Reparations for Harm to People Living with Dementia in Residential Aged Care

EXECUTIVE SUMMARY

by Linda Steele and Kate Swaffer

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About this document:

This document provides a summary of the Project Report of the project ‘Redressing Abuse and Neglect of People Living with Dementia in Residential Aged Care’ funded by a Dementia Centre for Research Collaboration – Dementia Australia Research Foundation Pilot Grant.

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Further information about the project:

Project Report: Linda Steele and Kate Swaffer, R*eparations for Harm to People Living with Dementia in Residential Aged Care – Project Report* (University of Technology Sydney, 2023).

Dementia Reparations Principles: 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).

Project website and blog: Dementia Justice: Dementia Redress Project *www.dementiajustice.org.*

The starting point

When people living with dementia are harmed in residential aged care their human rights are violated, and they must have equal access to justice and reparations.

Background

There is a significant and longstanding problem of harm to people living with dementia in Australian residential aged care, along with 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.[1]

There are an estimated 487,500 people living with dementia in Australia[2] and, without a medical breakthrough, this number is expected to increase to almost 1.1 million by 2058. In Australia in 2020, dementia was the second leading cause of death overall[3] and the leading cause of death in women (almost two-thirds of people who died from dementia were female).[4] It was reported that many people with likely mild cognitive impairment or some form of dementia living in residential settings also lack a formal diagnosis.[5]

In Australia in 2021, more than 371,000 people were using residential aged care (permanent or respite, approximately 191,000), home care (approximately 176,000) or transition care (approximately 3,700), two-thirds being women.[6] In 2021, there were 830 providers delivering residential aged care through 2,704 services.[7]

People living with dementia are harmed in Australian residential aged care. This harm is the result of various factors: institutional settings of residential aged care are coercive due to limited other options; physical and sexual assault; use of restrictive practices (such as chemical and physical restraints); confinement; non-consensual medication; and neglect in personal care, medical care, disability support and social participation.

This harm is also the result of lack of access to community-based support and housing, and living in residential aged care – including in segregated dementia care units – out of necessity rather than choice.[8] Although there has been limited formal reporting – for example, to the police or the courts – of harm to people living with dementia in residential aged care,[9] multiple formal inquiries and the Royal Commission into Aged Care Quality and Safety has reported that the incidence of violence, abuse and neglect of people living with dementia in Australian residential care facilities is a significant and persistent problem.

Some key facts and figures related to residential aged care are:

- 39.2% of people living in Australian aged care facilities experience elder abuse in the form of neglect, emotional abuse or physical abuse; the most prevalent were estimated to be neglect (30.8% of people), emotional abuse (22.6%) and physical abuse (5%).[10]
- The number of alleged incidents of unlawful sexual contact in 2018–19 was estimated to be as high as 2,520, or almost 50 per week;[11] in the last quarter of 2021, 530 incidents of unlawful sexual conduct or inappropriate sexual contact were reported, or a rate of around 44 per week.[12]
- Levels of poor nutrition and low hydration are high.[13]
- Some people's deaths in residential aged care involve high-risk medications.[14]
- There is reporting of inappropriate use of antipsychotic agents, especially regarding initial dose and excessive duration of treatment.[15] Additionally, there is widespread overprescription of antipsychotics for people living with dementia in residential care, despite major Australian studies confirming that 'by using a multi-strategic and multidisciplinary approach to deprescribing, antipsychotics can be tapered and ceased'.[16]
- There are long waiting periods for access to home care – more than 50,000 older Australians have died while waiting for home care since 2017–18.[17]

The impacts of this harm on people living with dementia are diverse and wide-ranging. People living with dementia can experience physical and psychological injury, trauma, increased disability and greater need for support, and even death. Families and care partners can experience moral injury and ongoing loss, guilt, betrayal of trust, trauma and anger about the harm to the individual living with dementia. Trauma and anger are often exacerbated by a lack of closure due to internal and external complaint processes that are ill-adjusted to their needs and do not deliver any validation, accountability or change.[18]

The harm to people living with dementia in residential aged care is a systemic and structural problem. It is facilitated by environmental factors (including geography and architecture), economic, legal and regulatory frameworks, and the operation of residential aged care.[19] Existing justice, regulatory and political systems have failed to recognise, redress or repair the harm, to hold perpetrators accountable and to ensure transformative systemic and structural change to prevent harm from continuing.

The Royal Commission into Aged Care Quality and Safety, which drew attention to harm to people living with dementia in residential aged care,[20] is just the latest of numerous inquiries over the past two decades to identify problems with residential aged care.[21]

Incredibly and regrettably, none of these inquiries has recommended a process for recognising, redressing and repairing this harm. Indeed, rather than enhancing accountability of residential aged care providers, in the aftermath of the Royal Commission into Aged Care Quality and Safety the Australian Government instead legislated to provide immunity to residential aged care providers from civil and criminal liability in relation to the use of restrictive practices in certain circumstances.[22]

We have a current situation in which the Australian Government, residential aged care providers, and the staff, board members and legal and health professionals who work within this system are largely unaccountable to people living with dementia, their families and care partners, and broader society.

This harm to people living with dementia violates their human rights under international instruments such as the International Covenant on Civil and Political Rights and the Convention Against Torture. As people living with dementia are people with disability (noting that the World Health Organization has recognised dementia as a major cause of disability for well over a decade), the harm also violates rights under the Convention on the Rights of Persons with Disabilities. Specific human rights violations include violations of rights to:

- freedom from violence and torture
- liberty
- personal integrity
- health
- rehabilitation
- legal capacity
- independent living, and
- equality.[23]

The UN Declaration on the Rights of Indigenous People provides that Indigenous People have rights to self-determination, practice cultural traditions and not to be forcibly removed from their lands, all of which can be violated in relation to First Nations people living with dementia who are compelled to live in residential aged care.

The UN Guiding Principles on Business and Human Rights provide a framework for residential aged care providers to see themselves as actors in realisation of human rights and for governments to hold residential aged care providers accountable as a matter of public procurement when they fail to meet these expectations.

The failure to deliver recognition, redress, repair and accountability to people living with dementia in the wake of this known harm violates their rights to equality and non-discrimination and to equal access to justice. People living with dementia, and their care partners and family members, encounter barriers to accessing civil justice through the courts, barriers to reporting harm to the police and ineffective complaint and prosecutorial processes.[24]

Moreover, people living with dementia have been treated unequally in relation to specialised redress; there is no redress scheme for people living with dementia who are harmed in residential aged care, in stark contrast to recommendations and official responses to similarly widespread harm in other Australian institutional contexts.

For example, the National Redress Scheme for survivors of institutional child sexual abuse was introduced by the Australian Government in 2018 following the Royal Commission into Institutional Responses to Child Sexual Abuse.[25] Over the past decade Australian state and territory governments have introduced reparations schemes for members of the Stolen Generations and their surviving family members.[26]

Additional to recognition and delivery of redress to individuals, there is also a need for ‘moral repair’ at the collective level of society at large. ‘Moral repair’ refers to society confronting its harmful history and present, to take responsibility for that harm and to undertake to restore hope and trust.[27]

International human rights norms provide for reparations for gross human rights violations.[28] While aged care might not be conventionally understood as a site of gross violations of human rights, we argue that ‘the paradigm shift brought about by the CRPD in terms of how human rights of people with disabilities are understood necessitates a ‘disabling’ of how the [international guidance on reparations is] interpreted and applied’ in order to extend to specific experiences of people with disability, including people living with dementia.[29]

Reparations can take multiple and diverse forms, including compensation, rehabilitation, apologies, truth-telling and legal reform.[30] Reparations can be a material and practical contribution to healing individuals, repairing damaged moral and social relations, holding perpetrators accountable and transforming systems. Reparations are not dependent on the unlawfulness of a perpetrator’s conduct, nor are they dependent on what remedies can be delivered by a court.[31]

Reparations have similarities to the National Redress Scheme and Stolen Generations reparations schemes, which focus on individual reparations in the form of monetary payments, counselling and individual apologies, but can offer a broader range of options, including those that operate at a collective and structural level.

To date, reparations have not been implemented or even explored in relation to people living with dementia in residential aged care. However, there is emerging international human rights commentary and academic scholarship on reparations in the broader context of people with disability.[32] There are some examples of reparations being used in overseas countries in response to sterilisation of people with disability.[33] Claims have been made in Australia by people living with psychosocial disabilities who have used mental health services, as well as their families, carers and supporters in some instances.[34] These developments provide a compelling basis for extending reparations to people living with dementia as a specific group of people with disability.

There is a dearth of existing research and practice on reparations in relation to people living with dementia and in the specific context residential aged care.

Project Aim

The aim of the project was to develop an evidence-base on the necessity, scope, forms and processes of reparations for harm to people living with dementia in residential aged care in order to support realisation of their human rights, particularly the right to equal access to justice and reparations.

We sought to contribute to Australian policy and law reform discussions around residential aged care, access to justice and human rights for people living with dementia; raise awareness amongst policy-makers, lawyers, advocates, and human rights practitioners about the need for action on reparations for people living with dementia; and initiate an international field of scholarship and advocacy on reparations for people living with dementia who have been harmed.

Project team and advisors

The project was led by chief investigator Associate Professor Linda Steele. Kate Swaffer was an associate investigator on the project. Dr Evelyn Rose and Hope Siciliano provided research assistance.

The project was supported at all stages by the project organisational partners Dementia Alliance International and People with Disability Australia and by the Project Advisory Group of people living with dementia, family members and care partners, disability and dementia rights advocates and lawyers, and social justice lawyers:

- Cheryl Day (Dementia Alliance International)
- Lyn Rogers (Dementia Alliance International)
- Barbara Spriggs (care partner)
- Francis Quan Farrant, Giancarlo de Vera and Karen Kobier (People with Disability Australia)
- David Skidmore (Multicultural Disability Advocacy Association)
- Sam Edmonds (Older Persons Advocacy Network)
- Bill Mitchell (Townsville Community Law)
- Dr Emma Phillips and Sophie Wiggans (Queensland Advocacy for Inclusion), and
- Ariane Dozer (National Justice Project).

Project methods

The project utilised a disability human rights methodology. This methodology involves research directed towards emancipation rather than marginalisation of people living with dementia and prioritising people living with dementia as leaders and participants in the research.[35]

The dearth of existing research and practice on reparations for harm to people living with dementia in residential aged care provided the research team with a unique opportunity to develop a foundational conceptual and empirical knowledge-base on the topic driven by the perspectives of people living with dementia and people who are close to and advocate with them. Thus, the primary research method was qualitative research with people living with dementia (who do not necessarily live in residential aged care or have not had personal experience of harm), care partners and family members of people living with dementia who have been harmed in residential aged care, volunteer advocates (individuals who, in an unpaid capacity, advocate improved rights and quality of life for people living with dementia and who generally have had experience as care partners or family members of people living with dementia), and lawyers and advocates (individuals working in a paid capacity in legal and advocacy organisations supporting disability rights, older people's rights or human rights more broadly). While priority was given to participation of people living with dementia in data collection, care partners and family members, and lawyers and advocates were also invited to participate based on their involvement in witnessing and advocating against the harm to people living with dementia, including individuals living with dementia who have since died.

The project was conducted July 2021 – December 2022 and involved four stages.

STAGE 1

Stage One involved gathering an evidence-base for developing the Dementia Reparations Principles. Following extensive recruitment efforts, our final sample of research participants in focus groups consisted of: people living with dementia (n=6), care partners and family members (n=13), volunteer advocates (n=8) and advocates and lawyers (n=11).

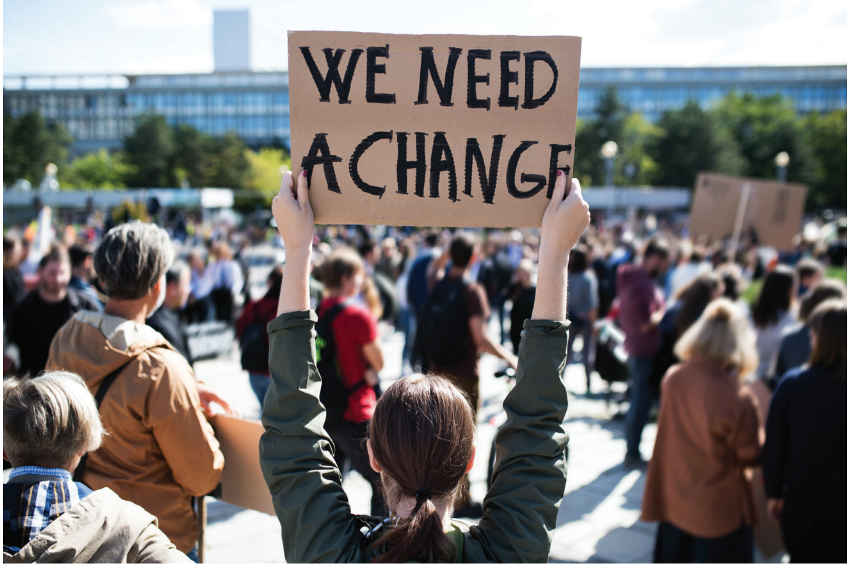
Overall, this was consistent with our targets, with the exception of low numbers of people living with dementia who participated. One difficulty recruiting people living with dementia is that the topic was not considered personally relevant to people we approached (e.g., they did not live in residential aged care, they did not have experience of harm, or it was too confronting due to the reality they may be facing the prospect of being in residential care in the future), even though such personal experience was not a requirement for participation.

These focus groups explored research participants' views on the necessity for reparations in response to harm to people living with dementia in residential aged care, and the forms of and processes for these reparations. Data from the focus groups were then thematically analysed. Research at this stage also involved analysis of international human rights norms on access to justice and reparations and analysis of the design and lived experiences of other Australian redress schemes.

STAGE 2

Stage Two involved development of draft 'Dementia Reparations Principles'. These principles were primarily informed by the findings from the focus groups.

The principles were also informed by international human rights norms on access to justice and reparations and the design and lived experiences of other Australian redress schemes.



STAGE 3

Stage Three involved workshopping the draft Dementia Reparations Principles. A series of stakeholder roundtables explored research participants' views on the content and wording of each specific draft principle and identified gaps in the scope of the draft principles. Following extensive recruitment efforts, our final sample of research participants in stakeholder roundtables consisted of: people living with dementia (n=10), care partners and family members (n=11), volunteer advocates (n=9) and advocates and lawyers (n=11).

Overall, this was consistent with our targets. The notable increase in participation by people living with dementia compared to the Stage One focus groups may have been due to the stakeholder roundtables concentrating on a policy document rather than more abstract discussion of a topic perhaps perceived as removed from personal experience.

Data from the stakeholder roundtables were then thematically analysed. Feedback on the draft principles was also received at two meetings with the project advisory group – one before and one after the stakeholder roundtables. We also received feedback from international human rights experts: Professor Gerard Quinn, Bethany Brown and Bill Mitchell.

STAGE 4

Stage Four involved the production of a final set of Dementia Reparations Principles through revision of the draft and insertion of additional principles. This stage was informed by the findings from the stakeholder roundtables and feedback from the project advisory group.

Limitations of the project

It is important to acknowledge three limitations of the project:

- First, the focus group and stakeholder roundtable sample sizes were small. It is vital to continue to prioritise participation of people living with dementia in further empirical research on reparations.
- Second, the project focused on the foundations and bigger picture of reparations and did not explore the finer level of detail. It is important for future research to consider the implementation of reparations and technical aspects of their operation in the Australian legal and service context.
- Third, there was insufficient scope in the project to fully explore intersectional issues, such as experiences of harm and reparations needs of specific communities of people living with dementia (e.g., women, First Nations people). It is vital for future research to engage with specific communities.

Project findings

There are four key interrelated concepts (which also form the title of our report) that drive the approach to reparations in the Dementia Reparations Principles. These four concepts are Recognition, Accountability, Change, Now.

Recognition

> ‘[T]he only type of redress that would be meaningful for me would be the costs of moving me to a safe place, where that was not going to happen again. That’s meaningful for me … it’s about this restorative justice, restoring someone to a state comparable to what they had before … I just want to be gone from where it happened because otherwise you’re just living in a trigger point.’ (Person living with dementia, PLWD09)
>
> ‘It is about feeling that you have been heard, you have been listened to and there is change.’ (Volunteer advocate, VA08)
>
> ‘[R]edress makes you look at what happened in the past, because without knowing your past, everything that you’re doing now is not based on concrete acceptance, that what was done in the past shouldn’t be repeated. You really need to acknowledge the wrongs before you move forward. I think that is important. I think that’s the importance of redress, because it forces people to be accountable, to hear what went wrong, how it impacted the people and therefore, implicit in that is we won’t do it again.’ (Advocate and lawyer, AL02)

Recognising the harm to people living with dementia in residential aged care and the wide-ranging and ongoing impacts of this harm on people living with dementia and their family members and care partners is important for three reasons. First, people living with dementia are devalued and are often not believed. A second reason is that family members and care partners who seek to advocate against this harm are positioned as problematic and disruptive and are silenced, and the failure to validate the ongoing impacts on them of their feelings of grief, loss and anger relating to the harm to individuals living with dementia confirms that the lives of people living with dementia do not matter. Finally, existing justice, political and regulatory processes have failed to acknowledge and provide people living with dementia, family members and care partners with the material resources and supports needed to address these impacts. Recognition sends the message that the harm is wrong and that the lives of people living with dementia matter. Recognition must be reflected in forms of reparations that provide opportunities for public acknowledgement of, learning about and action in response to the harm and its impacts. Recognition must also be reflected in reparations processes that centre the experiences and voices of people living with dementia and are shaped by their individual circumstances and identities.

Accountability

> ‘So redress obviously has to deal with responsibility and nobody in this system takes responsibility. No one. The doctors don’t. The nurses don’t. The providers don’t. The government doesn’t. The hospitals don’t. You can’t get redress when you have no authoritative system. … So the idea of redress is going to be rendered actually nonsensical in the system in which there is no accountability.’ (Volunteer advocate, VA08)
>
> ‘I feel a great sense of despair after spending over 90 million [dollars] on the Aged Care Royal Commission, after the last full stop, the abuse continues, so what is the point really? People have told their stories, mothers have cried, daughters have cried and still it happens today. Without that redress, without people saying, ‘Everyone is responsible, now we’re going to pay for it. We’re going to pay for it and have a national sorry day for all the people who have been wronged’, it’s just going to carry on.’ (Advocate and lawyer, AL02)

Holding accountable the individuals and organisations who have perpetrated harm to people living with dementia in residential aged care is important for several reasons. First, existing justice, regulatory and political systems have failed to recognise the wrongfulness – and, at times, illegality – of perpetrators’ conduct. A second reason is that perpetrators and other individuals and organisations have benefited – financially or otherwise – from the harm. Finally, the current absence of accountability legitimates the ongoing perpetration of harm. Accountability must be reflected in forms of reparations that reckon with and sanction wrongdoing, require forgoing of financial benefit gained through the harm, and ensure action that will stop ongoing perpetration of harm. Accountability must also be reflected in reparations processes that are safe, transparent and independent, and that hold individuals and organisations accountable for their role in reparations.

Change

> ‘[O]ne of our greatest fears is that we’re going to end up in one of these places and it’s still going to be going on. It’s a pretty good likelihood of that happening and, for me, I just would like to see everybody recognising that this isn’t just a few cases here and there, that it’s fairly commonplace, that it has been addressed, and will continue to be addressed and that moving forward, there’s going to be greater awareness and much better treatment of us when we’re in those circumstances.’ (Person living with dementia, PLWD05)
>
> ‘I think all of the people I’ve spoken to in my advocacy journey, the reason they are involved is because they don’t want what happened to them to happen to other people. That is the guiding thing. I don’t want anybody else to go through what my parents went through. I think that is really critical.’ (Care partner and family member, CPFM10)

Ultimately, reparations need to be directed towards bringing about change at the structural and systemic level. While reparations are necessarily responding to what has happened in the past, this must always be connected to preventing future harm at the individual and structural levels.

Again, there are several reasons for this. One is that reparations, if not followed up with meaningful action, can be experienced as empty words and people being ‘paid off’. A second reason is that harm arises from the structural and systemic dynamics of residential aged care, and thus the conditions for continued perpetration of harm need to be addressed. Finally, while the past cannot be changed, it is critical the lessons of the past are used to change the future.

Change must be reflected in forms of reparations that are directed towards human rights-based changes to laws and practices in residential aged care, and in each form of reparations having a clear connection between past harm and changes to make a better future for people living with dementia. Change must also be reflected in reparations processes that include people living with dementia in leadership roles and monitoring and enforcement of action to stop ongoing perpetration of harm.

Now

> ‘[T]he only type of redress that would be meaningful for me would be the costs of moving me to a safe place, where that was not going to happen again. That’s meaningful for me … it’s about this restorative justice, restoring someone to a state comparable to what they had before … I just want to be gone from where it happened because otherwise you’re just living in a trigger point.’ (Person living with dementia, PLWD09)
>
> ‘[T]he type of people that it affects, that it’s done in a timely way, because if you want redress to somebody, like a person living with dementia that have been harmed, you need that process to start really quickly. Depending on how advanced they are or how fast they are advancing, we need to ensure that it happens quickly.’ (Volunteer advocate, VA11)

Reparations are urgently needed and should not be delayed. There is sufficient historical and current evidence both of widespread harm to people living with dementia and of its impacts on people living with dementia and care partners and family members, such that further exploration of the existence of harm is unnecessary.

Additionally, reparations are already recognised in international human rights law and have been introduced in relation to widespread institutional harm in other Australian contexts, meaning there is an existing normative framework and a wealth of examples and experiences from which to draw. Finally, people living with dementia who have been harmed and are still alive are in urgent need of rehabilitation and support; many who have been harmed are older and there is a risk they will die before they can access reparations.

Unique challenges

There are unique challenges to realising reparations for harm to people living with dementia in residential aged care. These unique challenges include stigma, social death, paternalism and therapeutic nihilism; care partners and family members as perpetrators of or implicated in harm; a precarious and exploited workforce; the profit context of residential aged care; and the ongoing nature of harm. These unique challenges are not identified and addressed in the scholarship and practice on reparations, nor are they reflected in existing Australian reparations schemes for widespread institutional harm in other contexts. As such, they have informed development of the Dementia Reparations Principles, and must also be considered in any future use of these Principles.

The project report

The project report presents the Dementia Reparations Principles. These principles are the primary outcome of the project ‘Redressing Abuse and Neglect of People Living with Dementia in Residential Aged Care’ (2021–2023), funded by Dementia Australia Research Foundation.

The Dementia Reparations Principles apply to people living with dementia and their care partners and family members who are impacted by harm to people living with dementia in residential aged care.

This report is structured in five sections:

- **Section 1** provides background to the project’s focus on reparations.
- **Section 2** provides an overview of the project’s aim and methods.
- **Section 3** provides an overview of the project’s findings by reference to four key concepts: recognition, accountability, change, now.
- **Section 4** explains the Dementia Reparations Principles by primary reference to research participants’ perspectives, also drawing on international human rights norms and the design and lived experiences of the National Redress Scheme and Stolen Generations reparations schemes.
- **Section 5** identifies next steps to advance the longer-term program of work to realise reparations for harm to people living with dementia in residential aged care in Australian law and in international human rights practice.

Next steps

This project is a call to action for governments to implement reparations. Additionally, this project is the first step in a longer-term program of work to realise the introduction of reparations for people living with dementia in Australian law; recognition of and action on reparations for people living with dementia in international human rights practice; and development of an international field of scholarship on reparations and dementia. As a first step, the project provides a strong evidence-base for Australian law reform, a framework for future development of policy and practice on reparations, and novel empirical and conceptual insights to guide future research on reparations.

Broader relevance of the project

While the project focuses on reparations for people living with dementia in Australia, the project report and Dementia Reparations Principles are relevant to the many other nations where people living with dementia experience unredressed harm.[36]

Although our project is specifically focused on people living with dementia, as a particularly marginalised group within aged care, project report and Dementia Reparations Principles are relevant to responding to harm to all residents in residential aged care.

The Dementia Reparations Principles have possible utility more broadly within all institutional settings for people living with dementia, as well as people with disability and older persons more generally.

The project report and Dementia Reparations Principles might also apply more broadly to non-institutional settings such as home care where service providers perpetrate similar harms in the private home to those that occur in residential aged care.

Ultimately, the project report and Dementia Reparations Principles provide a conceptual framework and evidence-base for developing reparative approaches in response to calls for a fundamental reimagining of the future of aged care involving deinstitutionalisation[37] 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.[38]

Moreover, while the project is focused on reparations for harm to people living with dementia in the specific context of residential aged care, some of the Dementia Reparations Principles (notably those on process) will be relevant to the participation of people living with dementia in other contexts of reparations, including contexts not specific to people living with dementia (e.g., institutional child abuse, post-conflict, post-colonial). This is particularly the case given the absence of research on dementia and reparations.

Dementia Reparations Principles

Preamble

People living with dementia in residential aged care are harmed. This harm has diverse and ongoing impacts on people living with dementia and their care partners and family members.

Governments and justice and complaint systems are failing to recognise, redress and repair the harm and hold people and organisations accountable for this harm.

Human rights provide for equal access to reparations and justice, and people living with dementia must enjoy these rights as much as everyone else.

Therefore, reparations must be grounded in, and recognise and advance human rights of all people living with dementia, noting that people with disability have equal rights.

Public knowledge of truthful accounts of harm and of perpetrators is central to holding them to account.

The necessary centring of the needs and perspectives of those who have been impacted by harm must not result in ignoring who has caused this harm.

Therefore, reparations must be directed towards holding all parties to account for harm, including governments and residential aged care providers.

Reparations will be futile if they are not trying to stop current harm and prevent future harm.

The past can’t be changed, but the past can inform how we change for the future.

Therefore, reparations must be directed towards stopping and preventing people living with dementia being harmed in residential aged care, in a wider context of advancing equality and dignity of people living with dementia.

Many people living with dementia and care partners and family members who participated in the Royal Commission into Aged Care Quality and Safety shared personal experiences at great personal cost to them. It is important to recognise and honour these experiences.

The Royal Commission into Aged Care Quality and Safety made important recommendations about how to improve the aged care system, but omitted to consider or recommend systems for redress or reparations.

The Australian Government must act and implement the recommendations of the Royal Commission into Aged Care Quality and Safety.

Reparations are critical to prevent future harm in residential aged care, even though redress or reparations were not mentioned or recommended by the Royal Commission into Aged Care Quality and Safety. However, reparations must not undermine everything that was learned through the Royal Commission into Aged Care Quality and Safety.

Therefore, reparations must be informed by the experiences of people living with dementia and their families and care partners shared at the Royal Commission into Aged Care Quality and Safety, and support implementation of the Commission's recommendations.

People living with dementia and their care partners and family members experience physical, psychological, emotional and economic suffering and mistrust of and anger towards the aged care system, governments and health and legal professions.

Harm in residential aged care has caused broken social and moral relations.

Reparations must provide tangible repair for individuals, families and society.

Therefore, reparations must be an opportunity for healing and moral repair.

People living with dementia are often excluded from involvement in policy design and implementation because they are considered to lack capacity.

Co-design is one way to challenge paternalism and ableism towards people living with dementia and realise equality and self-determination.

Co-design of reparations enables direct involvement of people living with dementia and their care partners and family members who have been impacted by harm in residential aged care and reflects direct action by governments to validate and respond to their experiences.

Perpetrators must not be involved in the design or delivery of reparations.

Therefore, reparations must be led by people living with dementia and co-designed by people living with dementia and care partners and family members, in all aspects of reparations, and must not be led or influenced by those involved in perpetrating harm.

Principles

Each principle is presented in bold, followed by a series of bullet points elaborating on the reasons for and operation of each principle.

Necessity and scope of reparations

Principle 1: Human rights

Reparations are critical to realising and protecting the human rights of all people living with dementia.

- There have been failures to value the individual living with dementia and their equal access to human rights.
- People living with dementia experience unequal protection under the law.
- People living with dementia are subject to ageism, ableism and therapeutic nihilism.
- People living with dementia, and their families and care partners experience a lack of respect and dignity.

Principle 2: Recognition

Reparations are critical to officially recognising that the harm to people living with dementia is unlawful and wrong and that this harm has ongoing and longer-term impacts on people living with dementia and their family members or care partners.

- Harm to people living with dementia has not been acknowledged by governments, residential aged care providers, legal and health professionals or broader society as wrong and unjust.
- Care partners and family members are deeply impacted by what has happened to their relatives, and by how they themselves are treated by residential aged care providers and in complaints processes.
- The current lack of respect and care, lack of acknowledgement of harm and lack of apologies for harm impacts care partners’ and family members’ health.

Principle 3: Validation

Reparations are critical to ensuring the experiences of people living with dementia who have been harmed in residential aged care and their families and care partners are listened to, validated, and acted on, so these experiences are drivers of change which governments and residential aged care providers will be held accountable for making.

- People living with dementia are most often not believed, as staff are likely to dismiss their concerns about harm, saying it is part of their dementia, such as delusions, hallucinations or confabulation.
- Care partners and family members have experiences of being silenced, excluded and gaslit by residential aged care staff and managers and health professionals while trying to stop the harm when it is occurring.
- The system tries to silence people, to prevent governments and the aged care industry having to confront the issues and make structural change, thereby allowing them to protect themselves from any forms of reparation.

Principle 4: Accountability

Reparations are critical to ensuring all parties are held to account for harm, including governments and residential aged care providers.

- The Royal Commission into Aged Care Quality and Safety, and multiple inquiries before that, found abuse, violence and neglect existed in residential aged care.
- Acknowledgment by residential aged care providers of harm to people living with dementia is needed as part of reparations, especially for individuals who have already passed away.

- If it does not cost the system anything to harm people, the system will keep enabling harm.
- There must be legal, moral and economic accountability.
- Health professionals working in residential aged care, including medical professionals, have an ethical responsibility to review existing practices and protocols to ensure they are not repeating past harms (e.g., forced or coerced movement into residential aged care, use of restrictive practices).
- Legal professionals, who might be physically distanced from the sites of residential aged care facilities where harm is perpetrated, need to be held accountable for their role in enabling that harm (e.g., forced or coerced movement into residential aged care, use of restrictive practices).

Principle 5: Prevention

Reparations are critical to ensuring systems and structures are changed and that the harms experienced in the past are not repeated, now or in the future.

- One of people’s greatest fears is that they will end up in a residential aged care facility, and the abuse, violence and neglect is still happening.
- While the past cannot be changed, we can learn from the past to prevent further harm.
- Structural and systems change is needed to prevent harm.
- Reparations will contribute to how we achieve prevention.

Principle 6: Justice and regulatory failure

Reparations are critical because of failures of existing justice, regulatory and political systems to acknowledge and respond to this harm.

- The complexity and disempowerment inherent to complaints processes, and the fear of retaliation following a complaint are discouraging many people from making complaints and are barriers to justice and accountability.
- People living with dementia in residential aged care are often unable or too fearful of repercussions to advocate for themselves.
- Police and other investigative and prosecutorial do not respond appropriately.
- There is a vacuum in the justice system for recognising the rights of people living with dementia in residential aged care and providing court-based remedies for harm.
- Governments have failed to implement the recommendations of the Royal Commission into Aged Care Quality and Safety and to listen to people living with dementia and their care partners and family members.

Principle 7: Profit

Reparations are critical because people living with dementia have been harmed in a profit-driven industry.

- Despite the promise of care, minimal funds are used on care.
- Profit usually seems to be more important than direct resident services and care.
- Residential aged care providers are driven by reputational and risk management and an avoidance of litigation.
- Even not-for-profit residential aged care providers are increasing their asset bases.
- Profit is increased through violence, abuse and neglect of people living with dementia.
- Organisations are not made accountable for how they spend funds.
- Families and people living with dementia sense that residential aged care providers see them as ‘profit’.

Forms of reparations

Principle 8: Rehabilitation and improved living conditions

Reparations must include counselling, rehabilitation and restorative care, including support and resources to move out of one's existing residence and into the community.

- Rehabilitation does not necessarily make up for the harm to a person living with dementia but could assist with support for the disablement and/or trauma of having been harmed and ensuring a person is removed from a harmful environment.
- Immediate, resourced and coordinated support to move individuals to a safe environment in the community.
- An individual's healing from harm must be supported in a broader context of working to restore the connections, relationships and sense of belonging that an individual might have had to a specific place and community prior to entering residential aged care.
- Access to counselling and other support for care partners and family members who live with ongoing guilt and trauma is also necessary.

Principle 9: Truth-telling

Reparations must include publicly available, truthful accounts of harm to people living with dementia and the wide-ranging impacts of that harm, which validate the experiences of people living with dementia and their families and care partners and are followed by actions to prevent future harm.

- Reparations are about feeling that you have been heard, you have been listened to, and there is action being taken to ensure change.
- An individual being able to see that their experiences and story have impacted change can be more important than compensation.
- Truth-telling can help to define and educate others on the complex and diverse nature and extent of harm.
- Public truth-telling can enable society to reckon with what has happened and help to create an ecosystem of accountability and a foundation for moral repair.

Principle 10: Apologies

Reparations must include apologies by residential aged care providers and governments which are followed by actions to prevent future harm.

- Public apologies must be made by governments, residential aged care providers and legal and health professionals.
- Apologies are meaningless if they are not followed by concrete action.

Principle 11: Monetary payments

Reparations must include monetary payments to provide symbolic recognition of harm to people living with dementia, reimburse payments for residential aged care, cover cost of rehabilitation and restorative care, and fund advocacy and legal costs.

- Monetary payments signal to society and residential aged care providers harm has been done, they are accountable, and that people living with dementia matter and are valued, and have had their rights denied.
- Residential aged care fees must be reimbursed – people pay for care that was never provided.
- The requirement that residential aged care providers make monetary payments can be an incentive for them to change.
- It is less about the money, and more about having assurance that the harm is not going to happen again, action will be taken and the system will be fixed.

Principle 12: Sanctions

Reparations must include sanctions to hold residential aged care providers (including board and staff members), governments (including public servants), and medical and legal professionals accountable for harm.

- Reparations need to be at every level – e.g., staff on the floor providing care, board members and managers overseeing care, public servants and politicians making and administering policies and laws about aged care and regulating aged care, and legal and health professionals who work in residential aged care.

- Careful consideration must be given to how to approach accountability of staff in lower paid or insecure roles who are not in any position of control and lack choice in how they perform their duties.
- Preventing larger residential aged care providers from having such strong ties to governments is necessary as a way to enhance accountability, and to prevent policies that are part of a system that allows harm to happen, being accepted by governments.
- The potential use of anti-corruption, antitrust and competition laws can be explored as tools to prevent influence of residential aged care providers on governments.

Principle 13: Human rights-based reform

Reparations must include human rights reform of aged care governance, laws and practices led by people living with dementia and their families and care partners, in order to prevent future harm.

- Systems and policies at all levels need to be transformed.
- All reforms need to be human rights-based, so they do not result in more human rights violations.
- De-institutionalisation and de-segregation are needed in line with international human rights norms.
- De-institutionalisation and de-segregation are happening in the broader disability sector.
- Reforms need to prevent chemical, physical and other methods of restraint.
- Change in the future must be based on what is learned from the past, otherwise the past is repeated in reforms.

Principle 14: Staff and board training

Reparations must include training and education on dementia to healthcare and legal students and residential aged care providers and all staff and board members, including on human rights and dementia as a disability.

- The lack of training on dementia, and on dementia as a disability creates harm in itself.
- Education only about dementia is insufficient and inadequate, and also needs to be framed in human rights.
- Respect, dignity, and personhood are critical to provide the kind of change needed, and for a more humane person-centred care within Australian residential aged care facilities.
- Education must be co-designed with people living with dementia.
- All residential aged care staff must receive training, including hospitality and cleaning staff and training must be frequent, ongoing and updated.
- University and TAFE students also need training – ideas are formed before people start working in residential aged care.
- Principle 15: Empowerment and advocacy
- Reparations must include measures to empower people living with dementia to realise their human rights and provide resources to advocate.
- Too few people living with dementia are able or willing to speak up for their own rights.
- Families and care partners are often unwilling to make complaints or take legal action, for fear of retaliation and additional harm to the person living with dementia in care.
- The voices of people with the lived experience of dementia must be better represented, including from more diverse groups.

Reparations processes

Principle 16: Recognise diversity

Reparations processes must be centred on individuals' diverse identities and experiences, including individuals' gender, sexuality, disability, Indigeneity, cultural and linguistic diversity, and histories of institutionalisation, incarceration and victimisation.

- Reparations processes must recognise and respond to individuals and their experiences based on cultural, religious, gender identity or other factors, in particular people who experience intersecting forms of discrimination and associated structural violence, trauma and harm.
- Staff working in reparations processes and advocates must be provided with training in working with people living with dementia from diverse communities, with a human rights approach.

Principle 17: Trauma-informed

Reparations processes must be trauma-informed and culturally safe.

- Reparations processes must not retraumatise the people who have been harmed, or their families or care partners.
- Reparations processes must not cause further harm in trying to right previous harm.
- Accessible and affordable avenues must be available to receive the right advice, support and counselling.

Principle 18: Disability inclusion and access

Reparations processes must be inclusive and accessible to all people with disability, including disability associated with dementia.

- Existing court and complaint processes are not accessible to or adequate for people living with dementia.
- People living with dementia must be able to access information about reparations, e.g., Easy Read information, access to advocacy support.

Principle 19: Inclusive, accessible and equitable

Reparations processes must be inclusive, equitable and accessible to all people who have been harmed or impacted.

- All residential aged care facilities must have a mandatory notice board and other information about legal and human rights and reparations that are accessible for people living with dementia and their care partners and family members.
- The information must include details of advocacy organisations or legal services that can assist with complaints.
- Online and paper complaints must be made available, as not all have access to the internet.
- Public awareness of reparations, and what forms it can take, is vital.

Principle 20: Promote reparations

Reparations processes must be supported by dissemination and accessibility of information about reparations, including to people who are socially isolated or have cultural, language or literacy barriers.

- Reparations must be known about in order for people living with dementia to access them.
- Some people living with dementia might rely upon their care partners and family members for information, and for reparations.
- Not every person living with dementia has family and social networks to help them access information about reparations.
- Some people living with dementia have financial, cultural, location or cognitive barriers to accessing information about reparations.
- Residential aged care providers might not make information about reparations accessible – they act as gatekeepers.

Principle 21: Collective applications

Reparations processes must include an option for collective applications.

- Power imbalances between an individual and the residential aged care provider and/or governments.
- Group applications can address power imbalances and the sense of isolation, and also provide solidarity to individuals and their families.
- Residents may need an advocate, or a union to support them, and to ensure action is taken.
- A process is needed to counterbalance the reality that staff and other professionals are more likely to be believed than residents or their families.

Principle 22: Independent advocacy

Reparations processes must include access to free, independent and experienced advocacy.

- A person's ability to self-advocate – the power to represent oneself – is lost in residential aged care because of the closed and controlled nature of institutional settings, and the loss of individual agency caused in part, by institutionalisation and segregation.
- Reparations must be easily available to people living with dementia and their care partners and family members, including being accessible and affordable.
- A lack of personal funds must not hinder or prevent access to reparations.

Principle 23: Safe, timely, independent and transparent

Reparations processes must be safe, timely, independent and transparent, without risk of retaliation.

- People must be safe from retaliation by residential aged care providers, staff and health and legal professionals.
- People living with dementia must be safe from financial exploitation by family members, residential aged care providers, lawyers and advocates.
- Reparations must take place outside of the residential aged care facility and be independent of governments, residential aged care providers and legal and health professionals.
- Transparency is critical, particularly because of exposed problems with existing complaints processes.
- Reparations need to be determined within a specified timeframe to be effective, particularly if the harm is still occurring, the impact is severe and immediate support is required, or the person living with dementia is at risk of passing away.

Principle 24: Communication and enforcement of outcomes

Reparations processes must include communication of outcomes to individuals and monitoring and enforcement of outcomes.

- There must be a feedback loop to ensure that residential aged care providers, governments, and health and legal professionals take the action they promised to take through truth-telling, apologies and other reparations processes.
- Reparations are likely to be ineffectual and empty without monitoring of, and enforcement of actions.

Principle 25: Reform justice and complaint systems

In addition to reparations, individuals must have equal access to criminal justice, civil justice and complaint systems, and governments must make reforms to ensure these systems are safe, accessible and inclusive.

- If a person has dementia, their complaints or their family's and care partner's complaints about the harm are not taken seriously.
- Police and other investigative and prosecutorial authorities view people living with dementia as lacking capacity to report harm and give formal evidence in support.
- Reforms to all systems are needed, including criminal and civil justice mechanisms, and aged care complaint systems.
- Equal access to justice for people living with dementia means they should have equal access to the justice system, as well as to reparations.

References

1. 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.
2. ‘*Statistics*’, *Dementia Australia* (Web Page).
3. ‘*Causes of Death, Australia*’, *Australian Bureau of Statistics* (Web Page, 29 September 2021).
4. Australian Institute of Health and Welfare, ‘*Dementia Snapshot’*, July 2020.
5. Suzanne M Dyer et al, ‘Diagnosis of Dementia in Residential Aged Care Settings in Australia: An Opportunity for Improvements in Quality of Care?’ (2018) 37(4) *Australasian Journal on Ageing* E155.
6. ‘*People Using Aged Care*’, Australian Institute of Health and Welfare (Web Page).
7. ‘*Providers, Services and Places in Aged Care*’, Australian Institute of Health and Welfare (Web Page).
8. Bethany Brown, *‘Fading Away’: How Aged Care Facilities in Australia Chemically Restrain Older People with Dementia* (Report, Human Rights Watch, October 2019) Kate Carnell and Ron Paterson, *Review of National Aged Care Quality Regulatory Processes* (Report, Department of Health, October 2017) Aaron Groves et al, *The Oakden Report* (Report, Department for Health and Ageing, 2017); Royal Commission into Aged Care Quality and Safety, Neglect (Interim Report, 31 October 2019) *Royal Commission into Aged Care Quality and Safety, Care, Dignity and Respect* (Final Report, 1 March 2021).
9. Melanie Joosten, Briony Dow and Jenny Blakey, *Profile of Elder Abuse in Victoria: Analysis of Data About People Seeking Help from Seniors Rights Victoria* (Final Report, National Ageing Research Institute, June 2015).
10. Royal Commission into Aged Care Quality and Safety, *Experimental Estimates of the Prevalence of Elder Abuse in Australian Aged Care Facilities* (Research Paper 17, December 2020).
11. Royal Commission into Aged Care Quality and Safety, *Care, Dignity and Respect* (Final Report, 1 March 2021) volume 1, 140.
12. Christopher Knaus, ‘*“Shocking” Rate of Sexual Abuse of Aged Care Residents Barely Changed Since Royal Commission*’, *The Guardian* (online, 6 June 2022).
13. Marie Bernoth, Elaine Dietsch and Carmel Davies, ‘‘‘Two Dead Frankfurts and a Blob of Sauce’’: The Serendipity of Receiving Nutrition and Hydration in Australian Residential Aged Care’ (2014) 21(3) *Collegian* 171.
14. Natali Jokanovic et al, ‘A Review of Coronial Investigations into Medication-related Deaths in Residential Aged Care’ (2019) 15(4) *Research in Social and Administrative Pharmacy* 410.
15. Hee-Young Shin et al, ‘The Use of Antipsychotics Among People Treated with Medications for Dementia in Residential Aged Care Facilities’ (2016) 28(6) *International Psychogeriatrics* 977.
16. Kaye Ervin et al, ‘Time for Australia to Revisit Antipsychotic Use in Dementia in Residential Aged Care’ (2019) 12(5) *Australasian Medical Journal* 138; Kerrie Westaway et al, ‘The Extent of Antipsychotic Use in Australian Residential Aged Care Facilities and Interventions Shown to be Effective in Reducing Antipsychotic Use: A Literature Review’ (2020) 19(4) *Dementia* 1189.
17. Christopher Knaus, ‘*More Than 50,000 Older Australians Died While Waiting for Approved Home Care Since 2017, Data Shows*’, *The Guardian* (online, 22 April 2022).
18. Bethany Brown, *‘Fading Away’: How Aged Care Facilities in Australia Chemically Restrain Older People with Dementia* (Report, Human Rights Watch, October 2019);
Kate Carnell and Ron Paterson, *Review of National Aged Care Quality Regulatory Processes* (Report, Department of Health, October 2017);
Aaron Groves et al, The Oakden Report (Report, Department for Health and Ageing, 2017); *Royal Commission into Aged Care Quality and Safety, Neglect* (Interim Report,

31 October 2019)
Royal Commission into Aged Care Quality and Safety, Care, Dignity and Respect (Final Report, 1 March 2021).

19. Linda Steele and Kate Swaffer, '*Reparations for Harms Experienced in Residential Aged Care*' (2022) 24(2) *Health and Human Rights: An International Journal* 71.
20. *Royal Commission into Aged Care Quality and Safety, Neglect* (Interim Report, 31 October 2019)
    Royal Commission into Aged Care Quality and Safety, Care, Dignity and Respect (Final Report, 1 March 2021).
21. Jane Phillips, Deborah Parker and Michael Woods, '*We've Had 20 Aged Care Reviews in 20 Years – Will the Royal Commission Be Any Different?*', *The Conversation* (20 September 2018).
22. Bryan Keon-Cohen, '*When it Comes to Restrictive Practices, Legal Immunity is Not the Answer*', *Inside Ageing* (5 August 2022).
23. Yvette Maker and Bernadette McSherry, 'Regulating Restraint Use in Mental Health and Aged Care Settings: Lessons from the Oakden Scandal' (2018) 44(1) *Alternative Law Journal* 29
    Linda Steele and Kate Swaffer, '*Reparations for Harms Experienced in Residential Aged Care*' (2022) 24(2) *Health and Human Rights: An International Journal 71*.
    Linda Steele et al, 'Questioning Segregation of People Living with Dementia in Australia: An International Human Rights Approach to Care Homes' (2019) 8(3) *Laws*
    Laura Grenfell, Anita Mackay and Julie Debeljak, 'Human Rights Accountability and Redress for Systems of Ill Treatment in Residential Aged-Care' (2021) *Monash University Law Review.*
24. Kylie Burns, '*The Forgotten Injured: Recovery for Injuries in Aged Care'*, Griffith News (Web Page, 1 June 2021)
    William Mitchell, Andrew Byrnes, Anneliese Bergman and Caremelle Peisah, 'The Human Right to Justice for Older Persons With Mental Health Conditions' (2021) 29(10) *American Journal of Geriatric Psychiatry* 1027
    Royal Commission into Aged Care Quality and Safety, Final Report: *Care, Dignity and Respect* (Final Report, 1 March 2021) volume 2.
25. *National Redress Scheme* (Web Page).
26. '*For Stolen Generations Survivors*', knowmore (Web Page).
27. Margaret Urban Walker, *Moral Repair* (Cambridge University Press, 2006).
28. United Nations General Assembly, *Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law*, GA Res 60/147, UN Doc A/RES/60/147 (21 March 2006, adopted 16 December 2005).
29. Linda Steele and Kate Swaffer, '*Reparations for Harms Experienced in Residential Aged Care*' (2022) 24(2) *Health and Human Rights: An International Journal* 71.
30. United Nations General Assembly, *Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law*, GA Res 60/147, UN Doc A/RES/60/147 (21 March 2006, adopted 16 December 2005).
31. Linda Steele and Kate Swaffer, '*Reparations for Harms Experienced in Residential Aged Care*' (2022) 24(2) *Health and Human Rights: An International Journal* 71.
32. Carolyn Frohmader and Therese Sands, Submission to the Senate Inquiry into Violence, Abuse and Neglect against People with Disability in Institutional and Residential Settings (Submission, Australian Cross Disability Alliance, 2015);
    Tina Minkowitz, 'Reparation for Psychiatric Violence: A Call to Justice', in Michael A Stein, Faraaz Mahomed, Vikram Patel and Charlene Sunkel (eds), *Mental Health, Legal Capacity, and Human Rights* (Cambridge University Press, 2021).
33. Jonathan Chernoguz, '*Education as Redress*', *Eugenics Archives* (14 April 2015);
    Paul Weindling, '*Sterilization Compensation*', *Eugenics Archives* (28 April 2014).
34. Simon Katterl et al, Counting the Cost: *Advice to the Minister for Mental Health on Acknowledging Harm in the Mental Health*

System (Report, December 2022).

35. Anna Arstein-Kerslake, Yvette Maker, Olympia Ward, Ruby Bell, and Theresia Degener, 'Introducing a Human Rights-Based Disability Research Methodology' (2020) 20(3) *Human Rights Law Review* 412.

36. See eg Hannah Flamm, *'They Want Docile': How Nursing Homes in the United States Overmedicate People with Dementia* (Human Rights Watch, 2018);
Caroline Emmer De Albuquerque Green, Anthea Tinker and Jill Manthorpe, 'Human Rights and Care Homes for Older People: A Typology of Approaches from Academic Literature as a Starting Point for Activist Scholarship in Human Rights and Institutional Care' (2022) 26(4) *The International Journal of Human Rights* 717.

37. 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); Gerard Quinn and Ann Campbell, '*Nursing Homes Must be Made a Thing of the Past*', *Irish Times* (20 May 2020).

38. 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).