementia are being left behind.

People without disabilities due to dementia, now have the lived experience of isolation, exclusion, restrictive practices, stigma, discrimination, and lack of equal access to Universal Health Coverage and post diagnostic care and support, and to having to operate online, without face to face interaction, including for health.

The pandemic has created a human and social crisis of unparalleled scale, and the outbreak and its multidimensional influences have disproportionately affected persons with disabilities, including people with dementia, and especially those with pre-existing health conditions, people from low socio-economic backgrounds, those in low-and-middle-income countries and those living in institutional settings such as nursing homes.

Enforced segregation and institutionalization continues for people with dementia, and due to the pandemic, these and many other breaches of human rights have been under the spotlight as never before.



## Dementia and the CRPD

Non-disabled people don't talk about their 'right to live independently and to be included in the community', because their rights are not being denied, and the CRPD is meant to be an instrument to ensure the rights of people with disabilities. Living independently and being included in the community are essential to quality of life and well-being of all, including of persons with disabilities.

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.

### Article 1 - Eligibility

Persons with disabilities include those who have long-term physical, mental, intellectual, cognitive or sensory impairments which, in interaction with various barriers may hinder their full and active participation in society on an equal basis with others.

From a human rights perspective, the biggest barrier we face is the 'Iron Curtain' that separates dementia from disability.

This has led to the assumption that we are not included in CRPD and are solely a Health responsibility, rather than the joint responsibility of all government departments for the well-being of all their citizens.

This has led to persons with dementia being excluded by Member States from their implementation of the Convention and to the absence of evidence of the use of CRPD General Principles and Articles in the regional and national Dementia Strategies launched by Member States who have ratified it.

### Article 19 - Living independently and being included in the community

Living independently and being included in the community are essential to the well-being of persons with disabilities and living at home and in the community is not only the preferred choice of people with dementia but also an economic imperative for

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governments compared to costly residential care solutions. Yet, many persons with disabilities experience discrimination and numerous barriers, facing challenges on a daily basis without being able to enjoy these rights and freedoms. These have been exacerbated by the COVID-19 crisis.

With the adoption of the CRPD in 2006, the right to independent living and being included in the community was given legal recognition in the international normative frameworks as an essential part of the individual's autonomy and freedom. The CRPD advanced a human rights-based approach to the disability inclusion in many spheres of life. Article 19 of the Convention recognizes the right of all persons, with or without disabilities, to live independently and be included in the community, with the freedom to choose and control their own lives. It seeks to minimize abandonment, institutionalization, and segregation in domestic settings through protective mechanisms and enabling environments for all.

Persons with cognitive disabilities caused by any type of dementia, especially those who are more advanced in the disease and who have very complex communication or personal care requirements, are frequently categorized as needing to live in institutional settings for their own safety and are being segregated. Their autonomy is ignored, and such reasoning conflicts with article 19, which stipulates the right to live independently and be included in the community to all persons with disabilities, regardless of their level of cognitive capacity, self-functioning, or support requirements.

All States Parties to this Convention, including Australia must recognize the equal right of all persons with disabilities to live in the community, with 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:

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.

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19b. ...access to in-home, residential, respite, 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

The COVID-19 pandemic has caused unprecedented bias towards, as well as mistreatment or denial of medical treatment against people with dementia and other disabilities, through the withholding of medical and hospital treatment, including vaccinations.

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

Enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

26.b. Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

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The road to a diagnosis of dementia can be a long and extremely stressful, beset by unrealistic expectations, fears based on myths and stigma, as well as unfounded hopes and 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. People with dementia are not invisible; they are not children, and they should not be ignored. Nor should their rights be violated.

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. We still count, we are loved, sometimes well-educated, verbose, funny, and above all, they are human beings.

People with dementia are being left behind in the 2030 Sustainable Development Goals and the pandemic has significantly increased isolation and the violation of rights of persons with dementia.

They are also regularly excluded from an autonomous voice at many of the advocacy activities, or the global or national policy strategies and the development of National Dementia Action Plans to improve care and services for people with Non-Communicable Diseases (NCD’s).

We need much more than inclusion - a seat at the table, or to be ‘given a voice’ - we must be provided with equal inclusion and full and equal access to the CRPD, like all others living with disabilities.

Despite the Royal Commission into Quality and Safety in Aged Care (Aged Care Royal Commission), this process is needed to address all forms of violence, abuse and neglect of people with disabilities caused by dementia, as this was not adequately addressed in the Final Report of the Aged Care Royal Commission.

Nor has it recommended in its Interim report<sup>xxxi</sup>, complaint processes for victims/survivors of sexual assault or indeed, any other forms of abuse and violations



of persons rights, or their care partners and families who also experience harm, through support schemes, specialised redress schemes, or equitable access to justice.

Ageism and ableism, compounded with discrimination against people with disabilities, stigma, therapeutic nihilism, paternalism and discrimination more specifically towards people with disabilities due to dementia does not yet fit adequately within legal doctrine, legal processes and the legal profession and judiciary, and therefore ignores the need for co-design of future actions.

Subtle and passive discrimination against people living with dementia is apparent in the language used in the Australian National Age Care Classification too, most notably in the Behaviour Resource Utilisation Assessment tool, which was designed for school leavers with a disability looking for work, opens with the line 'Problem Wandering' and continues to use emotive language such as 'manipulative' and 'attention seeking'.

None of these terms are applicable in later stages of dementia as there is insufficient mental capacity to plan or execute such behaviour. The terms directly imply intent and have now been embedded throughout Residential Aged Care IT systems. There are no other disabilities where this language would be adopted, and it is unsurprising that sexual assault in residential age care is ignored if these attitudes are promulgated by the Department of Health itself.

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## Resetting the agenda of the Disability Royal Commission

The absence of outreach and community engagement by the Disability Royal Commission is likely to have impacted the number of public submissions, to the extent that people and organisations will respond to the agenda set by the Disability Royal Commission, rather than focus submissions on addressing harms such as sexual assault in residential and community care of older people and people with dementia. As such, the number of public submissions specifically addressing sexual assault should not be used as an indication of the level of interest in and need for sexual assault to be addressed and prevented in the future.

Hence, we provide the following as underpinning for the necessity for recommendations on the recognition and prevention of all forms of violence, abuse, torture, neglect and exploitation of people with dementia and older people, who are people with acquired disabilities, in community, respite and residential aged care facilities:

1. The UN Committee on the Rights of Persons with Disabilities has recommended in its 2019 Concluding Observations that the Australian Government: 'Establish a national accessible oversight, complaint and redress mechanism for persons with disabilities who have experienced violence, abuse, exploitation and neglect in all settings, including all those who are not eligible for the National Disability Insurance Scheme and, particularly, older women with disabilities' including people with dementia, and 'Ensure adequate resources and a redress mechanism for the Royal Commission into Violence, Abuse, Torture, Neglect and Exploitation of Persons with Disabilities'.
2. Other Disabled People's Organisations have called for accessible, non-institutional and non-segregated care settings, free from all forms of violence, abuse and neglect throughout the Disability Royal Commission, which supports this submission. DAI joins this call for accessible, non-institutional and non-segregated care settings, free from all forms of violence, abuse, torture, neglect and exploitation violence, abuse, torture, neglect and exploitation.



3. The Disability Royal Commission observed in its Interim Report states: 'it is clear that the question of redress, including compensation for serious harm, is worthy of further investigation.'
4. International human rights norms provide for equal access to justice such that people with disability including people with dementia should have equal access to court processes and remedies, complaint processes, and individual or collective redress schemes.
4. International human rights norms provide for remedies for specific human rights violations, such as deprivation of liberty and torture such that people with disability including people with dementia should have specific access to remedies and reparations when they experience any human rights violations.
5. International human rights norms provide for reparations for gross human rights violations including all forms of violence, abuse, torture, neglect and exploitation, such that people with disability including people with dementia should have access to justice and reparations when they experience gross human rights violations.
6. To prevent violence and abuse including sexual assault and build a more inclusive society requires confronting and reckoning with the past, otherwise (as we have seen since the Aged Care Royal Commission) harm continues. It must be designed into new systems, or people will not be able to realise the recognition, accountability, healing and justice for their past harms, or future harms.
7. We strongly suggest the recommendations in your Final Report should be made retrospective, at least as far back as the date of the commencement of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

As people with dementia, a condition causing progressive cognitive and multiple other disabilities, we must not be left behind in the recommendations of this Royal Commission, as we currently have been in the Sustainable Development Goals 2030 Agenda.



We are appreciative the opportunity to provide this submission and are hopeful it will remove the barriers highlighted in our submission, to rights based and equitable health and social care, disability support, and inclusion.

Finally, we would welcome the opportunity to meet with you, prior to closing the public consultation, and look forward to hearing from you.

Thank you.

A handwritten signature in black ink that reads "Kate Swaffer".

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

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