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

PROJECT REPORT

by Linda Steele and Kate Swaffer

Funded by a Dementia Centre for Research Collaboration
Dementia Australia Research Foundation Pilot Grant

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About this document:

This document provides an outline of the Dementia Reparations Principles, a key outcome 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:

Executive Summary: Linda Steele and Kate Swaffer, Reparations for Harm to People Living with Dementia in Residential Aged Care – Executive Summary (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: https://www.dementiajustice.org/.

Contents

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Abbreviations

Aged Care Royal Commission	Royal Commission into Aged Care Quality and Safety
CALD	Culturally and linguistically diverse
CRPD	Convention on the Rights of Persons with Disabilities
CRPD Committee	Committee on the Rights of Persons with Disabilities
DON	Director of Nursing
DPR	Direct personal response
EN	Enrolled Nurse
ICCPR	International Covenant on Civil and Political Rights
National Redress Scheme Joint Select Committee	Joint Select Committee on Implementation of the National Redress Scheme
NDIS	National Disability Insurance Scheme
NRS	National Redress Scheme
NSW	New South Wales
PCA	Personal care assistant
RN	Registered nurse
van Boven Principles	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

Research participant abbreviations

AL	Advocate or lawyer
CPFM	Care partner or family member
PLWD	Person living with dementia
VA	Volunteer advocate

1. Background to the project: Why do we need to research reparations?

This section provides a background to the project's focus on reparations.

1.1 The problem: Unredressed harm in aged care

There is a significant and longstanding problem of harm to people living with dementia in residential aged care, along with a failure to recognise, redress and repair and hold people accountable for this harm.

1.1.1 Harm in residential aged care

In 2019 an estimated 57·4 million people were living with dementia globally, and this is estimated to increase to 152.8 million cases by 2050.[2]

There are an estimated 487,500 people living with dementia in Australia,[3] and without a medical breakthrough this is expected to increase to almost 1.1 million by 2058. In Australia in 2020, dementia was the second-leading cause of death overall[4] and the leading cause of death in women (almost two-thirds of people who died from dementia were female).[5] It is reported that many people with likely mild cognitive impairment or some form of dementia living in residential settings also lack a formal diagnosis.[6] In 2021, more than 371,000 people were using residential aged care in Australia, including permanent or respite care (approximately 191,000), home care (176,000) and transition care (approximately 3,700), two-thirds of whom were women.[7] In 2021 there were 830 providers delivering residential aged care through 2,704 services.[8]

It is well established that people living with dementia suffer harm in Australian residential aged care. This harm is the result of factors including physical and sexual assault, use of restrictive practices (such as chemical and physical restraints, confinement, and 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 – typically a result of force or necessity rather than choice.[9] Although there has been limited formal reporting (for example, to the police and the courts) of harm to people living with dementia in residential aged care,[10] multiple formal inquiries and a Royal Commission tell us the incidence of violence, abuse and neglect of people living with dementia in Australian residential care facilities is a significant problem. Key facts and figures related to residential aged care include:

- 39.2% of people living in Australian aged care facilities experience elder abuse in the form of neglect, emotional abuse or physical abuse, with the prevalent being neglect (30.8% of people) followed by emotional abuse (22.6%) and physical abuse (5%).[11]
- 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,[12] and in the last quarter of 2021, 530 incidents of unlawful sexual conduct or inappropriate sexual contact were reported, a rate of around 44 per week.[13]
- Levels of poor nutrition and low hydration are high.[14]
- There is low reporting of inappropriate use of antipsychotic agents especially regarding initial dose and excessive duration of treatment.[15]
- Some people's deaths in residential aged care involve high-risk medications.[16]
- There is an overuse of antipsychotics prescribed 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'.[17]
- There are long waiting periods for access to homecare – more than 50,000 older Australians have died while waiting for home care since 2017–18.[18]

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 (see Section 3.2.2) and ongoing loss, guilt, betrayal of trust, trauma and anger about the harm to the individual living with dementia. Families and care partners can also experience ongoing trauma, anger and lack of closure as a result of internal and external complaint processes that are ill-adjusted to their needs and do not deliver any validation, accountability or change.[19] Family and care partners' ability to heal is impacted, as is their trust in systems and belief in the possibility of positive change.

The harm to people living with dementia in residential aged care is a systemic and structural problem. This harm is facilitated by environmental factors (including geography and architecture), economic, legal and regulatory frameworks and the operation of residential aged care.[20] For example, use of restrictive practices is regulated (rather than prohibited) by law. Operating residential aged care facilities for financial gain is permitted by law and supported by the funding framework. Non-consensual confinement in segregated dementia units is enabled by the built design of residential aged care facilities and substitute decision-making laws.[21]

1.1.2 Failure to redress harm in residential aged care

Existing justice, regulatory and political systems have failed to recognise, redress or repair the harm, hold perpetrators accountable or ensure transformative systemic and structural change to prevent continued perpetration of harm.

There are limited examples in Australia of successful litigation providing court ordered remedies to people living with dementia or to care partners and family members who are impacted by harm to people living with dementia in residential aged care.[22] There are well-documented problems with aged care complaint processes (internal and external to the residential aged care provider), including that they are difficult to navigate, slow to act, focused on keeping residential aged care facilities operating, and not transparent or independent in their operation.[23] Research in Australia and overseas identifies significant access to justice barriers experienced by people living with dementia.[24]

The Royal Commission into Aged Care Quality and Safety (‘Aged Care Royal Commission’) drew attention to the harm suffered by people living with dementia in residential aged care.[25] The Aged Care Royal Commission followed multiple other inquiries over the past two decades that also identified problems with residential aged care.[26] Yet none of these inquiries has recommended a process for recognising, redressing or repairing this harm. The Aged Care Royal Commission’s interim and final reports document diverse harms, including the widespread use of restrictive practices, neglect in medical and dental care, the denial of palliative care, neglect in personal care (e.g., rationing of incontinence pads), and physical and sexual assault.[27] The Aged Care Royal Commission acknowledged problems with complaint processes and access to remedies for violations of quality and safety regulatory requirements and recommended reform to enhance complaint handling and enshrine private rights to court action for damages for those who have suffered loss and damage by reason of breaches of proposed aged care legislation.[28] The Aged Care Royal Commission made no recommendations for an accessible redress scheme for individuals who are harmed in the future, nor did it make any recommendations for redress in response to the impact on people living with dementia and their families of harm that had already occurred. Regardless, the Australian Government has not acted on even the modest recommendations for future court-based redress, and, moreover, there continue to be stories in the media of systemic and structural harm in aged care, particularly the widespread use of restrictive practices and the incidence of neglect in personal care.[29] The Aged Care Royal Commission followed multiple other inquiries over the past two decades that also identified these problems with residential aged care.[30] Incredibly and regrettably, none of these inquiries have recommended a process for recognising and redressing this harm. Indeed, rather than enhancing accountability of residential aged care providers, in the aftermath of the Aged Care Royal Commission the Australian Government instead legislated to provide to residential aged care providers immunity from civil and criminal liability in relation to use of restrictive practices in certain circumstances.[31]

People living with dementia who have been harmed in residential aged care do not have an accessible redress scheme, unlike those who have experienced other categories of institutional harm and who do have access to a redress scheme. 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.[32] Over the past decade Australian state and territory governments have introduced reparations schemes for members of the Stolen Generations and their surviving family members.[33] Redress schemes have emerged in other diverse contexts of mass harm, such as the Office of the Commonwealth Ombudsman's Restorative Engagement Program for serious abuse within the Australian Defence Force[34] and the Victorian Government's current development of a redress scheme for Victorian women who had their children taken from them under historic forced adoption practice.[35] The absence of redress specifically for chemical restraint (which has been identified as a particularly widespread problem in residential aged care, with sometimes fatal consequences) stands in contrast to schemes related to the disabling and fatal impacts of chemicals in other health and workplace contexts, such as the Australian Thalidomide Survivors Support Program[36] and state and territory dust disease and asbestos worker compensation schemes.[37]

Additional to recognition and delivery of redress to individuals, there has been an absence of '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.[38]

Thus, currently governments, residential aged care providers, staff and 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.

1.1.3 Violating human rights

The harm to people living with dementia and the lack of recognition and redress of such harm is a human rights issue.

People living with dementia are people with disability. For example, the World Health Organization has recognised dementia as a major cause of disability.[39] Recognising that dementia causes major cognitive and other disabilities, and has a significant impact on the quality of life and independence of people living with dementia, is critical and relevant to ensuring people living with dementia are not denied their full human rights. Many people are either not aware that dementia causes disability, or find it preferable to view dementia from a purely medical, chronic health perspective. People living with dementia have historically been subjected to greater human rights violations by reason of cognitive and physical disability and older age.[40] However, following the entry into force in 2008 of the Convention on the Rights of Persons with Disabilities (CRPD), people living with dementia (as people with disability) are entitled to equal enjoyment of human rights and cannot be discriminated against by reason of disability.[41] Subsequent commentary by the former United Nations Special Rapporteur on the Rights of Persons with Disabilities has explicitly stated that older persons with disability are entitled to equal enjoyment of human rights.[42]

Institutional harm to people living with dementia violates their human rights under international instruments such as the International Covenant on Civil and Political Rights (ICCPR) and the Convention Against Torture. As people living with dementia are people with disability, the harm also violates rights under the CRPD. 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.[43]

People living with dementia are entitled to non-discriminatory treatment and disability support in terms of the care, support and accommodation they access in residential aged care. Confinement in segregated dementia units and restrictive practices violate rights to legal capacity;[44] to freedom from deprivation of liberty;[45] to personal integrity;[46] to freedom from torture and cruel, inhuman and degrading treatment;[47] and to independent living and community inclusion.[48] Physical and sexual assaults and the use of restrictive practices violate the right to freedom from violence.[49] Neglect in provision of personal care, medical care, disability support and social participation violates rights to rehabilitation,[50] health[51] and participation in recreation and leisure.[52] Being compelled to live in residential aged care by force or necessity rather than choice, including because of lack of access to community-based support and housing, violates rights to legal capacity[53] and independent living and community inclusion.[54] 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.

While noting that the obligation to respect and ensure human rights falls on the state (rather than nonstate actors such as corporate or charitable aged care providers or private medical professionals), the obligation of the state to protect against human rights violations clearly extends to taking steps to regulate the behaviour of nonstate actors and to provide remedies for violations.[55] 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[56] and for governments to hold residential aged care providers accountable as a matter of public procurement when they fail to meet these expectations.[57]

The failure to deliver recognition, redress, repair and accountability to people living with dementia in the wake of this harm violates rights to equality and non-discrimination, and equal access to justice.[58] The ICCPR provides that persons have the right to be 'equal before the courts and tribunals'.[59] The UN Declaration of Basic Principles of Justice for Victims of Crime and Abuse of Power stipulates that victims should have their right to access to justice and redress mechanisms fully respected.[60] The right to equal access to justice has been explicitly articulated in relation to people with disability. [61] The CRPD provides that in ensuring equal access to justice for persons with disability, States Parties will provide 'procedural and age-appropriate accommodations'.[62] These violations can, in turn, support cycles of perpetration as they contribute to a culture of impunity. The Committee on the Rights of Persons with Disabilities has noted that '[p]erpetrators may act with impunity because they perceive little risk of discovery or punishment as access to judicial remedies is severely restricted'.[63]

1.1.4 Profound moral wrong

The harm to people living with dementia in residential aged care, and the failure to deliver recognition, redress and change in relation to this harm, also gives rise to a profound ontological and moral wrong that denies full recognition as humans to people living with dementia. This has been described differently by scholars: as 'moral exclusion', 'ethical loneliness' and 'grievability'.

Drawing on the work of Ervin Staub, Susan Opotow defines 'moral exclusion' as occurring 'when individuals or groups are perceived as *outside the boundary in which moral values, rules, and considerations of fairness apply.* Those who are morally excluded are perceived as nonentities, expendable, or undeserving; consequently, harming them appears acceptable, appropriate, or just.'[64] Opotow explains that a common feature of forms of moral exclusion is that 'the perpetrators perceive others as psychologically distant, lack constructive moral obligations toward others, view others as expendable and undeserving, and deny others' rights, dignity, and autonomy'.[65]

Jill Stauffer defines the term 'ethical loneliness' as 'the experience of having been abandoned by humanity compounded by the experience of not being heard'.[66] Stauffer explains that ethical loneliness is a condition that is 'undergone by persons who have been unjustly treated and dehumanised by human beings and political structures, who emerge from that injustice only to find that the surrounding world will not listen to or cannot properly hear their testimony – their claims about what they suffered and about what is now owed them – on their own terms'.[67]

Judith Butler defines 'grievability' as the social loss arising from violence to an individual and as being grounded in the extent an individual is recognised as fully human. Butler explains that 'a grievable life … means that this will be a life that can be regarded as a life, and be sustained by that regard. Without grievability, there is no life, or rather, there is something living that is other than life … sustained by no regard, no testimony, and ungrieved when lost.'[68] According to Butler, some individuals lives are not 'real' in the sense of being recognised as human, and have 'suffered the violence of derealization'. Butler explains: 'If violence is done against those who are unreal, then, from the perspective of violence, it fails to injure or negate those lives since those lives are already negated.'[69] People who are ungrievable experience multiple levels of derealisation: '[O]n the level of discourse, certain lives are not considered lives at all, they cannot be humanized, and they fit no dominant frame for the human … their dehumanization occurs first, at this level, and … this level then gives rise to a physical violence that in some sense delivers the message of dehumanization that is already at work in culture'. [70]

Common to each of these three concepts is a double injury that cuts deeper than legal injustice and sits at the core of what it means to be recognised and valued by society as human. This double injury consists of the initial harm to individuals who are more violable because they are already deemed less than full humans, and a second compounding injury of the subsequent failure of society, legal and justice systems and governments to recognise this harm as a wrong that denies to these individuals the legal and political status of victim and thus exacerbates their dehumanisation.

The cumulative effect of the situation set out in Sections 1.1.1-1.1.3 reflects this double injury. The harm to people living with dementia is in part enabled by their devalued and dehumanised cultural status, which is then exacerbated by the failure of aged care, legal, justice and political systems and broader society to recognise and respond to the harm.

Two implications follow from understanding the harm to people living with dementia in residential aged care in the context of the notion of double injury and the concept of ‘moral relations’. The first is that the failure to redress the harm to people living with dementia in residential aged care – even beyond being a legal injustice and human rights violation – is a profound moral wrong that contributes to the persistent dehumanisation of people living with dementia. The second is that responding to experiences of harm through the Dementia Reparations Principles can have far-reaching social and political consequences for people living with dementia, extending beyond the immediate benefits of the response to the harm itself to recognition of their citizenship and humanness.

1.2 No existing solutions: Limited legal avenues for redress

There is a compelling basis for responding to harm to people living with dementia in residential aged care. However, there are limited avenues for redress in Australian legal systems.

The following sections outline the five main avenues available in the Australian legal system for delivery of redress.

1.2.1 Court ordered remedies

The Australian legal system provides options for individuals to seek redress through courts in the form of compensation and other remedies. For present purposes, these remedies are accessed by successfully arguing that the harm experienced in residential aged care fits within pre-existing categories of civil legal wrongs, such as negligence or assault. The meaning and scope of categories of civil legal wrongs have been developed by the courts across a wide range of populations and types of harm, not in the specific contexts of people living with dementia or residential aged care. Court remedies provide public and official recognition that people living with dementia have been wronged, for which those ordered to deliver remedies are to be held accountable. Beyond remedial orders, court decisions have the capacity to send a message to society about unacceptable standards of treatment of people living with dementia and to develop the common law that will apply to people living with dementia who might be harmed in the future.

There are significant limitations to redressing harm to people living with dementia through court remedies. Not be recognised as having legal capacity to commence litigation is one of the greatest barriers to people living with dementia accessing court remedies. Moreover, as we have noted elsewhere:

> Court action is premised on each victim-survivor or their family member having the financial and evidential burden of bringing their own litigation in order to obtain court-based remedies, even where the systemic nature of these harms might be widely established through media accounts, civil society reports, or government inquiries. Justice systems fail to adequately accommodate people's experiences of dementia, particularly by reason of rules about legal capacity and the complexity and expense of court proceedings. Court action requires a specific plaintiff and defendant, specific acts or omissions perpetrated, and a demonstrably direct causal relationship between the acts or omissions and the injury or loss experienced by the plaintiff. Yet harms in aged care occur over long timeframes, are perpetrated by multiple individuals, have complex causes, emanate from the environmental design of aged care facilities, and are supported by profit-driven models of care and state-driven regulatory, funding and legal frameworks. The quantum of any damages that are awarded through litigation will be limited because 'aged care residents will inevitably be already receiving some care and support as a result of existing conditions, will have retired from work and may not suffer further significant economic loss as a result of injury, and will have limited life expectancy'. Court remedies can rarely address the scope and complexity of harm in aged care, nor can remedies be obtained through courts for harms arising from the legal use of restrictive practices. Court-based remedies are also limited in their capacity to address wider familial, intergenerational and community impacts of systemic and structural harms of aged care. Limitations inherent within court-based responses can mean that rather than offering an effective remedy, these processes can create further layers of harm to people living with dementia, their families and communities.[71]

1.2.2 Settlements

People who have commenced litigation can reach an early resolution of their dispute (known as a 'settlement') prior to the court hearing and/or the final court judgment.

Settlement can tailor outcomes to the specific circumstances of the individual and the harm they have experienced. These outcomes are not restricted by legally defined court remedies. They can involve creative responses to the individual's needs and can also include requirements for structural and systemic change.[72]

However, generally settlements originate in commencement of litigation (although they might also arise in the context of Alternative Dispute Resolution or preliminary efforts to resolve a dispute prior to commencing litigation) and thus many of the issues raised above in relation to court remedies – such as cost and accessibility – also apply to the opportunity for settlement. There are additional limitations of settlements. Settlements are often confidential (such as through non-disclosure agreements) and this can restrict public knowledge and media discussion of the matter and outcome. Moreover, because a final court judgment is never delivered and the settlement outcome is devised outside of the court process, the settlement outcome does not contribute to the development of law that will shape future legal outcomes for other people living with dementia who are harmed in residential aged care.[73]

Furthermore, settlement is not always the first choice of both parties. One party can use an offer of settlement strategically to force a party into an outcome less favourable to the other party because of the risk of having to pay more legal costs (i.e., the other party's legal fees to their lawyers, expert witnesses etc.) if they refuse the offer. This is because courts' procedure rules provide that if a party rejects an offer of settlement and the court judgment is less favourable than the offer, the party who refused the offer might have to pay legal costs to the party who made the offer.[74] Repeat or well-resourced litigators (such as governments, corporations and large charities) will have more familiarity with the strategic use of settlement.

1.2.3 Victim support schemes

People can also seek recognition of wrong and financial and counselling support through state and territory victims support schemes administered by government departments (although the scope of each scheme varies between states and territories).[75] Generally, access to this support is available if the harm they have experienced is considered illegal violence under criminal law (e.g., physical assault, sexual assault).[76]

Victim support schemes can be more financially and procedurally accessible than court remedies or settlement through litigation. They can also have lower thresholds in relation to proof of harm.

However, victim support schemes have been criticised for being retraumatising and lacking transparency and accountability.[77] Additionally, such schemes will be of limited value in the specific context of people living with dementia harmed in residential aged care because they are restricted to illegal interpersonal violence and thus do not capture the broad range of harm in residential aged care, including legal use of restrictive practices, segregation designed into the built environment of residential aged care facilities, and neglect that falls short of physical or sexual assault.

1.2.4 Specialised redress schemes

A specialised redress scheme is an additional option that is sometimes available to individuals who have experienced specific categories of harm in particular contexts. Specialised redress schemes are available when specifically developed and legislated by government and often only operate temporarily in relation to a strictly defined scope of claimants, timeframe and harm. Specialised redress schemes are often designed in response to official recognition of the widespread nature of harm following government inquiries and community activism, such as the National Redress Scheme introduced following the Royal Commission into Institutional Responses to Child Sexual Abuse[78] or state and territory Stolen Generations reparations schemes introduced following activism by members of the Stolen Generations and their families and communities.[79]

Specialised redress schemes are delivered outside the court system and are not tied to legally defined wrongs and remedies, thus overcoming many of the substantive and procedural limitations of court remedies (and of victim support schemes, to the extent these are tied to criminal legal definitions of violence). Moreover, specialised redress schemes are designed in recognition of systemic injustices impacting a particular community or group of people, and thus do not require each individual to establish the wrongfulness of their particular experience where it fits within the scheme's recognised categories of harm. Specialised redress schemes typically deliver redress to individuals who are harmed (rather than to family members). They often involve a financial payment and counselling, and sometimes other supports such as access to legal assistance or funeral funding.[80]

In Australia, and internationally, specialised redress schemes (notably those for institutional child sexual abuse) have been criticised for the narrow categories of harm redressed, being slow to deliver redress, lacking transparency, not being trauma-informed and not being connected to systemic and structural change.[81] Regardless, as mentioned earlier, there is currently no such scheme in the context of people living with dementia who are harmed in residential aged care.

1.2.5 Specialised collective recognition measures

Governments can take measures (often in concert with or prior to a specialised redress scheme) that are directed towards an affected group (rather than specific individuals). These measures provide public recognition of past harm to the affected group, and sometimes commitment to non-repetition and systemic change. Specialised collective recognition measures include national apologies, memorials and public education. Examples include national government apologies in relation to Forgotten Australians, survivors of institutional child sexual abuse, and members of the Stolen Generations.[82]

Collective recognition measures have been criticised for sometimes lacking any material impacts, particularly if they are ‘empty’ and not followed by concrete action.[83] Regardless, there are currently no such measures in the context of harm to people living with dementia in residential aged care.

1.2.6 Conclusion

People who are impacted by harm to people living with dementia in residential aged care are currently not supported by any existing legal options. In particular, court remedies (and relatedly settlements) and victim support schemes are not suitable without considerable reform to broaden them and make them more accessible. Specialised redress schemes and collective recognition measures provide more flexibility in terms of responding to specific contexts of institutional harm (including harm which is legal) and to the particular needs and circumstances of those who have been impacted; however, existing schemes and measures do not extend to people living with dementia in residential aged care. Thus, people living with dementia who are harmed in residential aged care, and their care partners and family members who are also impacted by this harm, still await justice.

1.3 Reparations: A new way forward?

When people living with dementia are harmed in residential aged care, their human rights are violated and they must have equal access to justice. This project explores one framework through which equal access to justice might be achieved – reparations, a framework grounded in international human rights law.

International human rights law provides for the right to equal access to justice (as discussed in Section 1.1.3). Further to the right to equal access to justice in Article 13 of the CRPD, the International Principles and Guidelines on Access to Justice for Persons with Disabilities provide (non-binding) guidance to States Parties in relation to Article 13. In particular, Guideline 8 stipulates that States Parties should ensure that 'effective remedies are in place for human rights violations, including the right to be free from disability-based discrimination and the rights to restitution, compensation, rehabilitation, satisfaction and guarantees of non-repetition'. These remedies should be 'enforceable, individualized and tailored to meet the needs of claimants … [e]nsure that victims are protected from repeat violations of their human rights … [and a]ddress the systemic nature of human rights violations'.[84] This means that people living with dementia should have equal access to justice and remedy. There should be equality in the process of accessing a remedy and in the outcome delivered by the remedy itself.

International human rights law also provides for the right to remedy specifically in relation to human rights violations. The ICCPR requires that when individuals are subject to violations of their rights under the ICCPR, States Parties undertake to ensure that persons have an effective remedy, and that this remedy is determined by judicial, administrative or legislative authorities and is enforceable.[85] Violations of some specific rights also give rise to particular entitlements to redress. For example, individuals who are deprived of liberty are entitled to go to court to seek release from detention, and victims of unlawful detention 'shall have an enforceable right to compensation'.[86] Individuals who experience arbitrary or unlawful interference with privacy, family, home or correspondence have the 'right to the protection of the law against such interference or attacks'.[87] For those who are subjected to torture, a

State Party is required to ‘ensure in its legal system that the victim of an act of torture obtains redress and has an enforceable right to fair and adequate compensation, including the means for as full rehabilitation as possible’.[88]

In September 2022, the Committee on the Rights of Persons with Disabilities published guidelines on deinstitutionalisation which support Article 19 of the of the CRPD.[89] These guidelines provide (non-binding) guidance to States Parties to help governments realise the right to independent living and community inclusion. They also provide a basis for planning deinstitutionalisation processes and preventing future institutionalisation. The guidelines explain that institutionalisation of persons with disabilities ‘refers to any detention based on disability alone or in conjunction with other grounds such as “care” or “treatment”’.[90] Such institutions include those relevant to people living with dementia – psychiatric institutions, long-stay hospitals, nursing homes and secure dementia wards.[91] The guidelines identify a specific role for reparations in deinstitutionalisation, stating that governments should ensure that legal and policy frameworks

> enable the full inclusion of all persons with disabilities and guide deinstitutionalization processes towards the closure of institutions. Such frameworks should enable the development of inclusive community support systems and mainstream services, the creation of a reparations mechanism, and guarantee the availability, accessibility and effectiveness of remedies for survivors of institutionalization.[92]

In Part IX (remedies, reparations and redress) the guidelines state that governments ‘should provide individualized, accessible, effective, prompt and participatory pathways to access to justice for persons with disabilities who wish to seek redress, reparations and restorative justice, and other forms of accountability’.[93] The guidelines provide that reparations for institutionalisation should include formal apologies, financial compensation, include restitution, habilitation and rehabilitation, and establishment of truth commissions.

The 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 (‘van Boven Principles’) also provide (non-binding) guidance on redress and support for victims-survivors of violence that constitute gross violations of human rights. Gross human rights violations include ‘the types of violations that affect in qualitative and quantitative terms the core rights of human beings, notably the right to life and the right to physical and moral integrity of the human person’ and specifically extend to ‘torture or cruel, inhuman or degrading treatment or punishment … arbitrary and prolonged detention … and systematic discrimination’.[94] Elsewhere, we have argued:

> We propose that human rights violations occurring in aged care be considered ‘gross human rights violations’, particularly by reason of systematic discrimination on the basis of age and disability inherent to segregation, detention, forced treatment, and use of restrictive practices, as well as the widespread nature of these violations. 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 van Boven Principles are interpreted and applied in order to extend to specific experiences of people with disabilities (much in the same way that Méndez notes that the CRPD necessitates a shift in understandings of torture and ill-treatment to include restraint and seclusion). Indeed, the principles provide that their ‘application and interpretation … must be consistent with international human rights law … and be without any discrimination of any kind or on any ground, without exception’, thus supporting an interpretation of ‘gross human rights violations’ that is attentive to human rights violations under the CRPD.[95]

In general, pursuant to the van Boven Principles, the ‘obligation to respect, ensure respect for and implement international human rights law’ includes the duty to:

a) take appropriate legislative and administrative and other appropriate measures to prevent violations;
b) investigate violations effectively, promptly, thoroughly and impartially and, where appropriate, take action against those allegedly responsible in accordance with domestic and international law;
c) provide those who claim to be victims of a human rights or humanitarian law violation with equal and effective access to justice, as described

below, irrespective of who may ultimately be the bearer of responsibility for the violation; and

d) provide effective remedies to victims, including reparation, as described below.[96]

Specifically, the van Boven Principles provide that remedies for gross human rights violations include the victim's right to:

- 'equal and effective access to justice';
- 'adequate, effective and prompt reparation for harm suffered'; and
- 'access to relevant information concerning violations and reparation mechanisms'.[97]

Reparation 'should be proportional to the gravity of the violations and the harm suffered'.[98]

The van Boven Principles identify the following forms of reparations.

- **Restitution:** This 'should, whenever possible, restore the victim to the original situation before the gross violations of international human rights law or serious violations of international humanitarian law occurred'. Examples of restitution are 'restoration of liberty, enjoyment of human rights, identity, family life and citizenship, return to one's place of residence, restoration of employment and return of property'.[99]
- **Compensation:** This should be 'provided for any economically assessable damage, as appropriate and proportional to the gravity of the violation and the circumstances of each case'. The damage can include: 'physical or mental harm'; 'lost opportunities', including employment, education and social benefits; 'material damages and loss of earnings, including loss of earning potential'; and 'moral damage'.[100]
- **Rehabilitation:** This includes 'medical and psychological care as well as legal and social services'.[101]
- **Satisfaction:** This should include, where applicable, such forms as: 'effective measures aimed at the cessation of continuing violations'; 'verification of the facts and full and public disclosure of the truth'; 'an official declaration or a judicial decision restoring the dignity, the reputation and the rights of the

victim and of persons closely connected with the victim'; 'public apology, including acknowledgement of the facts and acceptance of responsibility'; 'judicial and administrative sanctions against persons liable for the violations'; 'commemorations and tributes to the victims'; and 'inclusion of an accurate account of the violations that occurred in international human rights law and international humanitarian law training and in educational material at all levels'.[102]

- **Guarantees of non-repetition:** These measures, which 'will also contribute to prevention', can include reviewing and reforming laws contributing to or allowing gross violations of international human rights law and serious violations of international humanitarian law'.[103]

Reparations provide an area worthy of further exploration, as we have explained elsewhere:

> Exploring in the context of aged care an approach to redress that includes reparations is proposed on the basis that reparations offer more expansive and multifaceted possibilities than what is attainable through courts, particularly in relation to what wrongs can be redressed, who can participate in redress, and how to enact redress. However, it is important to make two qualifications. First, we see reparations as operating in tandem with court-based remedies. Reparations should not be a substitute for access to justice through the courts. In particular, as a matter of equal access to justice, deficiencies in the court system (such as those identified in relation to Australia) must also be addressed in order to ensure that people harmed in aged care can pursue court remedies if they so choose. Second, reparations are additional to any human rights obligation on governments to take immediate action in response to harms in aged care, such as to facilitate an individual being freed from detention or facilitate the cessation of restraint or forced treatment.[104]

To date, reparations have not been implemented in relation to people living with dementia who are harmed in residential aged care, in Australia or elsewhere. In 2022 we published the first article on the specific topic of reparations for harm to people living with dementia in residential aged care.[105] However, there is emerging international human rights commentary and academic scholarship on reparations in the broader context of people with disability. As well as the international human rights commentary on reparations and institutionalisation discussed above, disability rights advocates have been calling for reparations for people with disability in relation to institutionalisation, sterilisation and forced psychiatric treatment.[106] There are some examples of reparations being used in overseas countries in response to sterilisation of people with disability under eugenics legislation.[107] Claims have been made by people living with psychosocial disabilities who have used mental health services, as well as their families, carers and supporters in some instances.[108] Moreover, some of the specialised redress schemes for institutional child sexual abuse that have been introduced in Australia and other nations extend to people with disability who were in institutions and schools specifically for children with disability. These developments provide a compelling basis for extending reparations to people living with dementia.

Therefore, this project provides an evidence-base for reparations for harm to people living with dementia harmed in residential aged care.

1.4 Structure of the report

The purpose of this report is to discuss key findings from the project and introduce and explain the ‘Dementia Reparations Principles’.

The Dementia Reparations Principles consist of a preamble – setting out the overarching values that shape the Dementia Reparations Principles’ approach to reparations – and 25 principles that guide the rationale, forms and processes of reparations. The Dementia Reparations Principles apply to people living with dementia and to 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 provides an overview of the primary output of the project, the Dementia Reparations Principles. It 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 state and territory 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.

2. Project aims and methods

This section provides an overview of the project's aim and methods.

2.1 Note on terminology: From 'redress' to 'reparations'

Our project was initially framed in terms of 'redress'. As explained (Section 2.2), our aims use the term 'redress'. We used the terminology of 'redress' throughout our Stage 1 Focus Groups, the Stage 3 Stakeholder Roundtables and the draft principles workshopped at the Stage 3 Stakeholder Roundtables. Thus, many of the quotes from research participants in Sections 3 and 4 use the term 'redress'.

However, in the final stage of our project we shifted to use of the term 'reparations'. This shift was in response to the popular association of 'redress' with the National Redress Scheme, which only operates at the individual scale and often involves monetary payments. It was always our intention to explore responses at the individual and structural level, and to embrace a wide range of modes of response not limited to monetary payments. The term 'reparations', as introduced in Section 1.3, captures this broader scope. Moreover, use of the term 'reparations' – which is associated with international human rights – aligns with our understanding of the harms in residential aged care as human rights violations.

2.2 Aim and research questions

The original aim of the project was to develop an evidence-base on the necessity, scope, forms and processes of *redress* for harm to people living with dementia in residential aged care in order to support realisation of the human rights of people living with dementia, 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 among policy-makers, lawyers, advocates and human rights practitioners about the need for action on redress for people living with dementia; and to initiate an international field of scholarship and advocacy on redress for people living with dementia who have been harmed. Our long-term goal was that redress would be available for past harm and form part of the solution to prevent future harm.

Key research questions that have guided the project are:

1. Is redress necessary and why?
2. What types of harm should redress apply to, and who should be able to access redress?
3. What forms should redress take?
4. What should be the process of delivering redress?
5. How can redress be inclusive and accessible to people living with dementia?

The intended outcome of the project was a set of principles to guide future discussion, exploration and action on redressing harm to people living with dementia in Australian residential aged care as a foundation for healing, repair and systemic and structural change.

2.3 Human rights framework

The project has its methodological foundations in respect for the human rights of people living with dementia and inclusion of people living with dementia in research and policy development processes. We utilised aspects of the disability human rights methodology.[109] This methodology involves the researcher 'play[ing] a role in rights realisation and emancipation as opposed to marginalisation'.[110]

One aspect of this methodology is 'prioritis[ing] the participation of disabled people as leaders and partners in research'.[111] In our project, people living with dementia have been involved as project investigators, organisational partners, project advisory group members and research participants.

Another aspect of the disability human rights methodology is using research as 'a tool for advocacy and social change'.[112] The project is directed towards contributing to advocacy and policy development on the human rights of people living with dementia in residential aged care. The project report will be submitted to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability to inform its deliberations concerning access to justice and delivery of redress to people with disability who have experienced violence, abuse, neglect and exploitation. The project report will also be provided to governments, residential aged care representative bodies and legal and health professional associations to encourage engagement with the issue of reparations in the context of policy development and service delivery. The project, and an Easy Read summary, will be disseminated to people living with dementia, older persons' and disability rights organisations to support advocacy for reparations and broader calls for justice and change for people living with dementia.

2.4 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 and Lyn Rogers (Dementia Alliance International), Barbara Spriggs, 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 organisational partners and advisory group members provided input at all stages of the project, including recruitment of research participants, format of focus groups and stakeholder roundtables, analysis of design and lived experience of Australian redress schemes, wording and presentation of the Dementia Reparations Principles, and knowledge translation.

2.5 Methods

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 or for them. Thus, the primary research method was qualitative research with people living with dementia, care partners and family members, volunteer advocates, and lawyers and advocates. While priority was given to participation in data collection of people living with dementia, 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 has been undertaken in four stages.

Stage 1: Gathering an evidence-base for the Dementia Redress Principles

The project investigators began by gathering an evidence-base for the necessity, scope, forms and process of redress in three ways.

(1) Focus groups: We explored perspectives on redress held by people living with dementia and those who are close to or advocate for them. The purpose of the focus groups was to ensure that the 'Dementia Redress Principles' (as they were initially called) were driven by the experiences and perspectives of people living with dementia. The focus groups were promoted through a project website, social media (Twitter, LinkedIn and Facebook) and by relevant legal, advocacy and support organisations. Noting the importance of participation of people living with dementia in the focus groups, the focus groups were promoted through Dementia Alliance, People with Disability Australia, and Dementia Australia, and through the StepUp for Dementia platform[113] Following extensive recruitment efforts, the final sample of research participants in focus groups comprised 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 the low numbers of people living with dementia. One of difficulties in 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. It is recognised that people living with dementia are underrepresented in the focus groups, and thus it is vital that there is further exploration with people living with dementia of reparations. Focus groups were conducted November 2021 – February 2022. These focus groups explored research participants' views on the need for redress in response to harm to people living with dementia in residential aged care, and the forms of and processes for redress. A trained counsellor was present at all stakeholder roundtables in which people living with dementia and care partners and family members participated. Due to the sensitivity of the discussions and the importance of maximising psychological safety and ensuring everyone had an opportunity to speak, research participants were organised into separate focus group sessions. Data from the focus groups was then thematically analysed.

(2) International human rights analysis: We analysed international human rights law on access to justice and on reparations. The purpose of this was to ensure that the Dementia Reparations Principles had a normative basis in international human rights and were themselves a vehicle for advancing the human rights of people living with dementia. Key sources included the CRPD and the van Boven Principles. A journal article containing our human rights analysis has been published in the open access academic journal *Health and Human Rights*.[114]

(3) Survey of Australian redress schemes: We analysed the design and lived experiences of Australian redress schemes relating to other institutional contexts, particularly the National Redress Scheme for survivors of institutional child sexual abuse and state and territory reparations schemes for members of the Stolen Generations. The purpose of this survey was to ensure that the development of Dementia Reparations Principles was informed by the successes and limitations of existing redress schemes and did not ‘reinvent the wheel’ nor repeat the mistakes of past schemes. We primarily drew on official reports on the design and evaluation of Australian redress schemes. While these reports include quotes from individuals who have participated in these schemes and quotes from advocates and lawyers involved in the schemes, we recognise that these reports cannot capture the full range of perspectives and experiences of these schemes.

Analysis at Stage One was guided by the project advisory group, including recruitment of research participants, format of the focus groups and choice of Australian redress schemes.

Stage Two: Drafting the Dementia Redress Principles

Stage Two involved development of the draft Principles. Drafting was guided by the findings from the analysis at Stage One.

Stage Three: Workshopping the Draft Dementia Redress Principles

Stage Three involved workshopping the draft Principles at two forums.

(1) Stakeholder roundtables: 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. The purpose of these roundtables was to ensure the text and intent of Dementia Reparations Principles comprehensively captured the needs and perspectives of people living with dementia. The focus groups were promoted through a project website, social media (Twitter, LinkedIn and Facebook) and through relevant legal, advocacy and support organisations. As well as recruiting new research participants into the project, research participants in the Stage One focus groups were invited to participate in the stakeholder roundtables. The stakeholder roundtables were promoted through Dementia Alliance, People with Disability Australia, and Dementia Australia, and through the StepUp for Dementia platform.[115] Following extensive recruitment efforts, our final sample of research participants in the stakeholder roundtables comprised 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. Eighteen of the 41 research participants stakeholder roundtables also participated in the earlier focus groups. 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 perceived as removed from personal experience. On the advice of the project advisory group, research participants had the option of participating in a mixed session or a session only with individuals from their specific group. A trained counsellor was present at all stakeholder roundtables in which people living with dementia and care partners and family members participated. Stakeholder roundtables were conducted July 2022 – August 2022. Discussion focused on the wording and content of the draft Dementia Reparations Principles. Data from the stakeholder roundtables were then thematically analysed.

(2) Project advisory group meetings: Two meetings of the project advisory group – one before and one after the stakeholder roundtables – concentrated on the draft

Principles. At each of these meetings project advisory group members provided feedback on the Dementia Reparations Principles.

(3) International human rights expert feedback: Following the stakeholder roundtables and the project advisory group meetings, feedback on the draft principles was also received from international human rights experts: Professor Gerard Quinn, Bethany Brown and Bill Mitchell.

Stage Four: Finalising the Dementia Reparations Principles

Stage Four involved the production of a final set of ‘Dementia Reparations Principles’ through revision of the draft ‘Dementia Redress Principles’, informed by the findings and feedback from Stage Three.

2.6 Ethics approval

Approval for the project, including the use of focus groups, was granted by the University of Technology Sydney (UTS) Human Research Ethics Committee (ETH21-6114).

2.7 Limitations of the project

This research project was a small-scale project conducted over 18 months with modest funding. Moreover, as the first project globally on this topic (to the best of our knowledge) and with no previous empirical, legal or conceptual literature on the specific topic, its priority was to take an exploratory approach to define and map out the key issues as a foundation for further research. With this in mind, there are four limitations of the project.

First, the focus group and stakeholder roundtable sample sizes were small. Further empirical research is required in order to continue to enrich the evidence-base on reparations for harm to people living with dementia in residential aged care, notably of specific forms of reparations and the processes through which reparations are delivered. It is vital to continue to prioritise participation of people living with dementia in any future 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 its operation in the Australian legal and service context.

Third, there was insufficient scope in the project to fully explore intersectional issues, such as the experiences of harm among and reparations needs of specific communities of people living with dementia (e.g., women, First Nations people, CALD communities, LGBTIQA+ people, and people with earlier experiences of institutionalisation and incarceration). Future empirical research must engage with specific communities in recognition of the fact that their procedural and substantive needs for reparations will vary.

Fourth, as the first project on the specific topic of reparations and people living with dementia, it was necessarily focused on establishing an empirical evidence-base with the impacted community; it was beyond the scope of the project to develop a theoretical framework on reparations and dementia and to critically reflect on potential complexities, limitations and pitfalls of reparations as a response to harm. We acknowledge that the findings discussed here have strong resonance with longstanding scholarship and practice in transitional justice (although that scholarship and practice has not, to date, engaged with dementia). It is anticipated that we will progress the theoretical and critical dimensions of our work in academic publications associated with the project and through convening an international network of scholars. We invite other scholars and practitioners to similarly engage with this report as a foundational document for a new interdisciplinary field.

Moreover, we recognise that people living with dementia in other institutional settings – such as prisons, public hospitals and boarding houses – are also subjected to harm and that people living with dementia at home may also be harmed. Ideally, the insights from this project and the Dementia Reparations Principles will provide a useful resource in addressing harm in these other contexts.

It is also acknowledged at the outset that reparations cannot do everything; rather, they form one part in a wider set of measures of transformative action directed towards achieving justice and human rights for people living with dementia and building new relations and spaces of support and belonging grounded in equality and dignity.[116] Yet reparations are an important and, until now, an overlooked piece in the puzzle of how to respond to and prevent harm to people living with dementia in residential aged care. As such, to dismiss their relevance and instead focus wholly on forward-looking reform invalidates past harm to people living with dementia and ignores the importance of learning from the past in shaping the future. Thus, the report offers the Dementia Reparations Principles as one part of a wider suite of measures aimed at transformative change of the aged care system and the realisation of human rights of people living with dementia.

2.8 Focus and broader relevance

This report is focused on reparations for people living with dementia in Australia. However, the report has broader relevance.

Although our project was specifically focused on people living with dementia, as a particularly marginalised group within aged care, the report and the Dementia Reparations Principles are relevant to responding to harm to all residents in residential aged care (including the many people living in residential aged care who are presumed to have dementia but do not have a formal diagnosis). This is particularly so given the absence of any research on reparations in residential aged care. Indeed, as a matter of equal access to justice, it is assumed that were reparations to be introduced in residential aged care they would need to be available to anyone, irrespective of disability.

Although our project focuses on reparations in the context of residential aged care, the report and the Dementia Reparations Principles have possible utility more broadly within all forms of institutional care for people living with dementia, as well as people with disability and older persons more generally. They might also apply more broadly to non-institutional settings such as home care where providers perpetrate in the private home similar harms to those that occur in residential aged care.

Although our project focuses on reparations as a response to the specific legal, political and service contexts in Australia, the report and the Dementia Reparations Principles are relevant at the international level and to the many other nations in which people living with dementia also experience unredressed harm.[117] The report provides a normative human rights basis and empirical evidence-base for developing reparative approaches in response to the calls for a fundamental reimagining of the future of aged care involving deinstitutionalisation[118] and the growing recognition in

United Nations and regional international human rights systems of the need for equal access to justice and remedies for people with disability and older people.[119]

While our project is focused on reparations for harm to people living with dementia in the specific context of residential aged care, some of the findings and 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.

3. Findings

The project found unanimous support among research participants for reparations, with the views expressed indicating that:

- Reparations must be multi-faceted and consist of a range of complementary measures that can be flexibly tailored to meet individual needs. Different individuals will have different personal and cultural preferences in relation to reparations, reflecting the idea of 'kaleidoscopic justice'.[120]
- Reparations must respond to the impacts of harm as experienced by specific individuals while also responding to the impacts of harm on people living with dementia as a collective.
- Reparations must facilitate individual support and healing while also ensuring those who have perpetrated this harm are held to account and will be prevented from continuing to cause harm.
- Reparations must turn to deal with what has happened in the past while also proofing future laws, systems and practices against the repetition of such harm.

Ultimately, no one form of reparation can satisfy all of these criteria and operate at different scales (individual and collective) and temporalities (past, present and future). Therefore, the Dementia Reparations Principles are designed to respond to the complexity and diversity inherent to this phenomenon.

This section provides an overview of the project's findings, introducing key concepts that must frame reparations and identifying a series of unique challenges to reparations in the dementia and residential aged care contexts. A deeper exploration of each of these concepts and challenges, including by reference to the focus group and stakeholder roundtable data is woven through the discussion in Section 4.

Sections 3 and 4 include quotes from participants in the focus groups and stakeholder roundtables. In order to preserve confidentiality and anonymity, research participants were allocated pseudonyms related to their participant category and these were numbered according to the order that individuals were scheduled to sessions (e.g., VA02 was allocated to a research participant who is a volunteer advocate and was the 2nd individual of that category scheduled to a research session; PLWD06 was allocated to a research participant who is a person living with dementia and was the 6th individual of that category scheduled to a research session). The full list of research participant acronyms is included at the start of this report.

3.1 Key concepts framing reparations

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

3.1.1 Recognition

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 often not believed. For example, CPFM02 explained that harm to a person living with dementia can be dismissed as part of that individual's dementia:

> One of the things that I've struck is, it's too easy for them to pass it off and saying as part of their delusion or hallucination or imagination, that it's not real and so it's not taken seriously because we don't know, they're not a reliable witness if you are trying to ask for evidence in a legal system.

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. The failure to validate family members and care partners' 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. The importance of recognition was powerfully captured by VA08, who described the phenomenon of 'silencing':

> [T]he fact that this is a system that tries to silence people, to prevent them from having to, in fact, confront of these problems. I mean, that’s just not good enough. Why should people be silenced? I mean, it’s the fact that they’re being silenced that allows the system not to change.

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 to address these impacts. Indeed, VA11 described the sum of these failures as ‘a justice failure, but not in a legal sense, like a community social justice failure’.

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 individual circumstances and identities.

3.1.2 Accountability

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 act on the wrongfulness – and, at times, illegality – of perpetrators’ conduct, even when harm has been officially acknowledged. For example, AL02 described her fear that the harm will ‘carry on’ despite the Aged Care Royal Commission:

> 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.

A second reason is that perpetrators and other individuals and organisations have benefited – financially or otherwise – from the harm. For example, AL01 explained that low-cost care causes harm but enhances profit:

> [P]eople look at people in ways of 'How can I benefit off you?' And the way that they look at a worker is, 'You can work for me so I will take care of you in a limited sense.' But for people living with dementia or people in aged care, the way you benefit off them is giving them really shitty care for as high cost as possible, and profiting off their mistreatment.

Finally, the current absence of accountability legitimates the ongoing perpetration of harm. For example, CPFM04 observed the issue of repetition of the past in the specific context of staff members who remain working in the facility:

> [T]hat person is still in charge of that facility and the same thing is happening with the current residents. So it's ongoing certainly. I hear from people who have their person in the facility that they're not happy because of the same people who are in charge of the facility and because the staff just have to do as they're told.

Accountability must be reflected in forms of reparations that reckon with and sanction wrongdoing, require the shedding of financial benefit that has been gained through the harm, and require action that will stop ongoing perpetration of harm.

3.1.3 Change

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 response must always be connected to preventing future harm at the individual and structural levels, for several reasons.

The first reason is that reparations can be experienced as empty words and people being paid off if they are not followed up with meaningful action. AL02 noted that if reparations did not involve such overhaul, reparations would not be effective:

> [M]y fear is that this will be nothing more than just lip service and a white elephant monument. And they'll just tick the box and say, 'Yep, we've done it. You've asked for it, we've done it.' Whereas it has to be a national conversation with a real willingness and a commitment to say that what has

> gone on absolutely cannot happen again. This is something that, without overhauling the system, we will not get.

Secondly, 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.

A third reason is that while the past cannot be changed, the lessons of the past can be used to change the future. AL02 explained that truth and acknowledgement are an important foundation for moving forwards:

> I think, quite simply, redress 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.

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 moral repair within broader society, 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 be reflected in the leadership of people living with dementia in reparations and in reparations processes that include monitoring and enforcement of action to stop ongoing perpetration of harm.

3.1.4 Now

Reparations are urgently needed and should not be delayed. Again, there are several reasons for this.

One reason is that 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 for further exploration of the existence of harm to be unnecessary.

Second, there is no need to spend years deliberating on the issue given that there is an existing normative framework and wealth of examples and experiences from which to draw. Reparations are already recognised in international human rights law and have been introduced in relation to widespread institutional harm in other Australian contexts.

A third reason is that 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. Care partners and family members – some of whom are also older persons – live for years and decades with the ongoing impacts of this harm. For example, VA11 noted the risk that individuals harmed might die while waiting for reparations:

> [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.

3.2 Unique challenges to realising reparations

The project also found there are unique challenges to realising reparations for harm to people living with dementia in residential aged care.

Multiple inquiries and reports, and the Aged Care Royal Commission, demonstrate that people living with dementia in residential aged care have for decades been subjected to human rights violations. The extent of these violations (and the concept that this harm constitutes a human rights violation) is challenging for most people to accept, and difficult for us as a society to reckon with in the absence of any official or community-led framework through which to do so. Although it may seem simple to right these wrongs – as all people irrespective of disability or age should be included in human rights and have access to justice – there are multiple unique challenges not only in recognising these wrongs, but also in addressing and preventing them. These challenges include stigma, social death, paternalism and therapeutic nihilism, perpetration by and implication of family members in harm, a precarious and exploited workforce, the profit context of residential aged care, and the endurance of institutionalisation and ongoing nature of harm.

The Dementia Reparations Principles have been developed in anticipation of these unique challenges. These unique challenges must be explicitly considered in any future research and action on reparations in the context of people living with dementia in residential aged care. This is particularly important because these challenges are not addressed in existing research and practice. For example, these unique challenges are not apparent at all, or to the same extent, in existing Australian redress schemes operating in other contexts (although those other contexts do, of course, have their own unique challenges). Nor are these unique challenges identified and addressed in the international human rights scholarship and practice on reparations.

3.2.1 Stigma, social death, paternalism and therapeutic nihilism

Although dementia is a major cause of disability globally, people living with dementia are relegated to being managed as people with a fatal, chronic health condition instead of being provided with disability assessment and support. Once a person is diagnosed with dementia, they experience shame, stigma, discrimination and increasing isolation. People living with dementia experience significant and negative impacts on their social and economic status,[121] losing their individual and professional (past or current) identity and their individual power and agency. They are denied access to universal health coverage and disability support, such as rehabilitation to maintain independence for longer, retain their quality of life and continue to live in the community.

People living with dementia experience stigma. Goffman refers to stigma as ‘spoiled identity’.[122] Link and Phelan discuss it in terms of persons being negatively labelled, a loss of status and power, discrimination and stereotyping.[123] Stigma affects multiple areas for people living with dementia and their care partners and families, including a person’s willingness to seek diagnosis, to seek support once diagnosed and to participate in research.[124] The care and support provided to be people living with dementia is also of a lower standard due to stigma within the health care profession, and services are distorted.[125] Scheff proposes that stigma increases feelings of shame,[126] and in 2021 Alzheimer’s Disease International reported people living with dementia still felt a deep sense of shame.[127] In its 2019 World Alzheimer’s Report, the Alzheimer’s Disease International found that negative attitudes towards people living with dementia are prominent.[128] The 2021[129] and 2022[130] World Alzheimer's Reports confirmed negative attitudes have contributed to poor diagnosis rates and very poor post-diagnostic care and support.

'Social death' is when a person is not accepted as fully human, is treated as a 'nonperson' and is discounted in social terms.[131] Sweeting and Gilhooly view dementia as an instructive example of social death,[132] and argue that those with dementia have already undergone a loss of personhood because of their diagnosis. Others have found that due to being distanced from their past lives and past relationships, people living in nursing homes may also experience social death.[133] Social death is evident in relation to people living with dementia in residential aged care through isolation and depersonalisation arising from circumstances such as: access only to meaningless group activities (rather than individualised or person-centred activities); lack of opportunities to exercise personal agency; lack of access to the community; and denial of access to health care and personal care services available to people without dementia.

Furthermore, since the majority of people living with dementia have late onset dementia, and are therefore older and often more advanced in the disease, they also experience ageism and age-based discrimination. People without dementia presume people living with dementia to be nearing death, or existing as 'empty shells', which makes it easier for others to perceive people living with dementia as socially dead and to ignore the institutional harm, and other rights violations, to which they are exposed.

The loss of a sense of uniqueness and personhood is tied to one's perceived social value: the biological death of a socially dead person is not considered a loss to society. Incarceration and further segregation in residential aged care fundamentally enacts these processes by separating people from society and inflicting what Goffman refers to in the context of institutions as 'a series of abasements, degradations, humiliations, and profanations of self'.[134] Incarceration causes social death, and solitary confinement, which deprives incarcerated persons of normal, direct, meaningful social interactions and environmental stimulation, represents an extreme enactment of social death.[135] Secure dementia units also deprive people living with dementia in the same way.[136] Yet society does not at present see residential aged care facilities as places of incarceration despite their use of confinement and detention. Social death was observed by some research participants in terms of the assumption of the irrelevance of human rights to people living with dementia. For example, VA03 explained that dementia means that people's rights go 'out the window':

> [T]here's lots of things, there's lots of laws that say that we can't harm or neglect for other groups of society, yet it's as though, I don't know. I seem to get where people just say, 'Oh, that person has dementia.' Therefore, it's as though all their rights have just gone out the window and it's just seen as a societal norm.

CPFM14 observed that there is a tendency to assume people living with dementia do not need human rights because of cognitive incapacity:

> [S]ome of society still perceive that the loss of cognitive abilities is an excuse for not respecting someone's human rights. Something that I personally still hear sometimes is that, 'Oh, she won't know or understand what's going on anyway.'

Paternalism and therapeutic nihilism in the context of institutionalisation are also significant challenges to recognising harm to people living with dementia in residential aged care. Paternalism is when one's life is controlled by others in what is perceived to be in their best interests. In denying control over their bodies and lives to people living with dementia, paternalism strips them of key aspects of personhood. Therapeutic nihilism is the belief that nothing can be done for people living with dementia – that, like other degenerative diseases with no cure, such as amyotrophic lateral sclerosis (ALS), it is 'hopeless'.[137] The denial of one's very personhood and humanity, as CPFM01 explained, is a striking example of therapeutic nihilism:

> Being told when my dad went into the final place that he was— that dementia was a terminal condition and not having his quality of life really discussed is just an example of how … people aren't seen as having a life to live in that period, from the time that they go into residential age care, people with dementia or people with quite bad dementia, anyway.

CPFM16 described the challenge of therapeutic nihilism in terms of self-evident associations drawn between dementia and being ‘out of control’:

> I think one of the issues as well is that our society doesn’t really know how to deal with ‘out of control’. And that the institution is reflecting the society. And that is that people are in institutions quite often because it’s beyond the carers at home. It’s beyond the community at home to be looking after very difficult to manage behaviour. And the assumption is that if you put the person in care, they will have the knowledge, the skills, the expertise, the finesse, to be able to deal with in an appropriate way. And that’s actually where our assumptions go wrong because there aren’t the resources. There aren’t— There isn’t the training, there isn’t the understanding. And also the institution is part of a society that has very retrograded means of dealing with people that are out of control, and who look different, and who act different. So part of the challenge is our whole society’s value system.

Paternalism and therapeutic nihilism play a large role in the context of neglect in care and support and coerced or forced institutionalisation. Once diagnosed, people living with dementia become objects to be cared for, losing agency and many of their human rights.

Stigma, social death, paternalism and therapeutic nihilism present unique challenges to reparations for people living with dementia in residential aged care, for two reasons. The first is the perceived inevitability and assumed benevolence of institutionalisation and its violation of the rights of people living with dementia, making it inconceivable that residential aged care is harmful, wrong and unjust. The second is the presumed futility and irrelevance of providing material support in response to harm to people living with dementia based on the view that such people are near death and their lives are thus not worth saving or enriching, and that supporting independence and the person’s individuality is futile.

3.2.2 Perpetration by and implication of family members

The increased disability support and health needs related to living with dementia, coupled with a lack of resources and funding for community-based accommodation, support and care can result in people living with dementia relying on informal support and care from family members. This can mean some family members or care partners come to have a greater role in the daily living and financial affairs of the person living with dementia, surfacing longstanding tensions, disagreements and even violence between family members. These dynamics can be heightened if some family members are concerned about physical and sexual violence against, and neglect or financial exploitation of, the individual living with dementia. At other times, people living with dementia might be financially exploited by family members or friends, resulting in assumption of a 'carer' role to enable access to and control of their housing and other assets or welfare payments.

For example, CPFM08 explained the family conflict related to her grandma:

> I think there's a bit of an overlap as well in family abuse and elder abuse prior to my grandma going into a nursing home and that was by my auntie and uncle. It was them versus my mum, my parents as the main carers, and that continues to this day in the aged care. Whenever we've identified some type of neglectful behaviour, it's always them who saying no everything's fine and lies. Sitting in a room with them to talk with management about issues is pointless.

This conflict, violence and exploitation can often involve use by some family members of enduring guardianship orders and enduring powers of attorney and guardianship and financial management laws as tools for gaining greater control over the individual. These tools can be used for reasons of protection and safety or as weapons of violence and exploitation in themselves. This then means the legal guardian or financial manager of an individual might not be the main care partner of the person living with dementia, with differing views on what is best for the person or even lack understanding of their legal and human rights obligations. Where these dynamics arise in community settings, people living with dementia can then be non-consensually moved into residential aged care and subjected to restrictive practices and other non-consensual interventions. Ultimately, in the midst of these dynamics, the autonomy and voice of the person living with dementia is marginalised, manipulated or completely lost.

These dynamics raise the challenge of how to deliver reparations to people living with dementia where family members are perpetrators of or complicit in harm. If these dynamics are not explicitly recognised in the delivery of reparations, family members who are perpetrators of or complicit in harm may benefit from reparations, as explained by CPFM08:

> And I think if there was opportunity in my case with my family, if there was opportunity for some kind of monetary compensation, I know the two that have always thought about money would just love to just grab onto that. And, and all of a sudden you'd see that, you know, 'Oh yes, Mum did go through abuse', and then they'd want to put in their claim because the story in our family is all about money. Putting her in a home, getting her inheritance, getting the cash she had in her house and spending that lavishly. So it's never really been about her welfare. It's been about money. So I'd be concerned with people that have, I guess, guardianship powers and not good intentions with caring for their family members.

Even in the absence of family conflict or family violence and exploitation, family members can unintentionally or indirectly contribute to harm. As we have explained elsewhere:

> Structural conditions – notably community stigma around ageing, disability, and dementia; lack of public funding for and access to community-based health and social care to support the changing physical, psychological, communication, and behavioral needs of people with dementia; lack of availability of alternative community-based housing when people with dementia can no longer continue living with their family; and a lack of support for unpaid care partners – constrain the ability and willingness of families to support people with dementia to continue living in the community … Care partners and family members might have consented to the use of restrictive practices or confinement in a separate dementia unit, only in the absence of alternative options and/or coercion by aged care operators.[138]

AL04 explained similar dynamics of harm in the context of the mental health system:

> And there can be harm going in lots of different directions. There might be harm from someone with lived experience to the family member, but there's also a lot of, I guess, unrecognised violence that occurs and trauma that gives rise to people's mental health issues from their care family too. And also just understanding the situations that families are in, where they don't know what

> to do and whatnot. They often become very complicit in these very violent systems for a lack of knowing of alternatives and just a general paternalistic kind of best interest culture that we've applied to mental health.

This kind of involvement in harm might be understood as family members and care partners becoming 'implicated' in harm to people living with dementia in residential aged care. Michael Rothberg offers the concept of the 'implicated subject':

> Implicated subjects occupy positions aligned with power and privilege without being themselves direct agents of harm; they contribute to, inhabit, inherit, or benefit from regimes of domination but do not originate or control such regimes. An implicated subject is neither a victim nor a perpetrator, but rather a participant in histories and social formations that generate the positions of victim and perpetrator, and yet in which most do not occupy such clear-cut roles.[139]

When family members and care partners witness harm to people living with dementia, and are also implicated in this harm, they might experience 'moral injury'. Jonathan Shay describes moral injury as the betrayal of what is right.[140] Moral injury 'can occur in response to acting or witnessing behaviors that go against an individual's values and moral beliefs'.[141] It is caused by 'failing to prevent, or bearing witness to acts that transgress deeply held moral beliefs and expectations may be deleterious in the long-term, emotionally, psychologically, behaviorally, spiritually, and socially'.[142] We propose that moral injury can be experienced by people living with dementia and their care partners and family members. Elsewhere we have alluded to the possibility of moral injury experienced by care partners and family members of harm to people living with dementia:

> Trust and hope that families often hold toward aged care operators to provide safe and supported environments are undermined by harms that people then suffer in aged care. These experiences are then compounded by ineffective internal and external complaint systems and ongoing experiences of guilt and trauma for supporting the admission of their family member into aged care.[143]

Thus, care partners and family members can become implicated in harm to people living with dementia in residential aged care, which can render the impacts of this harm on them complex and difficult to uncover, articulate and repair.

As we suggest in Section 4.2.9, truth-telling can be particularly useful in unpacking and understanding implication and moral injury, and in educating other people living with dementia and families about these risks. This is articulated by AL16:

> The redress scheme itself by building awareness, kind of creates the conditions for people in the future to understand the human rights of people going into, who have dementia. So, other family members. So, in situations where family members, through lack of understanding, are kind of captured by the system and become complicit without, and in the process, traumatised by that, when they become more experienced and start to understand how they may have contributed through the decisions that they've allowed themselves to take. For people in the future who are just entering that stage, this whole redress system seems to offer some kind of forewarning or have an educative purpose.

Thus, care partners' and family members' perpetration of or implication in harm to people living with dementia signals the need for a nuanced and sensitive approach to their involvement in reparations, not least because reparations might complicate the boundaries between victim and perpetrator and between healing and accountability.

3.2.3 Precarious and exploited workforce

Residential aged care workforces can experience precarity and exploitation. Many residential aged care workers are themselves from marginalised communities, such as migrants (with English as a new language), women, older people or those with low educational attainment.[144] Residential aged care workers are paid low wages and this impacts their own socioeconomic status, superannuation, sick leave, holiday leave and lifestyle.[145] They also frequently work in an environment of under-staffing and under-resourcing and have little control over their work conditions and the circumstances in their workplace.[146] Residential aged care workers work largely according to established routines and under the orders of health professionals and residential aged care management. So, while some staff do engage in interpersonal violence, including sexual and physical violence, financial exploitation and verbal abuse, many others have a more complex role in being implicated in harm in the context of entrenched structural and systemic conditions (see discussion of ‘implicated subject’ in Section 3.2.2). For example, AL08 explained:

> [T]here are lots of temporary migrant workers who are working in aged care and … they’re not exactly getting paid at reasonable levels. They’re under pressure in terms of shifts. And I don’t know if they have KPIs [key performance indicators], but those kinds of pressure probably don’t help. There’s downward pressure from the management about what they need to achieve, and there’s equally a lack of accountability within the system because those people probably feel like their jobs might be jeopardised if they speak out about abuse.

Similarly, PLWD03 explained:

> It’s more of a business. And when it’s a business, it becomes very muddy water because you can employ people who are newly into the country, they don’t know what their own rights and they are vulnerable to be getting those situations. We have to look at the bigger picture.

CPFM05, who also works in aged care, raised concerns about the lack of change in residential aged care:

> [W]e need to address [this] now because the thing is unless actually it happens to our own family member we don’t speak. The people who work in aged care, the problem is even though I’m working now, the problem is when you speak up especially in the small organisation, like a private aged care, I have seen personally, if you try to open they will reduce your shift. They will give you more hard work than— management does that because you open your mouth, to be very honest … The thing is, especially in the small organisations like private homes, you try to go and tell the RN [registered nurse], the RN won’t do anything. She will listen to you, she’ll just keep her mouth closed because she doesn’t want to be in problems because she needs to do documentations. To be honest, they all are hiding from more extra work, they won’t open their mouth.

The precarity of their employment and the lack of control staff have over their workplace conditions might also contribute to conditions that enable moral injury, similar to those discussed in relation to care partners and family members.

While the precarity and exploitation experienced by some residential aged care workers do not excuse the harm to people living with dementia, they do present a unique challenge to reparations for people living with dementia in residential aged care. Specifically, questions of accountability are more complex and networks of harm and violence that connect oppression of marginalised workers and people living with dementia are enlivened. This tension is reflected in an exchange between AL02 and AL18:

> AL02: I think it’s very easy to attribute blame and penalty to individual staff members. And a lot of focus goes on that, but how do we hold the government and their regulatory body accountable? I mean, they’re the ones who are tasked with ensuring the system is safe. So the minister for health or aged care, shouldn’t he be penalised? His salary should be docked. So it’s not just the nurse at the grassroots level who is having to juggle 80 residents on one shift by herself.
>
> AL18: Yeah. I will 100% agree with that. Because at the end of the day, the nurse might be responsible for what had happened in that instance, but the residential manager is responsible for that nurse and the CEO is responsible for that. And then you get that trickle-down effect. We do need to hold them to account as well, because this problem won’t be solved [while] we just keep penalising individual members.

AL02 explained this tension in the specific context of use of restrictive practices:

> [S]ome of the things that happen in age care, the individual has to carry out, but it is not the individual staff member’s choice. For example, in terms of chemical restraints or physical restraints. It’s because they just have a complete lack of staff; and therefore, the provider tells them, ‘Just give them this medication or just use this.’ So they’re just carrying out the orders of the provider, so to speak. So even though they are the ones who actually are on the ground, actually doing this, it’s the providers who are not putting on enough staff, number one. And number two, it’s the government not funding

> the sector properly. So what is the sanction for the government? Because they're the ones at the end of the day with all the power and with all the money. So one could say, well, their sanction is after three years, they get booted out. But it's not as simple as that. … Of course, in some cases, individual staff members are hitting and abusing with no direct orders from the top. And they shouldn't be in aged care and they should be sanctioned. But what about those who do things because they're forced to? It's not clear there.

AL10, in the same focus group, reflected on the need to explicitly acknowledge and explore this tension rather than simply avoiding the question of accountability:

> I think, though, in so many Royal Commissions and inquiries that have looked into systemic issues, often it is the defence of 'I was following orders' that has been relied upon which, leads to these harms occurring. ... I think just acknowledging that tension that you have in this setting between the dictative managerialism and the effects that has on staff and then also the need for individual accountability where that's appropriate is probably ... Just emphasising that tension upfront, I think would be useful.

3.2.4 Profit context

The legal and funding framework of residential aged care enables services to be provided for financial gain. Residential aged care in Australia is a massive industry. For example, a report found that

> in the 2018 financial year aged care providers (both home care and residential care) made \$1.1 billion in profits on income of \$25 billion with most going to the largest 60 approved providers. Residential care providers made \$0.4 billion in profits.[147]

Residential aged care providers include international corporations with shareholders, large charities and religious institutions with large asset bases.[148] Research participants noted the significance of the profit context of residential aged care. For example, AL04 described residential aged care as 'essentially an extractive industry' and CPFM09 stated that 'privately run aged care facilities are really just farms for old people, writ large and you're making profit from them'.

The *Aged Care Act 1997* (Cth) and *Aged Care (Transitional Provisions) Act 1997* (Cth) were implemented for the purpose of introducing the Australian National Aged Care Classification, which replaced the Aged Care Funding Instrument. Since that time, residential aged care has become increasingly market- and profit-driven, at the cost of best-quality care and support and high levels of accountability.[149] Reflecting on the legislation, VA06 stated that profit-making is designed into the current aged care system:

> [I]t’s the way the 1997 Act was drawn up that suits the providers and allows them to make these profits, they’ve just got to provide adequate care, according to that. Whatever adequate is, there’s no strengthening of what is required. They can get around the acuity levels and play games with that sort of thing to get extra funding. But for me, none of that’s going to really change until the political will is there. I know they’ve put it into the future that they’re going to do it, but they need to do it sooner rather than later. And that’s to rewrite the Act so that it reflects human rights of people living in age care facilities. Currently it doesn’t come from that base, it comes from ‘How can we best do this without spending a hell of a lot of money?’ And the providers have made hay while the sun shines, they’ve had basically two decades of being able to get away with this.

The profit context of residential aged care can also be a key driver of harm in residential aged care. For example, the profit context can amplify the use of restrictive practices,[150] rationing of personal care items such as incontinence pads[151] and limiting provision of rehabilitation and social activities.[152] All of these actions reduce residential aged care providers’ resource and labour costs in providing care and support to people living with dementia without necessarily being accompanied by a reduction in funding for provision of that care and support. AL01 spoke of the profit-making model of residential aged care enabling harm:

> I think the for-profit model of aged care is broken and should never have happened in the first place. I think it’s just the wrong way of looking at taking care of people. Of course, there are not going to be enough staff, of course they’re going to cut services, and of course they’re going to employ the wrong people if they don’t have any incentive to do better. We’ve just got the wrong

> incentives when it comes to aged care. If people want money, if that's the incentive that we're giving them, people will act in a way of that enables violence, abuse, and neglect because it's part of their profit-making model.

At the same time, the profit context of residential aged care has meant the Australian Government has not needed to be involved in direct service provision. Withdrawal from direct service provision reduces the legal risk and financial obligations on governments, which in turn benefits members of the public as taxpayers and beneficiaries of government funded services. AL04 explained:

> So I think it's important to acknowledge those power imbalances but not just how those power imbalances negatively affect older Australians but how they benefit people in government and people in the system. And importantly, us in the community. We don't have to pay as much tax. We don't have to worry about the issue as much because we don't hear from older Australians. And so we benefit from that too and we need to kind of own that.

The profit context of residential aged care is a unique challenge to reparations for people living with dementia in residential aged care, as it can impede support for transformative change that is more costly than current service provision and is viewed as a financial threat to governments and residential aged care providers (and even broader society).

3.2.5 Endurance of institutionalisation

Currently, moving into residential aged care is seen as the only and inevitable option when people living with dementia are unable to receive the care and support they need in their home. This situation is in part coercive, as there are almost no non-institutional alternatives for a person living with dementia requiring supported living outside of their current home. Society does not yet commonly provide accessible communities or housing built on the principles of environmental design,[153] which promote independence, improved wellbeing and a higher quality of life, in the way that has become more common for people with other disabilities such as physical disabilities. Further, often residential aged care facilities are not designed to be accessible to people living with dementia, such that people living with dementia end up segregated in 'secure dementia units' purportedly for their own safety and wellbeing.[154] Moreover, as noted in Section 3.2.4, residential aged care provision continues to be a viable business option. In short, this means that residential aged care facilities continue to be a key and default option for support and accommodation for people living with dementia.

Yet the ongoing nature of the harm in residential aged care runs deeper than the incidence of such harm. The foundational problem is that the ongoing existence of institutional residential aged care itself enables ongoing harm. Whilst it continues, people living with dementia will be harmed.

Article 19 of the CRPD provides people with disability the right to independent living and community inclusion. This means people with disability should be able to live where and with whom they choose. Providing access to accommodation in the form of large-scale residential institutions, however, is inconsistent with this right, and governments thus have an obligation to plan for deinstitutionalisation. In its 2017 general comment on Article 19, the United Nations Committee on the Rights of Persons with Disabilities (CRPD Committee) states that governments have the obligation to 'adopt a strategy and a concrete plan of action for deinstitutionalization'.[155] This should include 'the duty to implement structural reforms, to improve accessibility for persons with disabilities within the community and to raise awareness among all persons in society about inclusion of persons with disabilities within the community'.[156] Moreover, deinstitutionalisation

> requires a systemic transformation, which includes the closure of institutions and the elimination of institutionalizing regulations as part of a comprehensive strategy, along with the establishment of a range of individualized support services, including individualized plans for transition with budgets and timeframes as well as inclusive support services.[157]

The CRPD Committee published guidelines in 2022 on deinstitutionalisation to complement the 2017 general comment. These guidelines can help governments in realising Article 19. They also provide a basis for planning deinstitutionalisation processes and preventing future institutionalisation. The guidelines explain that institutionalisation of persons with disabilities refers to 'any detention based on disability alone or in conjunction with other grounds such as "care" or "treatment"'.[158] They further explain that such institutions include those relevant to people living with dementia, notably nursing homes, secure dementia wards, psychiatric institutions and long-stay hospitals.[159] The guidelines describe how governments have failed to deinstitutionalise and note that institutions continue to be harmful to people with disability: ‘Despite obligations under international law, persons with disabilities worldwide continue to be placed in institutions under life-threatening conditions.’[160]

The CRPD Committee observes that deinstitutionalisation processes are either not compliant with the Convention or are overdue, and that in the meantime people with disability are subject to human rights violations:

> Institutionalization is a discriminatory practice against persons with disabilities, contrary to article 5 of the Convention. It involves de facto denial of the legal capacity of persons with disabilities, in breach of article 12. It constitutes detention and deprivation of liberty based on impairment, contrary to article 14.
>
> States parties should recognise institutionalization as a form of violence against persons with disabilities. It exposes persons with disabilities to forced medical intervention with psychotropic medications, such as sedatives, mood stabilizers, electro-convulsive treatment, and conversion therapy, infringing articles 15, 16 and 17. It exposes persons with disabilities to the administration of drugs and other interventions without their free, prior and informed consent, in violation of articles 15 and 25.[161]

The idea of institutional settings as inherently harmful has been long argued by disability rights and disability justice activists and scholars.[162] Recently, the United Nations Human Rights Council has noted – in the context of eliminating all forms of violence against women and girls with disability – that forced institutionalisation per se is a form of violence that deprives women and girls of liberty on the basis of disability.[163] Moreover, in the context of an in-depth empirical study of Huronia Regional Center in Canada (a disability institution), Rossiter and Rinaldi propose that institutions are inherently violent and harmful:

> [A]ll practices of humiliation, degradation, neglect, and abuse inflicted upon institutional residents, regardless of intention or circumstance … while institutional violence is never acceptable, institutions themselves are inherently violent in form. We believe that practices of incarceration are in and of themselves violent, and necessarily produce further violence.[164]

The CRPD Committee summarises the obligations on governments:

> Institutionalization contradicts the right of persons with disabilities to live independently and be included in the community.
>
> States parties should abolish all forms of institutionalization, end new placements in institutions and refrain from investing in institutions. Institutionalization must never be considered a form of protection of persons with disabilities, or a 'choice'.
>
> There is no justification to perpetuate institutionalization. States parties should not use lack of support and services in the community, poverty or stigmas to justify the ongoing maintenance of institutions, or delays to their closure. Inclusive planning, research, pilot projects or the need for law reform should not be used to delay reform or to limit immediate action to support community inclusion.
>
> Persons with disabilities experiencing individual crises should never be subjected to institutionalization. Individual crisis should not be treated as a medical problem requiring treatment or as a social problem requiring State intervention, forced medication or forced treatment.
>
> Deinstitutionalization processes should aim at ending all forms of institutionalization, isolation and segregation of persons with disabilities, in both private and public spheres.

The guidelines provide that governments should not provide any further funding to institutions:

> Investments in institutions, including renovation, should be prohibited. Investments should be directed towards the immediate release of residents and the provision of all necessary and appropriate support for living independently. States parties should refrain from suggesting that persons with disabilities 'choose' to live in institutions, or using similar arguments to justify the maintenance of institutions.
>
> States parties should stop using public funds for the construction and renovation of institutions and should allocate them, including those from

> international cooperation, to ensure the sustainability of inclusive community support systems and inclusive mainstream services.

Governments are required to provide housing in the community:

> States parties should ensure safe, accessible and affordable housing in the community, through public housing or rental subsidies, for persons leaving institutions. Aggregating persons leaving institutions into communal housing arrangements or in assigned neighbourhoods, or bundling housing with medical or support packages, are incompatible with articles 19 and 18 (1) of the Convention.

And they should also provide access to individualised support in the community:

> States parties should prioritize the development of a range of high-quality, individualized support and inclusive mainstream services in the community, without delay.
>
> A core element of living independently and being included in the community is that all persons with disabilities have the support, based on their own choices, that they may require to carry out daily activities and participate in society. Support should be individualized, personalized and offered through a variety of options. Support encompasses a wide range of formal assistance, as well as informal community-based networks.

Thus, the CRPD Committee’s commentary on Article 19 of the CRPD make clear that the continued existence of residential aged care facilities as institutions is in itself a human rights violation that enables further human rights violations, and that the Australian Government is obligated to close residential aged care facilities on the basis they constitute institutions and to provide alternative styles of non-institutional supported living in the community.

> [O]ften reparations are a key strategy in society-wide transition away from the structural conditions of injustice, by recognising the injustices of the past and a commitment to a different future. Yet, in the context of harm to people living with dementia in residential aged care – and despite multiple inquiries and reports, the Aged Care Royal Commission and regular media stories about violence, abuse and neglect in residential aged care facilities in Australia –

> there has been no official decision to break with the past of institutional-style residential aged care. This failure presents a unique challenge to reparations for people living with dementia, because there is a tension between recognising past harm and enabling that harm to remain part of our present and future. As we have explained elsewhere:
>
> [O]ften reparations in the context of institutional harms are introduced once the institutions in which they were perpetrated have closed, and once there is widespread community and political recognition of those harms. Thus, it might be that reparations in the context of aged care will depend on a shift from the current institutional model of aged care, as well as community and political willingness to acknowledge these harms. This is perhaps the greatest challenge to reparations in the context of aged care, which, in many countries, is a well-established, state-sanctioned or -funded, and growing industry that many individuals and families depend on in the context of a vacuum of community-based options.[165]

Ultimately, the ongoing harm in residential aged care – and the ongoing existence of institutional residential aged care – may undermine the capacity of reparations to effect systemic change. For example, AL04 observed this tension, noting that

> the harms are ongoing within the current system. So there's very little likelihood that, in the short term, those harms are not going to keep occurring. So that's not necessarily, it doesn't dramatically undermine it. And in fact it might having a redress scheme of some sorts might drive those practices to change quicker. But I think it is a barrier too, as well, that those things are still being perpetuated.

4. Dementia Reparations Principles

This section discusses the Dementia Reparations Principles. The Dementia Reparations Principles consist of a preamble and 25 principles. This section sets out the preamble, followed by a discussion of each of the Dementia Reparations Principles, and concentrates on the empirical and human rights basis of each principle. In particular, we quote focus group and stakeholder roundtable participants to highlight and amplify the voices of people living with dementia, as well as care partners and family members and volunteer advocates who continue to advocate for justice for people living with dementia in residential aged care. We also include the perspectives of advocates and lawyers, given their engagement with existing justice and complaints systems. Where relevant to supplement or deepen the analysis of the focus group data, we note the design and lived experiences of other Australian redress schemes by primarily drawing on official reports on the design and evaluation of those schemes (while also acknowledging these reports do not reflect the full scope of perspectives and experiences).

The Dementia Reparations Principles apply to people living with dementia who live (or have lived) in residential aged care. Noting the wide-ranging impacts of harm to people living with dementia in residential aged care, the Dementia Reparations Principles also extend to redressing the ongoing impacts on care partners and family members of the harm to people living with dementia. The Dementia Reparations Principles may also provide a useful resource for developing reparations in contexts beyond the scope of this project, such as for people living with dementia who are harmed in other institutional or community settings, harm to other people in residential aged care who do not have dementia, and people receiving other forms of aged care (such as home care).

4.1 Preamble and Principles

This section states the Dementia Reparations Principles and associated preamble. Section 4.2 provides an explanation of each principle.

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 listed. Elaboration on each principle is provided in Section 4. A brief overview of each principle is provided in the separate Executive Summary.

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.

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.

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.

Principle 4: Accountability

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

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.

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.

Principle 7: Profit

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

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.

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.

Principle 10: Apologies

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

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.

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.

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.

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.

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.

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.

Principle 17: Trauma-informed

Reparations processes must be trauma-informed and culturally safe.

Principle 18: Disability inclusion and access

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

Principle 19: Inclusive, accessible and equitable

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

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.

Principle 21: Collective applications

Reparations processes must include an option for collective applications.

Principle 22: Independent advocacy

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

Principle 23: Safe, timely, independent and transparent

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

Principle 24: Communication and enforcement of outcomes

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

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.

4.2 Principles explained

This section the discusses the 25 Dementia Reparations Principles that guide the rationale (Principles 1–7), forms (Principles 8–14) and processes (Principles 15–25) of reparations for harm to people living with dementia in residential aged care.

4.2.1 Principle 1: Human rights

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

International human rights instruments provide the right to a remedy for human rights violations, as discussed in Sections 1.1.3 and 1.3.

Relating specifically to people with disability, international human rights norms explicitly provide for equal access to justice for people with disability and to remedies and reparations in the specific context of institutionalisation. The van Boven Principles provide that there can be no discrimination in the delivery of reparations;[166] thus, reparations should not be restricted or denied to people living with dementia on the basis of disability. Article 16 of the CRPD requires states to take ‘appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services’. It also requires that states ‘put in place effective legislation and policies … to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted’. Justice responses to violence, abuse and exploitation are also supported by Article 13 of the CRPD, which provides for ‘effective access to justice for persons with disabilities on an equal basis with others’.

The CRPD Committee has explained that, in implementing Article 5 of the CRPD on equality and non-discrimination, states must ‘[e]stablish accessible and effective redress mechanisms and ensure access to justice, on an equal basis with others, for victims of discrimination based on disability’.[167] The International Principles and Guidelines on Access to Justice for Persons with Disabilities provide that states should ensure that ‘effective remedies are in place for human rights violations, including the right to be free from disability-based discrimination and the rights to restitution, compensation, rehabilitation, satisfaction and guarantees of non-repetition’. These remedies should be ‘enforceable, individualized and tailored to meet the needs of claimants’, ‘[e]nsure that victims are protected from repeat violations of their human rights’ and ‘[a]ddress the systemic nature of human rights violations’.[168]

The CRPD Committee’s guidelines on deinstitutionalisation identify a specific role for reparations, stating that governments should ensure legal and policy frameworks

> enable the full inclusion of all persons with disabilities and guide deinstitutionalization processes towards the closure of institutions. Such frameworks should enable the development of inclusive community support systems and mainstream services, the creation of a reparations mechanism, and guarantee the availability, accessibility and effectiveness of remedies for survivors of institutionalization.[169]

In Part IX (remedies, reparations and redress) of the guidelines, the CRPD Committee states that governments

> should provide individualized, accessible, effective, prompt and participatory pathways to access to justice for persons with disabilities who wish to seek redress, reparations and restorative justice, and other forms of accountability.[170]

The guidelines provide that reparations for institutionalisation should include formal apologies, financial compensation, include restitution, habilitation and rehabilitation, and establishment of truth commissions.

The former UN Special Rapporteur on the Rights of Persons with Disabilities has stated that ‘States must ensure effective access to justice for older persons with disabilities’ as a critical contribution to ‘combating all forms of exploitation, violence or abuse against older persons with disabilities’.[171] States must also ‘eliminate all restrictions preventing older persons with disabilities from obtaining access to justice, including denial of legal standing and accessibility barriers’ and provide ‘procedural accommodations to facilitate the effective participation of older persons with disabilities in all legal proceedings’.[172]

An overarching ‘human rights-based approach’ should be taken to design of reparations. A ‘human rights-based approach’ has been described as ‘a conceptual framework directed towards promoting and protecting human rights, based on international human rights standards. It puts human rights and corresponding state obligations at the heart of policy.’[173] The approach has two objectives: to ‘empower rights-holders to claim and exercise their rights’ and to ‘strengthen capacity of duty-bearers who have the obligation to respect, protect, promote, and fulfil human rights’.[174] The approach is underpinned by five key human rights principles, commonly referred to by the acronym ‘PANEL’:

- Participation – everyone is entitled to active participation in decision-making processes which affect the enjoyment of their rights.
- Accountability – duty-bearers are held accountable for failing to fulfil their obligations towards rights-holders. There should be effective remedies in place when human rights breaches occur.
- Non-discrimination and equality – all individuals are entitled to their rights without discrimination of any kind. All types of discrimination should be prohibited, prevented and eliminated.
- Empowerment – everyone is entitled to claim and exercise their rights. Individuals and communities need to understand their rights and participate in the development of policies which affect their lives.
- Legality – approaches should be in line with the legal rights set out in domestic and international laws.[175]

The PANEL approach must shape all levels of the design and delivery of reparations, including co-design by and leadership of people living with dementia and their care partners and family members (see, e.g., Section 4.2.18); the scope of harm that is the subject of reparations as extending to all human rights violations experienced in residential aged care (see, e.g., Sections 4.2.1 and 4.2.2); the forms that reparations can take as ensuring both recognition and validation on the one hand (see, e.g., Sections 4.2.3; 4.2.8; 4.2.9) and accountability on the other (see, e.g., Sections 4.2.4; 4.2.10; 4.2.11; 4.2.12), and reparations processes being inclusive, accessible and empowering for people living with dementia and their care partners and family members (see, e.g., Sections 4.2.17; 4.2.18; 4.2.19).

Denial of human rights on the basis of dementia

People living with dementia are profoundly devalued and dehumanised (as discussed in Section 3.2.1), and this gives rise to a failure of justice, health and aged care systems to recognise and advance their human rights. Indeed, the fact that a person is living with dementia and living in residential aged care are often bases on which to arbitrarily deny human rights.

Instead of human rights being taken as a universal given, as they are for many other people, people living with dementia need to fight for recognition. This is captured by PLWD03, who stated:

> But the thing is, what are the laws that will protect all of us? Whether we are in a residential, what are the laws that will protect us when you're at home? Is it that we had to run behind the care providers and say, this is my right, this is my right? No, it shouldn't be that way.

VA11 explained that people living with dementia are separate from the community and not recognised as having human rights:

> [F]rom a practical perspective, it's almost like there is no recognition that people living with dementia in aged care have human rights. It seems to be really separate to the rest of the community.

VA07 described the recognition of human rights in residential aged care as purely for show, and not having any substance or effect:

> The thing about human rights and the facility's responsibility … people are shown or told what their rights and responsibilities et cetera, and so forth are, when they go in. Most facilities have the Charter [of Rights and Responsibilities] in a prominent place. And they feel that when it's in a prominent place, that that therefore ends their responsibility to all of those. The Charter of Rights and Responsibilities and the human rights stops at the door, basically. They've done their bit. They've displayed what they have to display. But they don't necessarily follow through.

This failure to recognise and advance human rights of people living with dementia lies at the intersection of ableism and ageism. For example, the former Special Rapporteur on the Rights of Persons with Disabilities observed that:

> Although ageism and ableism share common roots and consequences, inequality in older age is not the mere result of ableist biases. Ageism – the stereotyping of, and prejudice and discrimination towards, older people and older age – is a distinct form of oppression that affects older persons, including older persons with disabilities. Older persons are often perceived as a burden, dependent, unproductive, undeserving or helpless. While disability is increasingly understood as a social construct, inequalities due to old age are predominantly seen as 'natural' or 'inevitable'. Therefore, older persons with disabilities are discriminated against and disadvantaged not just because

> they have a disability, but also because of stereotypes about older people. While some of the barriers that persons with disabilities experience earlier in their lives remain the same or may be exacerbated by older age, those who acquire a disability later in life may be facing those barriers for the first time, and such barriers are also compounded by age-related barriers.[176]

Moreover, for women living with dementia this failure to recognise and advance human rights is situated at intersections of sexism, ableism and ageism and associated with the cultural, social and economic devaluing of older women with disability.[177]

Within this broader context, reparations are necessary to recognise that harm to people living with dementia constitutes a human rights violation, and in turn to contribute to recognition of human rights of people living with dementia more broadly. Reparations can realise equal access to justice and remedy. They can also realise access to rehabilitation and health, and independent living in the community. They can realise equality and dignity through the symbolic and material actions that send the message that lives of people living with dementia matter and are valued.

Harm as human rights violation

Reparations are an opportunity to recognise harm to people living with dementia in residential aged care as human rights violations.

As discussed in Section 1.1.3, harm in residential aged care violates human rights, including violations of rights to freedom from violence and torture, liberty, personal integrity, health, rehabilitation, legal capacity, independent living and equality. Indeed, CPFM06 explained that in the Dementia Reparations Principles, harm should literally be understood as meaning 'loss of human rights', and that an explicit human rights framing of harm to people living with dementia 'may start the slight connection to say, "Oh, that means that when you do lock somebody behind a door or when you do not give that person the dignity of change in their continence pad or tell them that they can't have a cup of tea, that's a loss of human right because it's a loss of choice and control."' Similarly, AL03 explained that reparations are central to recognising human rights violations inherent to the harm:

> I think it’s fundamentally a question of human rights … all humans should have the right to live free from violence, from abuse. They have the right to basic levels of care, healthcare and adequate food and housing and the rest. So fundamentally, I would say, of course it’s an injustice, it’s a wrong that should be righted.

Some PLWDs described human rights violations as inherent to residential aged care per se. PLWD12 observed the coercive context of residential aged care, referring to conversations with residents at the residential aged care facility where his wife lives:

> When I ask most of the residents, none of them really want to be there. So an aged care facility in itself is a violation of a person’s human rights.

PLWD 12 explained that the discrimination in the National Disability Insurance Scheme – in that it does not apply to people who apply when they are aged 65 years or older – is a core aspect of the coercive context in which people end up in residential aged care:

> They may be there because the family will assume that they can no longer look after them, but put them into an aged care facility. Or in my case, I’m also a person who [is living with] dementia. So I can no longer legally care for my wife, because she is a high-dependency person with a stroke and requires manual lifters to get her out of bed. And, none of that … I can provide. And also she had the stroke at the age of 65. So she wasn’t ... [able] to be qualified for the NDIS support, as I did, and as others did. So when you talk about violation of human rights, whether or not people get put into aged care because they’re of that borderline, like my wife, who should not be there and should be living with me and getting more support in aged care or whether I see abuse actually by residents of the aged care facility because to actual staff as well. I don’t think you can only just look at it as an easy sort of, staff are out there to abuse [residents].

PLWD12 elaborated on the inequality of his and his wife’s situation:

> I’m a person that lives with dementia. I’ve got a wife in an aged care facility ... She had a stroke ... I live in a retirement living area. So I live by myself. I’ve got support workers around me to help me cope with life. Very greatly

> supported by the National Disability Insurance Scheme. Really annoyed that my wife had her stroke at 65 and is excluded from it.

Two PLWDs saw segregation designed into residential aged care as part of the harm:

> PLWD06: Part of that, too, is the segregation and, well, go with the discrimination, in that sense. Because first of all, just the aged care itself is what's aged. And then when you've got internal to that, I won't say specialist but segregated dementia care, do they have separate care for people who have forms of cancer? No. Nothing else gets separated out, and they're quite capable of working as well as they can with that mixed environment, and even within the age concept.
>
> PLWD05: Segregation is abuse. Isn't it?

Equality and humanity of people living with dementia

Reparations are an opportunity not only to respond to human rights violations experienced by people living with dementia but also to holistically recognise the humanity of people living with dementia and their valid place in the community. For example, VA07 explained the need for reparations as a way to recognise human rights for people living with dementia:

> And it's just a matter of valuing the individual and the human rights, everyone in Australia is deserving of human rights recognition.

VA02 saw reparations as central to recognising people living with dementia as equal human rights subjects and citizens:

> [I]t's so important, because that's why nobody's protecting these non-persons. This is the whole root of the problem. This is why we need redress. Because we're saying society recognises these people as citizens, as equal citizens, and we don't do that to each other.

VA02 also stated reparations are a way to bring equality to people with living with dementia:

> I think absolutely there needs to be a sense of a recognition of the injustice and a sense of some kind of shame. You are not going to have behaviour

> change unless people think, ‘This is awful. I can’t believe we’re doing this’ … I feel on the most practical level, the recognition of injustice and naming it and articulating it and saying that people with dementia to whom this has happened and other older citizens … of course we protect all other groups in society and we can say, ‘You can’t touch me. I’ll sue you’, or ‘I’m going to call the cops.’ We are okay that this group of people, everyone’s going, ‘Oh, it’s shocking. It’s terrible, the violence, abuse and neglect’, and the police haven’t gone and jumped in. Why haven’t the police jumped in? Honestly, I’m not joking. Why haven’t the police jumped in and said, ‘Excuse me, well this has just come to light?’ It’s saying that they’re not full citizens, is what it’s saying.

Equal access to justice

Noting that other groups in society have access to justice and remedies, AL04 referred to reparations as being about equal treatment under the law, and thus cutting to the core of the rule of law:

> I do think it’s about fundamental human rights and dignity. And again, what does it say about our society? If we fail to uphold that for older Australians. There’s also a rule of law kind of companion to this that there’s effectively unequal protection of the law for particular groups … if you have any commitment to the rule law and equal protection before the law, which is another principle of human rights as well.

VA01 also emphasised the right to equal protection for people living with dementia:

> Well, if that happened to people who were not in homes, they would have civil [rights] ... If somebody beats you up, for example, in the street, you can sue them. What’s the difference between being in the street and being in a home? You should be able to do something about it.

4.2.2 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.

Residential aged care facilities are, by their very name, labelled as places of ‘care’. Yet residential aged care facilities are also, by their institutional nature, places of harm. The harm is diverse and has wide-ranging impacts on people living with dementia and their care partners and family members. The full scope of harm to people living with dementia in residential aged care has not been recognised as wrong by governments, residential aged care providers or broader society. Moreover, residential aged care providers have ignored harm or denied any responsibility for harm. Thus, reparations are necessary at a foundational level to recognise that harm occurs and is wrong. This recognition of harm is a foundational reason for the necessity of reparations because, through recognition, reparations can provide opportunities for individuals living with dementia, as well as care partners and family members, to heal from traumatic and damaging experiences. Additionally, reparations can provide opportunities for the mending of familial and social relations and building trust in governments and service systems – that is, for moral repair and restoring trust and hope.[178]

Through recognising harm, reparations can also serve a broader educative function of shaping understandings of what actually constitutes harm to people living with dementia – as explained by CPFM06, ‘part of this is to re-educate and have people understand clearly what this actually does mean’. Similarly, AL17 observed: ‘I think there’s a long way to go in terms of community understanding around the things that constitute harm before there’s some acceptance of responsibility.’ Relatedly, recognition of harm can shift cultural attitudes towards people living with dementia. For example, PLWD05 spoke about the lack of recognition of harm as linked to cultural attitudes towards dementia (reflecting the challenge of stigma discussed in Section 3.2.1):

> I think in a lot of cases, what we are talking about as abuse, a lot of people would not see it as abuse. A lot of people say, well, that person’s got dementia, they need to be a locked up, they need to be restricted, they need to be limited in everything they do. So there needs to be a much greater understanding generally of the alternatives of how it should be, and the fact that it is abuse and people don’t recognise that. So, until we do that, I’ve sat at round tables and people have said, ‘Oh I don’t want to be stuck with people with dementia because they’re violent. They’re going to hurt me. They need to

> be locked up, they need to be kept away from us.' And all the time, that's the attitude. Things really aren't going to change. Even the people that understand, that know, still have this basis of, oh, yeah, it would have to happen in some circumstances but it shouldn't happen under any circumstances … And certainly the public who really have little idea on when we talk about abuse, they think we're exaggerating and making a fuss about nothing. They don't recognise that we are being abused. So, yeah, it's knowledge, again, knowledge on what is abuse, what is happening, and alternatives.

Diverse harm to and impacts on people living with dementia

This section introduces examples of the harm experienced in residential aged care as described by research participants. While the section is long, simply listing the types of harm would not capture the depth and complexity of harm that is the foundation for reparations. Moreover, documenting the harm here, serves a truth-telling role of people living with dementia and their care partners and family members, defining the harm from their perspectives.

There is a wide range of harm to people living with dementia, and this harm is of varying scales, temporal duration, legality and visibility. For example, PLWD03 explained:

> Harm happens. It can be verbal. It can be physical. It can be sexual. It can be lots of things. Neglect our food, neglect of taking care of the person.

CPFM08 described some harm as 'very covert and very subtle' and as being 'so much harder to really point a finger or identify for us to see'.

Harm to people living with dementia in residential aged care also extends to physical and sexual violence. CPFM03 spoke of various forms of restraint in the residential aged care facility where his brother lives:

> Abuse, neglect. I don't how many times I've seen people who've got dementia being forcefully restrained subtly by putting— restrained subtly by putting him in a wheelchair, pushing it against the dining room table. And the lady who had a broken wrist could only use— and they put two break locks on, so she can release one, she can't release the other. She's pushed up against the

> table as restrained. I saw dementia patients walking around and also having a carer stand in front of them to stop their path, even worse, putting their hands on the walker and forcedly pushing back or turning them, and then find out they all of a sudden scream when a person decides you're blocking my view and the person goes forward. And all of a sudden the carer says, 'Oh, I'm being abused. I've been abused.' So, I've got a whole list of things. As I said, it's so much abuse happening in aged care, a lot of [it] subtle. I reported five cases of abuse, all that not answered and includes a complete circumference bruise around my brother's wrist. Obviously they were trying to contain him.

However, harm need not be related to acts of physical or sexual violence. It can arise from fleeting moments and minor interactions. PLWD01 observed:

> I had a nurse walk down the passage and she had one of those little tiny bells and she was ringing it. I have sensory problems and I went ... 'Please don't do that.' And she said, 'Why?' I said, 'I've got sensory problems.' So what did she do? She rang it again. And she said, 'Do you mean like that?' Lack of education? And I was beside myself and they said, 'What are you making such a fuss for?' So it is unbelievable. I reported her and they said, 'Oh, do you want it to go to management?' I said, 'What's the point?' I said, 'What I want,' I said, 'is for her to be educated.'

PLWD05 noted aged care staff having a lack of awareness of dementia as itself causing harm:

> I think it's abuse in itself, but it also leads to further abuse. The result of lack of education is an excuse or explain some of the things that happen, not all but some, some people are just bad. Most people are just uneducated in the area. You'd like to think that the majority of people go into, or a number of people go into the profession because they care, but knowledge is not available to them. Education, it's available but not easily accessible.

Harm can also be related to routine care delivery and how the labour, resources or space of a particular facility is organised. For example, CPFM and VA research participants drew on their personal experiences in witnessing a range of harm to people living with dementia in residential aged care. These are related to the daily operations of residential aged care, and associated with basic aspects of human functioning such as toileting, walking, sleeping and eating. And, they are intricately related to efficiency in service provision. The impacts of such harm on people living with dementia are in terms of the physical and psychological impacts (e.g., incontinence, physical immobility, distress), but also extend to a denial of identity, culture and humanity.

CPFM06 spoke of her mother’s experience in relation to toileting:

> [H]ow people are supported within a facility can be a big influence on whether the person continues to grow or lives with dementia per se, or deteriorates rapidly. Very quick example was an over use of suppositories. In the second facility my mother was in … she was there for a while and suddenly found out they were using suppositories on her. And I realised she was constipated. They said, ‘Hang on, she’s compacted.’ I was the one who noticed it, I was the one who took her to hospital. I was the one who got the results. So then they decided that they were going to start using enemas, but it was, again me who said, ‘You don’t need to go down that road, why are you even using suppositories?’ That in itself, took ages and ages to get sorted out. I had to get letters from doctors and that saying, I’m in the disability sector. I know enough about bowels to say that suppositories should only be used if a person is really requiring them, she didn’t. Dietary responses were much better. I eventually moved her out of there and she never had a suppository again.

Another CPFM01 spoke of her father becoming incontinent while in residential aged care:

> I’ve heard so many stories, and it was certainly my dad’s case, of people going into residential aged care continent, and very quickly becoming incontinent. And that being the very distinct impression that that is what is preferred. So it’s preferred to have to change people’s continence pads occasionally, not nearly often enough, than to have to help them to manage their toileting and use the toilet as much as they can and have access to bathrooms and toilets available for people with dementia.

CPFM13 observed how imposing schedules on individuals living with dementia in residential aged care denied individuality to people living with dementia:

> It is a 24-hour industry, but residents are treated like they have to conform to what we want, what we call normal life, sleep all night, play, work all day. This does not work. We need to cater for all sorts of people. Example, people that stay up late or have insomnia et cetera. They're just pushed to their bedroom and left, rather than have staff to cater for the 24 hour care of disabled. They don't have that.

CPFM13 spoke of her husband's experience of having no stimulation in a dementia care unit:

> [T]he two cottages that they class as high dementia, where [my husband] was, do not give social contact of any description. No recreation, no music, et cetera. And this has to stop. We are social, living people, dementia or not.

CPFM13 also spoke of how harm associated with a lack of stimulation can be embedded in the built environment of residential aged care facilities:

> I tried to take [my husband with dementia] for a walk a couple of times, and there's nothing but buildings and roads that you have to push up and down. You push down okay but getting back up, not so easy. No gardens. Although they say they've got gardens, they had hedges. There was nowhere nice to take anybody. Well, nursing homes build around busy roads, car parks, no gardens. And the elderly are sitting inside with no sun, no vitamin D, as prisoners. And basically that's what we're putting them into.

CPFM08 spoke of witnessing a more rapid cognitive decline in her grandmother once she was moved to a dementia care unit where she was medicated and had less stimulation:

> She recently was transferred into another section for people that, I guess, have more progressive stage of dementia and she is not at that stage. And so we were really fighting for her to stay where she was, but they insisted on moving and wanting to medicate her … And so she's just progressed more. And so for me, it's like … she has prematurely being transferred. Her dementia has progressed faster. This was someone that could make a sandwich, make a Milo, use a washing machine, all those things prior to going in there. Wasn't even ready to go in there. So I think that's an area too, where

> I would be looking at arguing, the lack of care or the type of care and the type of area or section that they're in and how that may have also progressed their dementia earlier than what it probably would have, if they had been at home.

CPFM03 spoke of an individual living in the same residential aged care facility as CPFM03's brother being denied any choice in order to fit the routines of the residential aged care facility:

> Getting people to bed early because we've not got enough staff, so we've got to get them to bed early and quieting down. Currently having a resident saying to me that if I press my call button and I can't get a response, well to find out that someone's unplugged it from the wall because he's a night owl. He sleeps during the day and he's awake at night. Didn't like it. So leave, unplug, walk his room, unplug it from the wall so he can press as much as he wants, and it won't activate. Abuse, neglect.

CPFM03 also spoke of his brother's physical mobility declining when he was in residential aged care because there were no staff to assist him in walking:

> Talk of abuse that's happening and my brother's experiencing. He was a gentleman who was very, very active in every sport and used to walk three hours a day before he went into the nursing home. Comes in the nursing home quite aware and then locked into his little room, locked into one wing ….
>
> Brother's got severe dementia. So he's non-verbal. His mobility's got worse because of the fact they're not moving him as they should. Earlier on, 12 months ago, 18 months ago, I gave him a walker, which he never, ever, ever needed. But because the physio just decided we've got to cater for the weakest link. Weakest link is not enough staff, not enough trained staff … So he was restricted, as I said, from walking, he was forced use a walker and quite a few other residents, if they go without a walker, all of a sudden someone says stop, you can't do that, shoves a walker in front of them. They're very risk adverse, but they forget the rights of individual … Brother still wants to have a sleep in the morning. No, you got to get up at a certain time. Where you can walk is restricted. When you can go out's restricted. So it's just ongoing.

Similarly, VA02 spoke of dehumanisation from routine and efficient care provision in relation to toileting, sleeping and eating:

> [L]ast time I worked on the floor, they're waking up citizens every two hours and putting their hands down their pants … That happened last night. So, while it's really important to talk about ... This is happening to citizens. And when they push the person away [who is seeing] if their pad is soiled and as anybody would have a reaction of pushing someone away ... And then they're written up as physical violence and then they're at further risk of being drugged. All of this is tied up in the craziness that is just the institutionally accepted.

CPFM17 shared her observations of harm arising from labour shortages:

> What I notice within the nursing home is little or no interest from carers in the resident, what their identity or persona actually is. And when people get old and go into a home their whole life before them is meaningless to carer. Some take trouble to talk. But very few, especially the agency staff couldn't care less. There's a lot of force feeding even when the patient doesn't want it. Sorry, I shouldn't say patient, resident. I wonder why that is. And there's very, very little stimulation. And now I realise staff shortages are a factor. And I realise that when you've only got three to 14 people, it's quite difficult. And I do realise with staff shortages at the moment with absolute dependency on agency staff, who I say, come in and go out and really don't care. I find it quite depressing that there's very little interest in setting up a relationship with a resident.

CPFM09 explained how organisation of labour can give rise to harm which is subtle but still has significant impacts:

> [M]y husband had carers who came and saw him regularly that he was very familiar with and comfortable with. But at certain times they would, for convenience's sake, rather than send a person that he was comfortable with in, they would then send somebody that he didn't even know to home, who he saw as an intruder. So that was harmful to him because he was very agitated and distressed by that. But for them they would say, 'Well, it's a roster industry.' So this is quite subtle, but it's also quite important for people living

> with dementia, for their wellbeing, to have that consistency of care. So to me, that's a harm, but that would be seen as quite petty. So, that's where the validation is sometimes needed … these more subtle things, which I think are equally important to the wellbeing of people living with dementia.

CPFM09 also spoke of the profound harm to her husband in being denied personal care to maintain his individuality and identity:

> [N]eglect's really insidious, as an example, my partner was very proud of how he looked. It was really all about him and everybody commented on that about him. He just turned into a dishevelled person in the last two weeks of his life. He was shaved more in that two weeks when he was actually unconscious than he was in the entire year that he was there. So that sort of neglect, that's the essence of who he was, was taken from him and that's entirely unacceptable. That sort of redress is really important for us to actually acknowledge that taking away a personhood from somebody, it's a criminal offence in my mind and it absolutely needs accountability and the only way to do that is to have a redress scheme as far as I'm concerned.

VA08 spoke of the dehumanising impact of the residential aged care environment:

> This is a photo of another friend of mine … So you can see, so [my friend is] sitting on the bed. That room has no chair. It has no bedside table. It has no pictures on the wall. It has absolutely nothing. It looks like a completely empty room. It's even more sparse than a hospital room. But that room is home for a woman with dementia who's actually lived in that place for four years … She has lived in that room for four years. And I just, I find that quite shocking, absolutely shocking.

VA08 also spoke about the denial of cultural identity in another residential aged care facility she visits:

> [W]hen I went to visit recently, I asked about food. And because we were visiting a Lebanese person, lived in Australia most of his life, but is Arabic speaking. And I asked about food and choices. Do they get any choice about what they eat? And this staff member was really quite funny. She said, 'Yes, of course we give them choices. When we have sandwiches, we give them a

> choice as to whether they’d like ham or cheese.’ And I thought, ‘Hey, wait a minute, we’re talking about someone who’s Muslim and you are offering them ham or cheese.’ But that’s their idea of choice, not for falafel or humus. And this comes back to what [family member focus group participant is] saying, they are all treated the same. Who they were collapses when they go into these places. But if you visit a place like that, and if you talk to the staff, you’ll get a very, very different picture to the one that you get if you hang around for a while and watch what’s really happening.

CPFM06 noted that harm in residential aged care is longstanding and cannot be blamed on external factors such as COVID-19:

> [A] lot of stuff in the aged care has been brought to the forefront through COVID, but there’s so much focus on how bad people have been treated and how COVID separated families. And I fully agree. My mother went downhill very quickly and we were only shut for 11 weeks, but she came out dehydrated from that 11 weeks. But I think there appears to be a lot of, ‘Oh, well it’s COVID. Oh, well, it’s COVID.’ And I’d like, to sort of see this redress go back before COVID days so that people can actually look at it and go, well, hang for a minute, we can’t just blame this on COVID and apologise and go, ‘Oh yeah, but it was COVID’, because I feel that seems to be what’s happening a little bit. There’s lots about COVID and lots of that stuff like that, but not, this is been happening for a much longer period of time and it goes a lot deeper.

In a similar vein, VA08 noted the systemic nature of harm in residential aged care:

> And we know that this is a very, very broken system … it’s not about individuals having problems in it. It is a broken system that screws up people in it.

Some research participants noted that what is experienced as harmful by a person living with dementia is shaped by an individual’s identity and life experiences. For example, PLWD08 noted it was important to consider people living with dementia from the LGBTIQA+ community, stating:

> Because some of the atrocities that they experience when they're putting care, are reprehensible. They shouldn't care. You know, I saw an example. There was someone who was a trans person and like to dress up in female clothing. Right? They had a right to do that … And yet, they were forbidden to do so because the staff for reasons of their own decided, no, that wasn't appropriate in that setting. You know? What exacerbated the situation was that their carers and family members can condone the actions of the staff in that home. So they're between a rock and a hard place. So they couldn't win … I mean, if we're going to be inclusive in these principles, then they need to be included.

AL13 spoke of the need for recognition of intersectionality in understanding harm and impacts of harm and the reparations that might be needed, including

> recognising those impacts on different groups and what changes they might need socially and economically beyond just a financial payment and apology.

It is important to note that, while not discussed in-depth by research participants, other advocacy and research has highlighted that what constitutes harm to people living with dementia in residential aged care will depend on intersectional factors, including an individual's identity, life history and material circumstances. This is demonstrated by three examples: Forgotten Australians / Care Leavers, First Nations people, and members of the LGBTIQA+ community. Forgotten Australians / Care Leavers (i.e., 'the estimated 500,000 children placed in institutional (for example, orphanages) and out-of-home "care" in Australia between the 1920s and the 1980s'[179]), can experience harm in residential aged care that is shaped by earlier experiences in out-of-home care, as explained by members of the Outcomes of the Inclusive Care for Older Trauma Survivors collaborative research project team:

> There are several aspects of being raised in institutional or out-of-home care that may render mainstream aged care services high-risk for Forgotten Australians / Care Leavers. These include, but are not limited to, lack of privacy, restricted choice, strict routines, lack of social support, kindness, and respect, threats to identity and autonomy, and high rates of sedation. Research with other traumatised groups, including Holocaust survivors, has shown that survivors are sensitive to aspects of aged care that can evoke

> distressing memories and intensify trauma-related fear, grief, and humiliation. Receiving aged care services, whether in community or residential settings, introduces a power imbalance that requires the survivor to trust both a providing organisation and the person delivering the care. The survivor is inherently required to accept limitations to their choice and control, directly threatening the most important component of recovery from trauma. Entering residential care also almost always results in a loss of possessions, sometimes including a home the survivor has cultivated as a safe space.[180]

Life histories and ongoing trauma might mean that Forgotten Australians / Care Leavers experience as profoundly harmful acts or circumstances that might be considered minor or inconsequential to others. For example, Schwartz and Cornell explain that Forgotten Australians / Care Leavers might experience the following circumstances as an invasion of privacy: a treasured possession is moved or touched; someone walks in to their room unannounced; someone overstays their welcome; the person is in a crowd; or there is too much noise and confusion.[181]

A second example of the intersectional nature of harm is First Nations people, including members of the Stolen Generations. Aboriginal and Torres Strait Islander older people who participated in consultations with the Australian Department of Health on supporting Aboriginal and Torres Strait Islander older people explained what is necessary in aged care services, stating:

> As 100% of the Stolen Generation will be aged 50 by 2023, we require:
>
> a. an aged care system that is aware of the harmful impact of colonisation and the trauma caused by removing children from families
>
> b. aged care services provided by organisations that do not have historical association with removing children from families
>
> c. aged care workers who understand the risks of retraumatising us survivors and the meaning of ‘healing’ …
>
> We expect greater service accountability to ensure ALL needs are being met in a culturally respectful way.[182]

The Aged Care Royal Commission observed that members of the Stolen Generations – Aboriginal and Torres Strait Islander people who as children were forcibly removed from their families and often institutionalised – may have a ‘fear of being caged in’.[183] The Healing Foundation has observed that: ‘There are more than 17,000 Stolen Generations survivors in Australia today. By 2023 all Stolen Generations survivors will be aged 50 and over.’[184] It has explained how members of the Stolen Generations might experience residential aged care:

> The majority of Stolen Generations survivors fear residential aged care4 and opt for home or community care where possible. …
>
> As a result of childhood trauma, Stolen Generations survivors may not be comfortable being touched (or having their belongings touched) and especially with intimate care.
>
> These things can remind people of the abuse or lack of control they experienced as children and may trigger trauma, particularly if they have been sexually abused. …
>
> Stolen Generations survivors often have particularly high standards of cleanliness, stemming from the strict dormitory life many experienced in institutions, where extensive cleaning duties and inspections were commonplace. This can become even more important to people as they get older and increasingly re-experience their childhood.
>
> Stolen Generations survivors may also closely associate cleanliness and appearance with dignity and respect, for example placing a great importance on being well dressed. …
>
> It can be very challenging for Stolen Generations survivors to spend time in an unclean environment, especially if attempts to speak up about this are met with unhelpful responses (for example cleaners in a dusty room saying they are only responsible for mopping the floor, or needing to ask multiple people about cleaning up a spilled drink because some staff ‘are not allowed to do that’).[185]

The Healing Foundation has also explained the particular experiences in residential aged care of members of the Stolen Generations who are living with dementia:

> Survivors who develop dementia may experience terrifying flashbacks to their childhood, which they are unable to distinguish from reality. Aboriginal and Torres Strait Islander people are three to five times more likely to develop dementia than non-Indigenous Australians, and Stolen Generations survivors are even more likely to develop dementia as a result of the trauma they experienced.
>
> At a residential care facility, a Stolen Generations survivor with dementia started refusing to have a bath. Mary would get angry and become difficult for staff to manage. When her daughter became involved, it emerged that as a child (in an institution) Mary's skin had been scrubbed regularly in the bath to try and 'make it white'. Her childhood was now coming back to her and she was afraid she would be treated the same way.
>
> For some it is the singing of particular Christian songs [learned while in an institution], for others it is hearing a sound and acting on it e.g. panicking when they hear something similar to a bucket being kicked as this reminds them of the warning signal given by other children when their minders were coming.[186]

Legal Aid NSW noted in the context of the development of the New South Wales Stolen Generations Reparations Scheme the importance of recognising diversity of harm:

> any reparations scheme [must] … recognise that 'harm' may take forms which are not ordinarily recognised by western conceptions of 'harm'. While many people have provable forms of trauma, conditions and illness, many more are struggling with the cultural and spiritual effects of the policies of the Stolen Generations and the collective harm that comes from broken kinship relations, disconnection to country, removal from sacred sites and systemic and structural inequalities in health and education.[187]

First Nations older people being made to move into residential aged care facilities that are away from Country can also be harmful. For example, the Aged Care Royal Commission observed:

> Many Aboriginal and Torres Strait Islander people want to stay on, or near, Country when they age and may choose not to access services if they are unable to stay connected to Country.[188]

A third example on the intersectional nature of harm is members of the LGBTIQA+ community, whose experiences of harm in residential aged care might be shaped by earlier experiences of discrimination and medical violence, as explained by the National LGBT Health Alliance:

> For LGBTI people in residential aged care, it is important that distress, for example, is investigated in context. It is reasonable to express distress at being discriminated against. It is reasonable to want to escape an environment where an older LGBTI person feels unsafe, or where they are denied access to their normal support structures.[189]

Restrictive practices can be triggering and cause trauma and psychological harm for people who have had previous experiences of institutionalisation, forced treatment and restraint. This is explained by the National LGBTI Health Alliance:

> Care needs to be taken with related consequences of restraint because of historical and contemporary practices of attempted psychiatric ‘treatment’ of LGBTI people, such as aversion therapy, which is still legal and used in some parts of Australia …
>
> The majority of aged care services are provided by faith-based organisations. Some faith-based organisations continue to advocate for the efficacy of conversion therapy despite there being no evidence that it is successful in changing a person’s sexual orientation or gender identity. Older LGBTI people understand that conversion therapy practices are ineffectual and harmful and feel vulnerable to any kind of physical intervention related to their behaviour. LGBTI older people with a lived experience of electro-convulsive shock therapy can experience added trauma if chemical restraint is used.[190]

Recognition of the diverse and wide-ranging harm and impacts of harm – along with the related human rights violations – is a foundational reason for reparations. Indeed, an alternative narrow approach to harm has been critiqued in the context of the National Redress Scheme, which offers payments for harm associated with specific, individual instances of sexual abuse. This approach has been criticised for overlooking non-sexual abuse and the broader abusive context of institutionalisation. For example, an anonymous survivor quoted in a 2019 report of the Joint Select Committee on Implementation of the National Redress Scheme ('National Redress Scheme Joint Select Committee') stated:

> Overall my experiences in Care have affected my life greatly, all types of abuse must be considered, they are just as important as sexual abuse. The sexual abuse I suffered was horrific, but nothing compared to the psychological abuse. I still carry the scars, though they may not be visible. I can't believe Redress is only about sexual abuse – even when combined with physical! I was in an orphanage for 10 years of my life, up at 5am doing 12 hours of labour. The physical and mental abuse should count for something. Did they not care or listen to what we have been through? ... I am exhausted by all of this, it just falls on deaf ears.[191]

Care Leavers Australia Network was quoted in a 2019 report of the National Redress Scheme Joint Select Committee as arguing that for a redress scheme 'to truly serve the purpose of recognition and justice for those abused in the Child Welfare system, it MUST include ALL forms of abuse' because 'all forms of abuse are intertwined' and it is 'unreasonable to only assume sexual abuse was the most damaging'.[192] One of the reasons all harm interlinks is the institutional context of child welfare. For example, Frank Golding explains that the closed institutional settings of out-of-home care were pervasively brutal and sexualised.[193] The institutional nature of child welfare means not only that all harm is interconnected but also that it can be difficult to pinpoint specific events, as explained by Daly:

> Care leavers were abused in total institutions, where sexual abuse is diffuse and part of a sexualised environment, in which there is no separation in the spheres of life. For these reasons, it can be difficult for survivors to trace sexual and other abuses ('injuries') to acts that occurred on specific dates, or to obtain documents that can verify what occurred.[194]

The point we are making here is not that the sexualised nature of child welfare institutions is identical to the circumstances in residential aged care (although the sexualised nature of residential aged care is an area in need of exploration given the high rate of sexual assault in residential aged care). Rather, our point is that these criticisms of the scope of the National Redress Scheme highlight the importance of recognising, through reparations, the pervasive and interconnected harm associated with residential aged care facilities by reason of their institutional nature, and of not singling out for reparations specific forms of harm such as those related to physical and sexual violence.

In contrast to the National Redress Scheme, state and territory Stolen Generations reparations schemes provide a payment in recognition of the removal of individuals from family under the relevant historical legislation. This approach identifies the harm that is redressed as associated with the act of removal and its ongoing impacts, rather than harm being associated with the standard of treatment and specific acts of violence within the out-of-home care settings in which individuals were placed after removal. While not in any way likening harm in residential aged care to the experiences of members of the Stolen Generations or suggesting that this approach is the ideal approach in the context of Stolen Generations, Stolen Generations reparations schemes demonstrate that it is possible to identify an overarching wrong inherent in institutionalisation (e.g., residential aged care) that could be the subject of reparations, rather than needing to itemise discrete types and instances of harm as is required under the National Redress Scheme.

Impacts on care partners and family members

Care partners and family members are deeply impacted by what has happened to persons living with dementia, and by how they themselves are treated in complaint processes, or who feel complicit about the entry into residential care of someone in their family or care. Including care partners and family members as subjects of reparations is supported by the van Boven Principles, which recognise the broad scope of victims, including family members and those who have intervened:

> For purposes of the present document, victims are persons who individually or collectively suffered harm, including physical or mental injury, emotional suffering, economic loss or substantial impairment of their fundamental rights, through acts or omissions that constitute gross violations of international human rights law, or serious violations of international humanitarian law. Where appropriate, and in accordance with domestic law, the term ‘victim’

> also includes the immediate family or dependants of the direct victim and persons who have suffered harm in intervening to assist victims in distress or to prevent victimization.[195]

PLWD05 identified the importance of reparations recognising the impacts on care partners and family members of harm to people living with dementia:

> I think if family members are surviving and it’s clear that people are deeply impacted by what’s happened to their relatives, then certainly that needs to be acknowledged and addressed … it’s not the first thing that springs to mind but certainly, if they’ve suffered and have watched their family members suffer and have tried to address it and it’s not been addressed, that needs to be dealt with as well. It’s really important and we all know the impact that can have on people’s own health and wellbeing.

Care partners and family members can experience ongoing sadness, grief, guilt, anger and exhaustion from having witnessed harm to a person living with dementia in residential aged care, particularly where they have supported that individual’s admission to residential aged care. In Section 3.2.2 we framed this in terms of ‘moral injury’. For example, AL10 referred to ‘guilt and shame’ experienced by care partners and family members:

> [T]here an element of kind of guilt and shame, which crosses like all those other kind of classifications of demographics, because age is something that’s going to happen to everyone, and the responsibility older persons that a certain number of people might feel guilt over that sort of fosters a reluctance to engage further with the issue … But maybe it’s all a bit hard and that some people, even if they do do their best feel that maybe they could do more.

Similarly, VA03 referred to a ‘burden of responsibility’ felt by care partners and family members:

> [I]f there was, say, some sort of national recognition, then in their own way, they could maybe come to peace with it or at least plant their flower or do their way. But if it’s not acknowledged that ... Because we talk about systems and we’re not just talking about the institutional, we’re talking about family, friends, significant others, and the pain that stays with them, it’s as though you’re told

> that, well, this person has dementia, you've done everything you possibly could and you couldn't really do much more cause the doctor said this or the OT [occupational therapist] said this, or the nursing home, they said that. So I guess it's people have this burden of responsibility or burden that they should have done more or could have done more, so at least if it's acknowledged.

Care partners and family members can have their hope and trust in the aged care system destroyed, and this can have impacts on their own lives in terms of damage to their sense of safety and trust in their own future care arrangements. For example, CPFM06 explained that her father living with dementia, who still lived at home, had a complete mistrust and fear of residential aged care since witnessing his wife's treatment in a residential aged care facility:

> Something that everybody's asked me is, 'Oh, he's home on his own at night?' And you know, 'He's only got these carers that come in to see him twice a day. What if he falls over?' My answer is, and this is quite traumatic, my answer is, 'Well if he falls over, then he will probably hurt himself, he will probably die. And that's okay with him. And that's okay with us because he sat by my mother's side for three years in three different nursing homes and the trauma that put him through watching the way she was treated.' He will never go into a nursing home. And I also know that if he was to go into a nursing home, he would be terrified of all these different faces staring at him. He would not know where the toilet was and become incontinent for a very proud man who is still making his way to a toilet, even though he wees on the way. It would devastate him. Absolutely be the cruellest thing ever. So when you are, when we're looking at a redress and trauma, yes, it does go into families. It does go into in-home care and so forth.

CPFMs and VAs did not propose that their own experience was more severe or significant than the experience of the person living with dementia who was harmed. Rather, CPFMs and VAs made clear that the harm and primary wrong and injustice was to the person living with dementia, and that their experience in relation to that harm was of the impacts on them of that primary wrong and injustice. The secondary and relational nature of this wrong and injustice mirrors the nature of their very identities as care partner and family member, which is, by definition, contingent on their relationship to the person living with dementia.[196] For example, CPFM08 spoke of the importance of recognising the impacts on her of the harm to her grandmother, without erasing the primary harm to her grandmother in residential aged care:

> And sometimes I felt like I can't talk about that part because it's, about me or about my mum and not about my grandma, but it is important. And prior to my grandma going into nursing home, my grandfather had been placed in one, seven years ago. And so a lot of our trauma is transferred from one institution and one grandparent to another. And so I have been doing therapy and it was really the two stories of both grandparents kind of coming together. And I think it is important that we also look at what it means for people that are carers, family members have guardianship because that is part of the story. I guess, I just haven't felt like if I talk about how it impacts me, like I'm erasing her story.

VA08 emphasised that the experiences of people living with dementia in residential aged care should not be individualised, and to instead take a relational approach. VA08 explained this by reference to CPFM13's experience of her husband in residential aged care:

> And the other thing about individualising people is that, and this is particularly important in the case of dementia, it is not treating people as part of social units, as part of a family. So [CPFM13] got completely marginalised. And in fact, the way in which she was treated over her complaints for the last four years has been a continued attempt to marginalise her. Oh, your husband's dead. What are you going on about? Oh, you are the grieving widow … Oh, everything is kind of justified. And in that sense, the anguish that people are feeling, the grief and the anger is just compounded by these responses.

Complaint processes can be traumatic. CPFM10 spoke of the traumatising impacts of engaging with complaints processes:

> [T]he amount of retraumatising that happens by going through the complaints process. We were asked to resubmit, resubmit, 'Oh, send me that email again, send me those photos again, can I have another look at?' We were continually asked, would we meet with the facility? Even though we said, we did not want to see those people again. We were asked because conciliation is one of the ticks for getting complaints done. Even when we asked for

> review, I was asked, would I attend a meeting with the facility? And I said, no, but the fact that I was continually asked …

The extent of the impacts on care partners and family members – both of witnessing the harm to and its impacts on persons living with dementia and having their own negative experiences of intervening and complaining – can result in some care partners and family members seeking recognition and justice for years after the individual living with dementia has died. For example, VA08 described the phenomenon of care partners and family member becoming advocates:

> [T]here are two kinds of people who are carers in the context of dementia … I'm coming across them all the time. There are the ones who become activists, because absolutely committed to changing the system. So it doesn't happen to other people. I suppose I'm one of them … And then there are the people who simply want to forget it ever happened because it was so traumatising.

CPFM13 described her advocacy in relation to residential aged care after her husband's death as her 'lifetime work':

> I've got to talk. I wouldn't accept anything if I have to stop talking, not at all. Because this is my lifetime work, this is what I've worked for all my life. And it's going to be what I work for until the day I die. If my husband hadn't have taken ill, I wouldn't be sitting here today.

CPFM11 referred to getting 'justice for Mum':

> Yes. I feel like that has been my mission on my own for the past few years, because I felt like there was no justice with what happened to my mum, even when things were found out that went wrong and they admitted stuff and it was just like, 'Well, we've said that it went wrong', and that was it. So I felt like that's... I don't know. I feel like they got away with it, is my take on it. I just felt like it wasn't fair. At one time a lawyer got involved and was ready to do negligent case. It was a strong case for that, but we didn't go ahead because it wasn't for Mum. It was only the psychological trauma for us, not Mum. Didn't matter what happened to her. That wasn't the money value placed on what had happened to her. And we just at the time, we thought, 'We just don't want

> that, we want justice for Mum.' We felt like that wasn't going to happen ... So we didn't go down that legal way, even though the lawyer has kept pestering us for years since, wants us to go ahead with it. Yeah, so I don't know. I don't know what that form of redress would be, but I feel like there need to be some, there needs to be.

Reparations for the impacts on care partners and family members of harm to people living with dementia is necessary to recognise the extent of the damage done through the harm. Rather than detracting from the harm to people living with dementia, this more expansive approach to *who* can be the subject of reparations ultimately supports restoration of the dignity and humanity of people living with dementia. This is by honouring the life of a person living with dementia and demonstrating that they mattered and were loved (countering the dynamic of grievability discussed in Section 1.1.4), and by sustaining the quest to realise justice even that individual after their death, so that they cannot be defeated or forgotten in their deaths.

The importance of recognising broader impacts of harm to people living with dementia in residential aged care on their care partners and family members can be supported by the experiences of survivors in the context of other Australian redress schemes. For example, the narrow approach in the National Redress Scheme of only providing redress to individuals who were sexually abused has been criticised for not recognising the impacts of the sexual abuse on others:

> Redress is very traumatising for care leavers and their families who are the silent victims. We don't hear enough about the families who have to pick up the pieces or the care leavers who are not eligible for redress, who get rejected by redress, and those people need to be heard as well.[197]

Recognising the broader impacts of harm to people living with dementia on care partners and family members and, indeed, wider communities, is particularly important in the context of First Nations people. It is important that impacts on family and kinship relations and broader communities are recognised in delineating who is impacted by harm to First Nations people living with dementia. For example, in the context of the development of the New South Wales Stolen Generations Reparations Scheme, Legal Aid NSW submitted that the scheme needs to be open to applications from diverse applicants and must adopt a broad conceptualisation of victim-survivors to encompass family and kinship networks who suffered.[198] In a different redress context, the Victorian Government recently passed reforms to its victims support scheme to broaden the range of claimants 'to recognise Aboriginal kinship relations, LGBTQ+ "chosen families" and close extended family members, while children exposed to family violence will be considered victims in their own right'.[199]

4.2.3 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.

The pain, resistance, and distress that individuals living with dementia express in response to experiencing harm in residential aged care is often attributed to dementia and disbelieved, dismissed or pathologised by residential aged care staff and police. Sometimes harm is instead variously viewed as legal, benevolent, therapeutic or necessary. Thus, people living with dementia experience silencing and invalidation of their experiences of harm. This can be understood by reference to the concept of 'epistemic injustice'. Miranda Fricker explains epistemic injustice is 'a wrong done to someone specifically in their capacity as a knower'.[200] She identifies two specific forms of epistemic injustice: testimonial injustice and hermeneutical injustice. As she explains:

> Testimonial injustice occurs when prejudice causes a hearer to give a deflated level of credibility to a speaker's word; hermeneutical injustice occurs at a prior stage, when a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences. An example of the first might be that the police do not believe you because you are black; an example of the second might be that you suffer sexual harassment in a culture that still lacks that critical concept. We might say that testimonial injustice is caused by prejudice in the economy of

> credibility; and that hermeneutical injustice is caused by structural prejudice in the economy.[201]

This silencing and invalidation in relation to experiences of harm occurs in a broader context of people living with dementia having their perspectives and needs invalidated and ignored by reason of specific stigma associated with dementia and broader ableism, ageism and sexism. For example, people living with dementia can be moved into residential aged care against their will, be subjected to restrictive practices against their will, not have their individual identity and preferences recognised, and have their right to take risks removed from them.

Care partners and family members who seek to intervene or complain are positioned as irrelevant or disruptive, leading many to advocate for justice and change years after the person they cared for has died (as discussed in Section 4.2.3).

Thus, reparations are necessary in order to validate the experiences of people living with dementia, and of care partners and family members.

Validating the experiences of people living with dementia

People living with dementia are not listened to and believed when they experience harm. Mental and physical signs of harm are pathologised as part of an individual's dementia. Alternatively, the harm is not even recognised because it is justified as benevolent or necessary on the basis of dementia.

Some research participants discussed people living with dementia not being believed because of their cognitive incapacity. AL04 spoke about the epistemic injustice to people living with dementia:

> People spoke about not being believed and I think that's connected to a kind of epistemic injustice again, which is connected to age-based discrimination. And which is that older people and particular people who are labelled or diagnosed as having dementia aren't reliable witnesses. So it's only the bruises and things like that can be pointed to. And even then they're not reliable witnesses because maybe they were elevated or they become invisible, they just become their diagnosis.

VA07 drew an analogy with disbelief of sexually abused children:

> I liken it to sex abuse in children many, many years ago, where the voice of the child wasn't heard, and it's only been more recently with Royal Commissions and stuff, that has been recognised that children were sexually abused in the past.

CPFM11 spoke of her realisation upon reading through her mother's residential aged care facility notes, that she might have been sexually assaulted and no action had been taken at the time because her behaviour was attributed to her dementia:

> [There were] allegations Mum had raised, comments from staff that [Mum] said about a male carer or there was an old man. There's another page where a resident was found in her bed, all these things that I just went, 'Oh my God, something may have happened to her.' At the time when we said it, they said, 'Oh, she's just hallucinating. It's part of the disease. You're not accepting it.' Had all these, and I went … I went, 'Oh, shit. They should have reported that at the time. Something might have happened. They might have got investigated.'

CPFM13 spoke of her husband being chemically restrained in a residential aged care facility after having returned from a hospital stay:

> When he come back from … Hospital, they had him so drugged. And when he come back, it was the manager that asked the doctor again to put him on more. It's on paperwork. And the manager's trying to say, 'Oh no, no, no, no, that's all up to the doctor. That's all up to the doctor.' And the doctor says, 'I assume that you have spoken to [CPFM13] about this.' And his reply was, 'Oh, [CPFM13] understands all the side effects.' I didn't even know he was getting these drugs. He never talked to me about it. So there's a lot going on that we don't know and people don't know, and they're just blaming the resident for being... 'Oh, this is what dementia is.' And there's no denying, we can all get angry without dementia.

CPFM08 explained how her grandmother's weight loss while in residential aged care was blamed on her grandmother's dementia:

> And I think also it's the type of, I mean, not everyone in an aged care facility has dementia, but this is a particular area that we are looking at and the kind

> of, the nuance of abuse and neglect with dementia, because they'll say things like, 'She's not eating.' 'Oh, well, that's what happens when people have dementia.' Or, 'She's lost excessive amounts of weight.' 'Yes, that's to be expected.' And, but everything is, it's to be expected, it's normal, that's dementia. And when we push back, we actually find that she is eating now, so what's changed and she has gained weight now, so what's changed. And so I think it's also using dementia to also hide abuse and neglect, which that makes it harder for redress as well.

Listening and validating the experiences of care partners and family members

Listening to and validating the experiences of care partners and family members is important because many have not been listened to when they sought to intervene and stop the harm to an individual living with dementia, and/or sought to carry on the legacy of that individual and honour their lives through seeking justice after the death of the individual. 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, or seeking recognition and justice of the harm after the person has died.

Some care partners and family members can devote years and much money to seeking recognition and justice. For example, CPFM13 explained how much she had spent on legal fees:

> They didn't care. They didn't care for him. I did all his care. And then when they couldn't cope, they sent him hospital, five weeks with a guard at the door and not let a man out a room. And then they sent him crazy trying to get out and then they'd inject him and give him more medication five weeks while the public were paying for that money. Five weeks in the hospital and [organisation operating facility where CPFM13's spouse was harmed] was taking my money for a name to room. And also, I counted up all his medication and I got a cheque for $265. I'm going to send you a package and explain it all. Not that you might can do anything with it, but it I'll give you the idea of why I'm so strong in fighting this. They come and [organisation operating facility where CPFM13's husband was harmed] refused to see me. And it took me four years … And they wouldn't give me the notes. So I got the

> solicitor and that cost me up till about $10 or $12,000. And it’s cost me $18,000 to try and get $18,000 back. It is crazy. I know I’m crazy, but that’s how strong I am.

Indeed, as we discussed in Section 4.2.2 above, some care partners and family members who have had such experiences go on to become volunteer dementia advocates and focus for years on working for systemic change in aged care policy and practice.

A common point made by some research participants was that the system has silenced them. CPFM13 observed this silencing starts during the provision of care:

> You hear it all the time, nurses and doctors, they won’t take any nonsense from you as a person. I had to keep my tongue between my teeth and sometimes I just walked back with silence up and down, because they could have put me out and not allowed me back in to visit [husband]. And they would’ve scheduled him. So I had to be very careful. And this is where you’re silenced. I couldn’t turn to a nurse and say, ‘You’re not doing your job.’ They never even come and ask me if I needed any help. They never come and say, ‘How are you doing? How is this? And how is that?’ Not once. There was not one good nurse that I came across in the whole ward.

This silencing then carries over into advocating against abuse once it occurs. CPFM02 explained her exhaustion at the obstructive response of the residential aged care provider:

> I moved my mother from the facility that she was in because of her behaviour that resulted from poor management and her behaviour’s not difficult. She was being neglected. And the issues that I tried to address with the manager at the time, the RN, I was appalled and shocked and contemplated writing a complaint to have her nursing registration reviewed … And when I did put in a complaint, it was investigated internally and that is problematic. So it was covered up and no information was forthcoming. My mother was safe. And so part of the issue is, if she remained there, she was always, ‘Don’t create waves because there’ll be repercussions.’ So, that’s a huge problem. So I don’t know. Maybe I should have kept it going, but I was too exhausted to deal with it. And the things she [the manager] screamed at me were so

> unprofessional and so out of order, that I just ... I'm still, years down the track, a little bit traumatised from it, that was beyond my understanding of why anybody would behave that way. And she's a manager.

This silencing then carries on to making complaints after the person dies, as noted by CPFM11, whose mother's private information was disclosed by the residential aged care provider after CPFM11 publicly spoke out about her mother's experiences:

> So I'm fighting. I just feel like I'm exhausted by it all because Mum's gone and I haven't moved on, and they're basically getting away with it. They're getting away with covering up sexual abuse allegations. And they're getting away with breaching someone's privacy. And they're getting away with intimidating thousands of residents by telling them, if you speak up, this is what we'll do to you.

CPFM15 spoke of the lack of validation through the complaints system:

> I ended up going through the Aged Care Quality and Safety Commission, doing a full complaint that took ages. And it ended up that the Aged Care Quality and Safety Commission said, 'Yes, you're completely right in everything that you've done, and they're responsible for your father's death', but that's it. There's nothing. Having that validate, I really like that because I think that's absolutely crucial because to go through all of that, if you had a redress scheme that would say, 'We're validating what you're doing' and I don't think what I got from the Quality and Safety Commission was really validation. I just wanted to say that.

Thus, reparations are necessary to validate the experiences of people living dementia and care partners and family members and in turn to achieve justice and bring about change that has been prevented through silencing.

4.2.4 Principle 4: Accountability

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

Reparations are necessary to ensure moral accountability, legal accountability and economic accountability, in relation to governments, residential aged care providers and all other parties who perpetrate or are complicit in harm. Orienting reparations exclusively towards those who are harmed or impacted will undermine actions directed towards supporting recognition and healing of those individuals; they must be accompanied by actions to explicitly recognise and condemn the actions of perpetrators. Those who have perpetrated or financially benefited from the harm must take responsibility for those wrongs. Otherwise, as we continue to see reported, their behaviour will continue.

Accountability must extend to the health and legal professions. 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. 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).

AL02 explained that reparations must constantly foreground the wrongdoing of perpetrators in reparations, because focusing only on recognising and responding to the experiences of harm can slip into erasing the responsibility of perpetrators and, in turn, overlooking the accountability of those who have caused the harm:

> [Y]ou see the word ‘people with dementia’, you see the word ‘family’, you see ‘care partners’, but you don’t see the words ‘government’ or ‘governance’ and ‘providers’. So I think it is important to have those words there. And to attribute some responsibility up front here. This is where I would say it’s important to know their presence, because they’re like an amorphous thing in the background, but you can see the people with dementia, they’re named.

While the Aged Care Royal Commission, and other inquiries before it, found abuse, violence and neglect in residential aged care, neither these inquiries nor existing regulatory systems have facilitated accountability. This is in contrast to the Royal Commission into Misconduct in the Banking, Superannuation and Financial Services Industry which resulted in some regulatory action.[202] For example, CPFM10 contrasted the failure of residential aged care providers to accept accountability with the actions of banks in the aftermath of the Royal Commission into Misconduct in the Banking, Superannuation and Financial Services Industry:

> In the Banking Royal Commission, the banks had to acknowledge and … were fined. I think when you're talking about redress, like in my case, my parents have passed away. There is no sort of redress for them, but there needs to be acknowledgement that this happened, I think that needs to come from providers. The providers have not come forward and say, we dropped the ball, there was a lot of bad stuff happen. I think there certainly needs to be some acknowledgment.

The general failure of anyone to accept responsibility for harm to people living with dementia in residential aged care – individual staff members, residential aged care management and board members, medical and legal professionals, public servants and governments – reinforces the dehumanisation of people living with dementia by suggesting experiences of harm do not constitute wrongs deserving of justice.

Accountability is important so that individuals responsible for perpetration of harm are stopped and punished. Accountability is additionally important because if perpetrators are not negatively impacted in some way – particularly financially – they will continue to perpetrate harm. CPFM07 proposed that the issue of accountability needs to confront the financial model:

> I did want to also touch on that motivation to profit over quality of service and the whole redress conversation needs to shine the spotlight on that particular motivation. The motivation to do the right thing over the motivation for profit, quality of care can come down to simple things like hydration, not getting sufficient stimulation, the boredom that's in nursing homes because of the lack of educational, stimulating activities. You'd never see that in a childcare setting, but we see it all the time in age care settings. I think the conversation around culture in the workplace and motivation to do the right thing is imperative.

Some ALs observed that the provision of extra funding to residential aged care providers to improve the aged care system could undermine the need for economic accountability:

> AL10: I suppose we've... With all the statements on underfunding of aged care, too, a lot of people might think, well, that money that could be put into

> redress where many of the perhaps victim have passed on could be better put into the sector for future needs.
>
> AL07: But the argument against that is if it doesn’t cost the system anything to harm people, then they’ll keep doing it. Because it’s cheaper that way. There needs to be some accountability and economic accountability.

VA04 saw redress as a potential catalyst for organisational accountability and change:

> When you look at aged care facilities, a huge majority of them have got a dollar sign at the bottom of the page that drives an awful lot of things in that organisation … To me, if the idea of compensation being very close to the front of many people’s minds in cases of abuse, I’m just wondering whether that would be the catalyst that would take these CEOs and their boards and their management, to a point where they would say, ‘Absolutely everybody in this organisation is going to sit down and do a three month online course or whatever it is, they will have to show evidence of learning.’ And I don’t know how you do all this stuff, but I’m wondering whether it would be the bottom line on their accounts that would drive a change in environment in terms of looking at redress that can be legislated, and then seeing how that would change the whole attitude.

Shifting beyond the accountability of residential aged care providers and governments, and resonating with the earlier discussion of ‘implicated subjects’ (Section 3.2.2), VA01 noted that redress is necessary because of broader society’s complicity in what happens in residential aged care.

> Well, I think, as individuals, we’re all part of a community. I’m probably not expressing myself properly. We don’t live on an island. Well, we do live on an island, but you know what I mean. We are part of a global village. We’re all responsible for what happens to one another … Just in the same way we’re all responsible what happens in climate change. We’re all responsible for what happens in various other things. We all have a part to play in all these things that are going on. In many ways, we here are just as responsible for some of the things that are going on in Europe with migration and that kind of thing, because we have not accepted people, so they’ve gone in another

> direction and fallen by the wayside in trucks moving across the channel … I think we've got a moral obligation to make sure that people who have been harmed in some way or other... Even if the redress was very, very minimal, it still needs to be there.

Reparations can be more appropriate for exploring the complexities of complicity and implication, as noted in Section 3.2.2.

4.2.5 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.

Reparations are necessary to prevent further harm to people living with dementia. Reparations can have a role in harm prevention when they provide tools to confront the past and use the past as an opportunity to learn, change behaviour and change systems for the future. Reparations are described as having a dual temporality. They have a retrospective dimension because the impetus for reparations is past harm. However, they also have a prospective dimension, in two respects. The first is 'repairing' or restoring individuals, relationships, communities etc. for current and future benefit, and the second is reforming systems and institutions so as to remove the structural conditions for further harm.[203] This dual temporality is arguably a key defining features of reparations and distinguishes it from court ordered remedies and even some specialised redress schemes.

Importance of harm prevention

Reparations are also necessary to prevent further harm. One of the overarching points made by research participants was that past harm could not be fixed or taken back, but it should be possible to stop this harm from happening to anyone else. For example, CPFM10 stated:

> 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.

CPFM02 similarly noted the importance of learning from the harm to fix the system:

> I don’t think money and payment for problems that have arisen is going to fix it. It doesn’t make any difference to the situations that I’ve experienced. So it’s not about money and therefore it’s not even about an apology, which could be a hollow apology anyway, it’s more about, ‘Okay, what are we going to do to fix this’ and prevent it recurring.

PLWD05 noted the need to change systems for the collective benefit of everyone in the future:

> [I]f I look at it from a personal perspective, most of us, I think one 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.

CPFM15 explained that an exclusive focus on individual recognition, healing and accountability will not fully ‘right the wrongs’ of residential aged care because it fails to address the structural conditions enabling this harm:

> I think a lot of providers see sort of compensation and redress as something that is ridiculous and they don’t want to go near. And I think people need reminding that it’s about stopping people from... It’s not just writing off if they did have to pay compensation. Not just writing that off as a cost, but as a ‘This is actually to stop them being harmed.’ So I think that’s key.

AL02 elaborated on the need for reparations to avoid repeating history:

> I think we have to abolish the current system of aged care because the current system perpetuates this. So to really, if you really want to have a proper redress scheme, you have to completely redesign aged care and disability care, otherwise you’re just going around and around in circles. Every five years, here’s another apology, here’s another 60 million [dollar]. I mean, it’s... So basically a real redress is an acknowledgement that the current system is not the right one and we have to completely overhaul it.

AL04 phrased this need for non-repetition in terms of reparations being about prevention:

> [R]edress is connected to prevention, to me. So I think that if we want to prevent these things in the future, redress is part of doing that.

It is necessary that reparations approach prevention of further harm through a human rights framing that is grounded in the equality and dignity of people living with dementia. Harm prevention in relation to people living with dementia often occurs through paternalistic, oppressive and even violent interventions in their bodies and lives (e.g., prevention of injury could involve non-consensual use of restrictive practices; prevention of sexual and or physical victimisation of people living with dementia in the community could involve their non-consensual admission into residential aged care). That approach to harm prevention punishes the individuals experiencing the harm rather than perpetrators, and also does further harm to the individual. Where prevention of further harm impedes the equality and dignity of people living with dementia, the human rights framing of reparations is fundamentally undermined. For example, the current UN Special Rapporteur on the Rights of Persons with Disabilities, Gerard Quinn, has noted in the context of armed conflict that protection of people with disability must not slip into paternalism. He explains that '"protection" in the [CRPD] is part of a broader agenda of personhood, inclusion and participation: a vision of active human agency'.[204]

Addressing structural conditions for harm

The prospective dimension of reparations can facilitate addressing structural conditions of harm. CPFM15 explained that systemic and structural change is necessary because otherwise funding models and laws can support and legitimate continued harm:

> [Structural and systemic change to stop harm] is an imperative because government is funding models of care that are outdated, that are abusive of human rights, and government won't change it. So I can see a lot of providers saying, 'Well, it's completely legal that we do this. We're funded by government, et cetera, et cetera.' But we I'm presuming, I would say all of us are well aware of the gaps in regulation and monitoring, et cetera. So I think it's so important and critical to have that.

This connection between past and future harms through a focus on prevention is not automatically designed into redress schemes. One criticism of the National Redress Scheme is that it does not have an explicit focus on prevention, as noted by two ALs with experience of the Scheme:

> AL 12: [M]aybe I'm a bit cynical, but I'm not sure that we're seeing [prevention] out of the National Redress Scheme. And I suppose the NRS [National Redress Scheme] was primarily about recognition of harm … but I think we do see some institutions that are still sort of dragged kicking and screaming to the scheme, and that I think there's something about it, I think, that it seems sort of separate to that ongoing reform and systemic change. So yeah, I think I was interested by the idea that redress could provide that. And I'm not saying it can't, but I think then it's interesting to me because I think having that principle then very much would inform the design of a redress scheme in this space that I think then would look quite different to what we have in the NRS [National Redress Scheme] …
>
> AL 13: I very much agree with that. I think that the context of the redress scheme being set up following the Royal Commission [into Institutional Responses to Child Sexual Abuse], where a lot of the cases in the spotlight were historic cases of abuse, so I think there's definitely, as [AL12] said, a lack of mechanisms in place to make sure that change is happening today in those institutions.

Transformative change

Some research participants identified the need for reparations to include transformation of the entire aged care system. AL02 referred to the need for reparations to 'overhaul' the current system:

> [A] real redress is an acknowledgement that the current system is not the right one and we have to completely overhaul it.

CPFM18 explained that transformation must be the focus rather than simply assuming the problems can be solved through more funding:

> I mean, we've been through a lot of barriers kind of on the way. In terms for me, the biggest barrier is the aged care system not changing enough. Not that

> it doesn’t change quickly enough because it’s not going to, but I just think politicians seem to think that throwing money at it is going to work. But I think that whole aged care system needs a complete reboot and I don’t see how that’s going to happen very easily. And that’s my worry about the future really. How are they going to implement a big reboot? It’s like they almost need to start again. They obviously can’t change what’s already in existence, but they need to put a new system in place and get everybody else to follow, because just throwing money at it will just go all through the cracks that already exist and it’s not going to make a big difference.

As well as reparations being necessary to transform funding, legal and service systems and structures, reparations are also necessary to transform cultural understandings of dementia. PLWD08 described the need for a ‘paradigm shift’:

> There has to be a paradigm shift. It really does. That’s not only for people who are live in full-time care that are aged, but also in the community … Yeah. So there has to be a cultural change.

Related to cultural transformation, PLWD09 explained the need to balance power between people living with dementia and residential aged care providers:

> ‘Cause ultimately, without being paternalistic, the person living [with] dementia is vulnerable no matter what way you look at it, we’re vulnerable. And it’s just part of redress is how do you redress that imbalance? Not just for people who things have happened to, but we’re also redressing this imbalance for everyone. And I think that’s something that I’d really like to see acknowledged in here, is that it’s not just redress as in punitive or this happens so we've got to fix it. It’s redress that people are vulnerable, we’re paid to support them. How do we balance this up? So it’s more of how do we address this as well as redress?

In a similar vein, AL04 drew on his experience in mental health advocacy to speak of the need to transform the power relations between people living with dementia and governments and residential aged care providers:

> [I]n mental health, one of the reasons that we would talk about these processes is to address the power imbalance between providers. And there’s

> lots of different ways you can frame that, but not even restore a better relationship, but create a better, more equitable relationship to actually see people as humans, to sort of restore their standing within society.

4.2.6 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.

There has been a complete failure of existing systems to acknowledge and respond to harm to people living with dementia in residential aged care, particularly the wide scope of harm described in Section 4.2.2. Yet international human rights instruments provide for the right to equal access to justice and remedies, including for human rights violations, as discussed in Sections 1.1.3, 1.3 and 4.2.1.

While reparations are one way in which to respond to the current limits of justice systems, as we discuss in Section 4.2.25, reparations should complement rather than replace justice systems. Reparations must not come at the cost of transforming justice systems to make them equally available to people living with dementia and their families and care partners.

Failure of complaints and regulatory processes

People living with dementia can fear retaliation if they complain about their treatment. PLWD01 spoke of her own experiences of being silenced in residential aged care and suffering retaliation when she made a complaint:

> [Y]eah, there’s that fear of speaking up. Will you be heard? And will you be, ‘Oh, well, she has a lot to say.’ So I could be disadvantaged with my care because of that.

PLWD01 went on to describe being silenced and marginalised to the extent of being infantilised (‘a little bit of strife’):

> So, I think, I get myself probably into a little bit of strife because I do speak up. But I think they need to hear it and we will have a residence meeting, but I’ve been saying of late the lack of communication here doesn’t get followed through. We have a residence meeting and these suggestions are brought up,

> but nothing happens. There’s no follow through. I know I’m finding that very frustrating. So they don’t listen to us. Yeah. They don’t listen to us.

Complaint processes are not accessible to people living with dementia, in part because residential aged care providers make it hard to know about the right to make complaints, as PLWD06 explained:

> They’re too difficult to work out how to access. And I think for the, well, in any of the care facilities, if the individual is trying to make the complaint, how do they get to that point to able to do it? Because be it’d very easily to subtly prevent that occurring in of lots of ways, and likewise in what might be historical cases for family to do it, they’ve got to know that it’s available, how to do it, et cetera. And probably 90% of the people aren’t going to be in ability to do that, particularly I’m sure all the information will be available publicly online, 27 levels down. It’s there for anyone to find by chance, but if you’re looking for it, you may never find it. And the timeframe that it occurs in is going to be another issue too, it has to be fairly quick.

Complaints processes are also not experienced as transparent or safe by care partners and family members (who are often the individuals making complaints in relation to harm of individuals living with dementia). CPFM11 noted the problem of retaliation in complaint making:

> [I]t’s very rare anyone puts in a complaint because you face [retaliation]. The interesting about Mum’s is that then, since I’ve forensically analysed every page of her notes, was the amount of [retaliation] we faced and Mum faced once we spoke up at the time of about the medication issues. Let alone what happened when we spoke publicly and they came after us.

There is also the perception of complaint processes as being more directed towards the continuing operation of residential aged care facilities than redressing the harm that has occurred in those facilities, as noted by VA07:

> I think that most people go to the Aged Care Quality and Safety Complaints Commission thinking that they’re going to get redressed. But the process of that particular government agency is legislative, to make sure that the legislative compliance ... to make sure that the facility is complying with the

> legislation. And once you make a complaint, they’re actually not interested in your story or you anymore. Their whole focus is on compliance of the facility. And even if the facility does a little bit, then that’s how they sign up on compliance. So I think for the individual to seek redress for some sort of harm abuse, et cetera, it has to be done through another agency, because that’s not the appropriate agency to deal with individual people complainants.

CPFM10 emphasised the role of complaints as returning residential aged care facilities back to compliance rather than being focused on the individual living with dementia:

> I think any redress should also look at the role of the regulator, because I think the regulator has really dropped the ball on a lot of issues and has allowed neglect to continue really, because certainly we went through the whole process from all the way through to a review. And really the main aim of regulation is to return the provider to compliance. It’s not about addressing wrongs. It’s not about really improving the system. It’s about how the paperwork looks.

This sense of futility and that complaint processes just keep the system running is reflected in CPFM03’s experience of making a complaint:

> Classic example, I put a complaint in last year about medications and the complaint system with two or three complaints. It took 10 months before the Commission got back to me and said ‘nothing found we can’t do anything about it’. Then a couple of months after that an accreditation team came in and the same provider, same nursing home failed five parts of the accreditation. and two of those were medications and complaints. So just exactly what I said. So I put a complaint through, he gave me information why, and then got told nothing found, everything is good. Accreditation goes in, finds the problems. Then, unfortunately, two months later, after changing some paperwork or whatever, they get full accreditation ... So, they don’t learn.

CPFM11 explained the problem of blurring of complaint and regulatory roles, which compromises the capacity for a focus on people living with dementia and issues of accountability:

> It’s a mess from the very top down on this. Age Care Quality, it’s a mess now. They put all the regulatory together along with the compliance and the complaints. It’s sort of a mess when they’re all in the one department. One minute they’re educating them, and then next thing they’re meant to [be] mad at them.

Similarly, PLWD01 reflected on the lack of independence and transparency in current regulatory processes:

> Yeah. There’s just so much cover up. You know? As I said, when the accreditors come in because they’ve had a whisper, so everything just looks as if it’s running so smoothly. When underneath, if they can just call in unexpectedly, then they would see the true workings of what’s happening and what’s not happening, I should say.

Internal complaints processes can be experienced as ineffective. This is explained by PLWD12, whose wife lives in residential aged care:

> [W]hen I talk to [the residential aged care provider] about quality systems and what they’ve done is that … their quality system would make a lawyer run away and hide because it’s there to actually confuse the issue more than actually provide information … we need to radically change aged care providers and even make it so that their quality systems are accessible to outside people. That people outside can actually see their complaints book. Because when I talk to them and say, well, okay, I’m making a formal complaint, I want to know what the root cause analysis of this complaint is. I want to know what follow up actions they’re taking, and I want to know what you’ve actually done about that. And they just run away and hide and sort of say, well, we’ve got a quality system that actually does that, that we’ve put things in our daily records, we do this, but we don’t have a root cause analysis in there. We don’t do this and we don’t do that. But try to drag information out of their system. Like when my wife complains about how it took two hours to get somebody to respond to a buzzer … They come back and say, well, according to our system, which is an electronic monitored system, we responded to her within 30 seconds. And I said, there’s no way that could be because when I walk outside of her room and I look up at her at this stage,

> the time that's listed overhead in the call board is half an hour out from real time. So there's no way that their system time could be accurate. And when I ask basic questions about how often does this system actually get tested? Does anybody ever actually sit there with a stopwatch and actually press a buzzer and see simple things like do they actually do things like that and actually test the system and actually look at what their system says, oh no, that's actually monitored by an external provider. What I'm finding with aged care is that there's all of these rules, regulations and everything that's been in place, that there is not common sense.

Internal complaint processes can also be experienced as unsafe by care partners and family members. For example, CPFM15 stated:

> [O]ne of the things I don't, and I'm sure other people experienced it too, is when you go through the problems with an aged care provider, I had a particularly bad experience with the facility manager who would actually follow me around threatening me that she would ... I wasn't my father's power of attorney. She said, 'Look, I'm going to tell the power of attorney for your father that you are causing trouble so that he can try and ban you from coming in, perhaps put an apprehended violence order out on you so that you can't see him', things like that. And just the amount of trouble we went through.

Failure of justice systems

The justice system fails to respond to harm to people living with dementia. Police are not always aware of how to support, or are unwilling to support, people living with dementia; court processes are time-consuming; legal assistance is expensive; not all harm will satisfy legal causes of action; and compensatory remedies are more beneficial to people who experience harm at a younger age. Moreover, harm to people living with dementia that amounts to indictable offences might end up with prosecutorial officers who do not have the knowledge or skills to prosecute crimes against people living with dementia.

AL17 described the inaccessibility of justice systems:

> Redress is necessary because of the failures of existing inaccessible justice systems, basically. That might be a way of emphasising the experiences of

> people with dementia as a form of disability and lack of ... There are many ways in which the justice and regulatory systems are not accessible to people with disability. People don’t provide support, decision-making, all that kind of thing … It just made me think of, in the disability sector, trying to play. There was an advocate and they might say, ‘Oh, well, there’re safeguards in place’ … People with dementia have very specific communication needs and I guess that is one of the whole problem. It feeds into this broader picture of structural harm.

CPFM10 noted the failure of police to respond to harm in residential aged care:

> My mother-in-law, who was at what I would consider a good facility, was actually assaulted by a staff member. Now she had dementia and she was able to say how her injury happened. And the story from the staff member was different. But there are three doctors in the family who all looked at her injury and said, ‘That’s not consistent with the story of the nursing home.’ And my mother-in-law was able to get that story. The nursing home themselves contacted the police. The police came and spoke to my mother-in-law, who gave them the same story that she’d given the family, but they didn’t pursue it because they felt she would not be a good witness. Now we later discovered that they could have videoed her interview, and that could have been all the evidence that was needed. So what happened was the staff member resigned, they were a carer, there’s no registration. They can just go and work down the road at nursing home B, with no record anywhere. So work needs to be done within the criminal justice system that people with dementia are important and valued. And they can’t always remember people’s names, but they can remember what people did or how people made them feel.

AL06 described a ‘vacuum’ in the justice system for people living with dementia:

> They’re our most vulnerable people. They’re too unwell to access their own advocacy. I’m dealing with a case right now where a person is extremely ill and clearly needs legal advocacy and there’s complete vacuum. So somebody has to come in to act and to organise because it won’t automatically happen that this person will get some kind of advocacy. So it’s the fact that they’re vulnerable people and the fact that we know the violence

> and abuse does occur and that there is a vacuum in the system for recognising their rights.

AL07 referred to the limits of common law compensation in relation to harm of people living with dementia in residential aged care:

> I do wonder, and I’m just putting this out there, the law, the legal system discriminates against the elderly. In terms of economic loss, which is one of the thresholds and the barriers to serious compensation, or even any compensation in some states, you’ve got, you’ve got real problems if you’re a retiree, right? The system is designed to lock them out. So I do wonder, though, whether there’s no pressure on the system, because lawyers are generally not looking at this area as one of fruitful compensation, and that’s because of the discrimination in the legal system itself. I’m not saying that’s the only reason, but it may be one.

AL07 went on to note other issues with the justice system:

> I do believe that in this context, compensation and court process is really not appropriate. I mean, you may have people with dementia, they’re not going to enjoy that process. And they may not succeed in a normal court process. So alternative forms of finding justice would be a most desirable outcome, but, and even criminal charges or disciplinary charges … incredibly difficult, unless you’ve got a witness who’s fully competent and can make an adequate healthcare complaint … they’re very difficult to get up. And then you’ve got issues of privacy. If you got to record ... I’ve often thought that perhaps there should be a motion detector, if someone comes into a room at an agreed time, there should be a camera, but then there’s privacy issues. You’ve got a whole bunch of issues going on there.

AL01 observed the traumatic impacts of ‘broken’ justice processes:

> I guess the other aspect to look at is, how else can we get redress in our society as it’s currently set up? Then we have a court system that’s completely broken when it comes to righting wrongs, and the fact that the process is so traumatic, everything’s so hard to prove. You have to have so

> much documentation and so many accounts of the kinds of abuse that are, in their nature, so hard to prove.

CPFM11 described a situation of no system – regulatory or justice – being able to assist, and being constantly moved between them in relation to her mother's sexual assault:

> Cops didn't want to see it. All he said was— his report, you wouldn't— I've only read half of the police report because it was so horrific. Because he decided, from not speaking to me, not speaking to the age care thing and just reading a little bit of the timeline where the head nurse, the DON [Director of Nursing] said something about hallucinations. She used the word hallucinations. That he said, 'Oh, your mother had a rape fantasy.' So that's the cop. Seriously. So we've got cops... So there's systematic errors on every level. We've got police that just said, 'Well, we won't deal with it. Let Age Care Quality deal with it.' Age Care Quality said, 'Well, that's really a policing issue.' Police won't touch it. Age Care Quality don't do anything about it. It's just there's so many incredible systematic errors … Police won't deal with you. Ageing and Disability Commission won't deal with anyone in aged care. And they're useless, Age Care Quality, they're next to useless. So there's no one really looking after anyone in aged care in any sense.

Failure of political system

The Australian Government has failed to learn from and act on the findings and recommendations of the Aged Care Royal Commission, and earlier inquiries into residential aged care. For example, VA08 described a lack of political will:

> [I]t is not in this society's interest to listen to these stories. And that hierarchical system serves to silence them. I mean, basically it's because Anne Connolly did such an incredible job of bringing stories to light that we got the Royal Commission, but the Royal Commission's only one of dozens of inquiries into aged care. And a lot of that's going to disappear the way all the other ones did, because you have to have a will to want to change. And that then feeds into economics again and power, let alone getting into things like ageism and stuff like that.

While some research participants felt the failure rested with the Australian Government's response to the Aged Care Royal Commission, other research participants were critical of the Aged Care Royal Commission itself and felt it had been too supportive of residential aged care providers. For example, CPFM11 reflected:

> Royal Commission, I found I was very disappointed by that. I felt like it was more industry-led. When you look at those witnesses that stood up, it was 7% of aged care residents' families. It was 93% of people that spoke at that Commission, or 90%, were industries or academics. Hardly anyone spoke up. There was a handful of things … But that people get to tell their stories. And that didn't happen. There was a handful of cases where they analysed a couple of nursing homes, and a couple of people got stood up. The whole public, we thought they'd be just getting up, and just talking about case after case. A bit like with the child abuse ones, of getting up and saying cases, and people getting a chance to speak up. And it wasn't. It ends up being just a love-fest for the providers, who got up. They got too much say in the whole matter. And they still have too much say in the matter … I suppose. Well, we thought something like the Royal Commission would at least listen. I thought someone would contact me after I sent my submission in, and say, 'This needs to be this, that and the other.' No one. You just felt like, 'Did anyone read it?'

CPFM10 spoke of the traumatising impacts of engaging with the Aged Care Royal Commission, seeing it as having similar effects to harmful complaints processes:

> I think really, after my experience with the Complaint Commission and even the Royal Commission, I think there hasn't really been acknowledgement of the trauma that is suffered by families. When the Royal Commission asked for submissions from individuals, they put that out just before Christmas. Providers had already been able to submit, individuals were asked to submit, I think it was Christmas Eve. No idea. I actually put that in as part of my submission, do you not realise how traumatising it already is for people who are thinking about putting in submissions, but then to do it at that time year was really terrible. I was contacted by the Commission and asked if I would

> give evidence in [capital city]. I was told I might not be asked, but I spoke to one of the lawyers and they said they would let me know. I didn't hear back from them. So I was just left hanging for two weeks. Am I going to [capital city]? Do I need to organise myself? Am I not going to [capital city]? But I'd just relived it all again, the whole process. And then they didn't even get back to me. And I thought, well, how are they going to deal with really, with the issues, if they can't even deal compassionately with the people who have had the trauma. And I think that whole thing needs to be acknowledged, as well, that some of the things that happened even calling the Royal Commission was not addressed adequately.

The Aged Care Royal Commission provided an important forum for highlighting the harm in residential aged care, coming after a series of reports over the past two decades. This would not have been possible without the contributions of submissions and witness statements by people living with dementia and their care partners and family members. These contributions might have come at great personal cost. Therefore, it is important to recognise and honour the experiences shared at the Aged Care Royal Commission, and ensure that reparations are used as an opportunity to validate those experiences and do not contribute to the pattern in justice and regulatory systems of silencing and invalidation towards people living with dementia and their care partners and family members (see Section 4.2.3). Reparations should not excuse the Australian Government from implementing recommendations of the Aged Care Royal Commission that will contribute to preventing harm.

4.2.7 Principle 7: Profit

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

People enter residential aged care with the promise of 'care', which they pay for. However, as discussed in Section 3.2.4, profit often seems more important than care, and it is possible for residential aged care providers to experience financial benefit when people living with dementia are harmed. This is then compounded by a lack of accountability. People living with dementia and care partners and family members sense that residential aged care providers see people living with dementia as a source of profit.

A range of research participants specifically observed that harm in residential aged care occurs in a profit context. VA08 noted a profit model that runs throughout residential aged care, including in charities:

> VA08: [E]verybody at the moment … is focused on staff. And the nurses, of course, making a lot of noise. Well, yes, we need nurses but they're only a part of this bigger picture. But where we don't have a focus is on the providers. Who are they, what is their ethos? And there is no doubt that the not-for-profits are looking after shareholders, they're not looking after residents. Sorry, for-profits. And not-for-profits are building empires. And you might think, 'Oh, they-re not-for-profit.' I mean, [major residential aged care provider] itself for instance, is becoming bigger and bigger and bigger—
>
> Focus group facilitator: Are they a charity or for-profit?
>
> CPFM13*:* They're supposed to be a charity. Yeah, supposed to be.
>
> VA08: Well, it just means that they don't have shareholders, but it doesn't mean that they're not expanding all the time. So in other words, the model upon which they operate is almost identical to the for-profit model, it's just ultimately the profits are going in different directions. The for-profits probably should all be banned, but of course, they'd be far too worried about doing that because the government's not going to pick up the tab. But you can't privatise something like age care. I mean, that's a social contradiction in itself. Why should aged care be reduced to the kind of ... commodification.

In a similar vein, CPFM10 observed that not-for-profit residential aged care providers are 'busily building their asset base' even if they are not making profit in the technical sense of the term. AL04 also observed that it 'seems like people, harm, abuse and neglect, they are just externalities within that corporate model, that are embedded within it'. VA03 pointed out that 'the medical and legal profession … also profit from harm'.

CPFM13 framed the profit in terms of individuals paying for care that they do not receive:

> Money. We're sending our residents into a nursing home because they promised the care, but money stops it. Not good enough. We paid for it.

AL14 who had worked in residential aged care explained this:

> [W]hen the facility I work for changed, was taken over. It was a not-for-profit was taken over by a for-profit. One of the, as I say, big four, we had a meeting about it. It all seemed very good. But the only thing I remember them saying, and this is about four years ago, we exist for the shareholders. And after that, the culture went gradually downhill. Some would say more than gradual … There's a promise of care, but lack of funds used on care. And I would say it's indirect, but I would say there's a type of profit from harm when they exist for the shareholders.

VA11 explained that people living with dementia who enter residential aged care might be promised (and charged for) an even higher and more specialised standard of care, which is ultimately not provided:

> [W]ith people with dementia, we've often paid or we are expecting dementia-specific care and we're not getting that either. We're not even getting basic care, but we're ... [not] getting that either. We're not even getting basic care, but we're not getting dementia-specific care. And often, like with my mother, they're like, 'Oh, she needs to be in a dementia-specific unit', so that she's cared [for] in a special way, but she's not even getting basic care let alone dementia-specific care. So again, that's a different level that they're profiting from harm in that they're telling the government they're giving this person really specific dementia care, but they're not even giving them basic care.

Recognition of harm in the context of profit has not been a key rationale for Australian redress schemes in relation to other forms of institutional harm. However, economic benefit from harm has been recognised in other overseas contexts of restitutionary reparations, such as in the context of reparations for slavery.[205] We are not directly equating the harm in residential aged care with slavery or other similar contexts where restitution is associated with the economic ownership of humans, extraction of physical labour and taking of real and personal property. Rather, the harm and the profit dimension manifests differently in residential aged care where economic gain and advantage arise from holding people in facilities for a fee in harmful conditions and with minimal provision of care and support. These other contexts of restitution show there is precedent for reparations that are not only premised on detriment and disadvantage to those who are harmed, but additionally on the basis of the economic gain and advantage that accrue to those who perpetrate or are otherwise complicit in the harm. Exploring restitution-style reparations in the context of residential aged care requires a nuanced and complex understanding of the relationship between profit and harm that stretches beyond conventional understandings underpinning restitution in other contexts. Development of this understanding can be aided by the writings of disability justice activists and critical disability scholars on the political economy of disability.[206]

4.2.8 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.

Reparations must include access to multiple types of individualised rehabilitation to support the physical and psychological healing and recovery of people living with dementia who are harmed in residential aged care. Rehabilitation in the form of counselling and legal and social services must also be available to support the healing and recovery of family members and care partners who are experiencing grief and trauma as an impact of the harm to a person living with dementia.

'Rehabilitation' is recognised by the van Boven Principles as one form of reparations for gross human rights violations. 'Rehabilitation' should include 'medical and psychological care as well as legal and social services'.[207] Rehabilitation is also recognised as a key component of Australian redress schemes. The National Redress Scheme and state and territory Stolen Generations schemes provide access to counselling. The Territories Stolen Generations Redress Scheme, which is operated by the Commonwealth, includes access to free practical and emotional support, legal advice and financial counselling.

Rehabilitation is the first form of reparations to be identified in the Dementia Reparations Principles because it is the most tangible and immediate form of reparations for people living with dementia.

People living with dementia

Rehabilitation and improvements in living conditions must be a priority for reparations to individuals living with dementia who are harmed in residential aged care.

PLWD09 argued that the priority for reparations in relation to people living with dementia should be rehabilitation in a restorative framework, which would extend to moving a person living with dementia from their existing residence:

> [W]hat I would like people to understand is that when the harm has happened for us, we're left with the feelings, not the facts. So, for example, if I was sexually assaulted, I would still have the feelings of that, but I wouldn't necessarily know why. And the 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. And that would include support to find a new residential care place. And so, it's not just the money to go and pay another down payment, it's the support to go and move the person to somewhere that they will feel safe. … I just want to be gone from where it happened because otherwise you're just living in a trigger point … You've got to be gone, and it's not like the government would've said, like going out shopping for a mortgage, it's not like that when it's residential care. Sometimes you're stuck. So, part of this whole redress scheme really needs to address how and quickly, can you get a person out of that place, because no matter what they do, we will be living in a trigger point. Yeah, it's like a [domestic violence] and staying with your partner, you're always going to be triggered and on edge. Even though things are good, you're still like that.

PLWD09 suggested the need for an independent third-party organisation to facilitate moving residences:

> Yeah, even if it's moving you back to the community and supported housing, whatever it might look like, it doesn't matter. To me, that is the number one thing that I want is that there's somebody, some organisation that are funded to come to my family and say, 'Okay, this happened, let's move Mum, start

> again.’ And not everyone might want that, but surely, that’s something that I think needs to be available, is support. Not just between the organisation or the business and the person, but there needs to be an independent organisation supporting how this transpires. We need a third party.

PLWD07, at the same stakeholder roundtable session, agreed with PLWD09’s approach:

> No, I really liked [PLWD09’s] points because yeah, it would be constantly in your face, there’s no escaping. So, even if say you were given, I don’t know, say $200,000, it’s still in your face. You’re still living with it if you don’t get opportunity to shift and different type of care to support you through it.

PLWD01, who lives in residential aged care, spoke of the importance of reparations extending to improved care:

> [B]etter food and activities. My goodness, that is a huge one, particularly here. And then also about the allied health services available and the physio being important and not, ‘Oh, well, it doesn’t matter if they don’t turn up this week.’ Some of us really do need our physio regularly and they don’t seem to get that message at just how important for our health that is.

CPFM14 spoke of ‘trying to get someone back to the state that they were in prior to these unfortunate events happening’.

VA04 recognised that people living with dementia who are harmed in residential aged care might still be living in the facility where they were harmed and require improvements in their living circumstances:

> Because I think this idea of having redress, surely we want to make it a vehicle for them moving on into not only making sure that incident doesn’t happen again, but moving on because we still have a person there who’s being cared for, and we want that person’s care to be optimal, the very best that it can be. And so if we look at the redress issue … I think it’s a really personal, all the parties involved in an incident can be the best way of talking around it and all that sort of thing. I don’t know how often, and obviously from what we’re hearing, many times the incident is just pushed under the carpet

> and it’s rejected, but I’m talking about an incident where we can actually say, ‘What would you like us to do so that we can move forward?’

Research participants used a variety of terms to refer to rehabilitation. PLWD09 referred to ‘restoring someone to a state comparable to what they had before’. CPFM09 spoke of ‘re-ablement’ to provide an ‘enabling’ living environment. VA03 mentioned the importance of ‘improved quality of life’. VA11 spoke of ‘support’, including support ‘to move facilities’.

Rehabilitation should be provided in a broader human rights context, including the human right to independent living and community participation discussed in Section 3.2.5. Rehabilitation must not be paternalistic or coercive and must itself advance human rights (noting the discussion in Section 4.2.5 of human rights framing of prevention). AL17 suggested rehabilitation could be grounded in Article 19 of the CRPD:

> supports to live independently in the community, that’s very much pretty non-controversial human rights language ... Participation in the community and things like that. So yeah. Rehabilitation and improved care could maybe be linked to that.

Rehabilitation should be designed in recognition of various challenges in delivering improvements in care and support specifically to people living with dementia. First, it might be difficult for people living with dementia to recover from the level of harm they have experienced, and/or they might die before they are able to access such support. Second, harm is so embedded in residential aged care systems and processes that necessary improvements at the individual level are not possible without a complete transformation of aged care. Third, there is an absence of access to enabling medical and psychological services for people living with dementia and a broader issue of people ending up in residential aged care because of an absence of such community-based services. So, the delivery of this form of reparations requires broader transformation to enhance general access to support within the community.

Rehabilitation must be situated in a broader context of deinstitutionalisation and enhanced community-based accommodation and support. As is discussed further in Section 4.2.13, development of community-based alternatives to residential aged care is necessary in recognition of human rights and avoiding repeating the injustices of the past. However, it is important to note when facilitating individuals moving into the community that many people have a specific place and community that is theirs, and their connections to that place and community are broken when an individual living with dementia moved into residential aged care. Thus, the challenge of rehabilitation as a form of reparations is not simply to support an individual to heal in any safe environment which is available within an assumed singular, homogenous community. Instead, rehabilitation must support an individual's healing from harm 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.[208]

Some research participants spoke about the need for broader reform to practices within residential aged care for the benefit of all residents. An exchange between two CPFMs reflects the need for immediate change to residential aged care:

> CPFM02: Well, on a positive note, I can say that whilst I can be critical with some aspects of the place that my mother's in, I'm so relieved that she's there and that I moved her from the other one where she had spent a couple of years already, a few years. So there is no perfect world. I'm very aware of that. I can wish and have a wishlist and all sorts of things, and money's not a thing that's going to solve all these problems. I think it's very much about systems and how do we change the systems.
>
> CPFM01: But money would help with staffing at least, at least get more staff. And I know I've heard the argument that it's not always about more staff, it's often about the quality of the staff, and I'm sure the quality of the staff is really, really important, but I find it really hard to believe that more staff aren't also required.

CPFM13 spoke of the need for the highest priority to be given to a shift in approaches to how care is provided by residential aged care providers:

> And number one is tender, loving care. When you are in there, you need TLC. You need nurses. Even if they can't do much at the moment, they can talk to you nicely. They can rub your hands. They can take you a little walk around. ... And that's where we start. Not having them sitting in a room like this,

> because they get another load of drugs. Stop the regular drugs. Whenever they get up in the morning, there you go. And that starts it off for the day.

CPFM07 referred to the need to implement recommendations of the Aged Care Royal Commission related to staffing:

> [F]undamentally I would like to see the recommendations of the Royal Commission implemented as quickly as possible. Staff ratios was the biggest thing and that will be the biggest game changer, as well as staff or workforce salaries. I think retaining the workforce because there is such a high churn and burn. One of the areas that we see time and again where neglect occurs is with agency staff who are incompetent or under-trained, and are just filling in and have no skin in the game. And so redress that forces government to ensure that facilities have the right staffing ratios, as well as professional staff ratios. At the residential nursing home where our mother is, we have one RN for 85, high support needs residences, two or three ENs [enrolled nurses] and the rest PCAs [personal care assistants] … So from my perspective, increasing the salary of the work force, might mean that we actually attract a workforce who are committed to quality standards of care. And if they're not doing extreme amounts of time, providing extreme services in the time that they've got, so that they're then looking for shortcuts time, which I can understand, maybe we wouldn't see some of the neglect that we do see.

Design of rehabilitation as a form of reparations should also learn from the challenges to provision of counselling as a form of redress which have been noted in the context of other Australian redress schemes. The National Redress Scheme's counselling has been criticised for being inadequate and inequitable, especially for remote, disadvantaged applicants and those without access to technology. Indeed, it has been suggested it can be very problematic and potentially harmful.[209] It has also been noted in relation to the National Redress Scheme that inadequate counselling and care provisions further exacerbate pre-existing disadvantage and vulnerability for certain applicants, notably those with disability, due to the limited availability of professionals who are skilled at working with people with intellectual and cognitive disabilities and who require supports and accommodations to communicate with others.[210] There are also major shortages in counselling and care services in regional and remote areas.[211]

There are also lessons to be learned about provision of counselling specifically to First Nations people. The National Redress Scheme Joint Select Committee noted in its 2021 report that counselling must be flexible and culturally appropriate, potentially encompassing diverse notions and practices of communication, care and healing for First Nations survivors. Tania Bin Bakar from the Kimberley Stolen Generation Aboriginal Corporation is quoted in the report:

> Aboriginal people don’t see counselling the same way non-Indigenous people do. They’re not going to go to a counsellor and sit down and talk about their issues. That’s not what works for them and it’s not culturally appropriate for them either.[212]

Care partners and family members

Care partners and family members of individuals living with dementia who experience ongoing impacts – including the complex impacts of moral injury (discussed in Section 3.2.2) – must also have access to rehabilitation in the form of counselling. Other forms of rehabilitation in the form of legal and social support (which is specifically identified in the van Boven Principles) might also be useful in light of the ongoing legal and complaints processes that care partners and family members may be involved in after the death of the person living with dementia.

For example, PLWD05 noted the importance of support to family, particularly if the person living with dementia has died:

> The thing is, no money makes up for what’s happened or the abuse that’s occurred, and yeah, it’s not always about money. Sometimes if the person has passed, but the person or the family member is surviving, financial compensation or getting the money back may take the edge off, but there’s much more to it. That’s not going to take away the pain. And so some form of government funded or service funded through fines to the service could pay for the people to receive anything that’s going to help them emotionally to have to deal with it.

AL05 similarly observed:

> I think that it should be available if that person the carer support partner whoever that may be, if they suffered trauma as well then their trauma should be recognised too. And I think that's really important just because they weren't the person who was abused doesn't mean that abuse had no impact on them. There could be different ways of recognising that … psychosocial supports like counselling could be made available. If it was decided that … a compensation payment wasn't appropriate but there's different ways of supporting those people. And if it's possible, I think they should be recognised.

VA11 spoke of the importance of counselling for care partners and family members in light of her own experiences of trauma:

> And for myself, I've been diagnosed with post-traumatic stress disorder from probably the things that I've dealt with and witnessed with my mum, and definitely like her human rights, just going out the window. But it's definitely, as soon as this process is starting, that support is made available to whoever needs it. It might be staff also working on this because we know that us sharing these stories is quite traumatic as well, because often accessing counselling is really difficult, and especially now in COVID, I just feel that we are opening a real big box here, that, that support has to be available. And some of these people will have died and there'll be a sense of grief and loss also when you are telling these stories. That's just a big picture thing, too.

The absence of counselling to families was recognised as a significant shortcoming in the National Redress Scheme. In its 2021 report, the National Redress Scheme Joint Select Committee found that counselling must be available to both applicants and their families throughout the whole application process of redress, rather than only being an outcome of redress.[213] For example, Hanina Rind from the Victorian Aboriginal Child Care Agency stated:

> To provide the full benefit to survivors on their healing journey, counselling and psychological care must be available from the beginning of their rigorous journey, it must be available across the lifetime of the survivor, and it must be available to survivors' family.[214]

4.2.9 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.

A key concern driving reparations (as discussed in Section 4.2.3) is that individuals be heard, be listened to, and that their experience drives change. In order to bring about this collective recognition and motivation for change, truth-telling and public education initiatives must be utilised to document the harm both from the perspective of people's experiences and from information in the control of governments and residential aged care providers. Truth-telling and public education initiatives can humanise individuals living with dementia, enable the community to reckon with what has happened and create an ecosystem of accountability.

Truth-telling might be a form of reparations more relevant to care partners and family members. For example, PLWD09 explained that truth-telling would not be of relevance to her, as a person living with dementia; instead, it would be more important to address her immediate residency situation and material circumstances:

> [N]ot so much on the truth-telling, because for me with dementia, that won't matter … The truth-telling would be for everyone around me, who are shocked and need an opportunity to express that.

Similarly, PLWD10 indicated that truth-telling would be more relevant to care partners and family members:

> If the person that has experienced harm, there's people with dementia, some of them may or may, depends on what level and what incapacity they've got. It might be more relevant to the family, or to the person just depending on what the dementia does to them … so if you are living with dementia and you can't get up and actually do anything about it, but your family might want to anyway. So, I think, it's important either way.

Thus, whereas rehabilitation is a priority for people living with dementia, truth-telling is a priority for care partners and family members.

Research participants suggested different models that truth-telling could adopt. Some proposed a victim impact statement model. PLWD10 suggested victim impact statements, as did CPFM12 (reporting on an earlier discussion with his spouse PLWD04) and CPFM09. CPFM18 suggested something like ‘the Truth and Reconciliation Commission process that happened in South Africa … even on a small scale’. VA07 proposed ‘an independent aged care ombudsman where perhaps we would be able to lodge stories about our loved ones’.

Some research participants mentioned the importance of truth-telling being public and identifiable (if so chosen). VA11 said:

> You may choose to speak out and be recognised for speaking out. So yes, it’s great to know that it can be confidential and de-identified, and I like the idea of naming and shaming, that’s really effective and it’s a really good way of deterring people. But I want the option to be able to be recognised as somebody who spoke out, because I think there’s a strength in that that other people may speak out if they can contact someone or whatever. I don’t want it to be exclusive. We know that other people in other sorts of criminal actions fight really hard to be allowed to be identified, and I just don’t want it to be limited in any way.

CPFM12 stated:

> I know it’s a something to do with privacy, but you can lose a lot of information by de-identifying.

Truth-telling is a key form of reparations in the van Boven Principles. Satisfaction can take the form of:

> Verification of the facts and full and public disclosure of the truth to the extent that such disclosure does not cause further harm or threaten the safety and interests of the victim, the victim’s relatives, witnesses, or persons who have intervened to assist the victim or prevent the occurrence of further violations.

The van Boven Principles also provide that informing the public and providing access to information are central to learning the truth of human rights violations:

> States should develop means of informing the general public and, in particular, victims of gross violations of international human rights law and serious violations of international humanitarian law of the rights and remedies addressed by these Basic Principles and Guidelines and of all available legal, medical, psychological, social, administrative and all other services to which victims may have a right of access. Moreover, victims and their representatives should be entitled to seek and obtain information on the causes leading to their victimisation and on the causes and conditions pertaining to the gross violations of international human rights law and serious violations of international humanitarian law and to learn the truth in regard to these violations.

Truth-telling can take different forms, with international examples ranging from state-led truth and reconciliation commissions through to civil society truth-seeking initiatives.[215] In Australia, the Yoorrook Justice Commission is ‘looking into past and ongoing injustices experienced by Traditional Owners and First Peoples in Victoria in all areas of life since colonisation’.[216] The Kinchela Boys Home Aboriginal Corporation operates a Mobile Education Centre for truth-telling on Kinchela Boys Home, and the experiences of the Stolen Generations, by survivors of Kinchela Boys Home.[217] Public repositories of stories are utilised in relation to institutional child sexual abuse through the public availability of personal narratives from the Royal Commission into Institutional Responses to Child Sexual Abuse.[218] Redress schemes can also facilitate greater access to records and information, which can in turn support truth-telling and public education. For example, the Tasmanian Stolen Generations Scheme provides individuals with access to their files and records.

AL01 suggested that truth-telling could also take the form of some kind of memorial or site of commemoration of individuals with dementia who have died. The van Boven Principles also provide for reparations in the form of ‘Commemorations and tributes to the victims’.[219]

Commemoration and remembrance is designed into some Australian redress schemes. The NSW Stolen Generations Reparations Scheme provides for access to a one-off payment from a ‘Funeral Assistance Fund’ to assist with funeral costs. In a similar vein, the Victorian Stolen Generations Reparations Package includes a

Funeral Fund that provides eligible applicants a one-off payment of up to $10,000 to cover the costs of a funeral. There are also examples of commemoration through specialised collective recognition measures (discussed in Section 1.2.5), such as memorials to members of the Stolen Generations and to children abused in out-of-home care. The South Australian Stolen Generations Reparations Scheme includes the option of redress through the Community Reparations Fund, which provides funding for projects that promote healing for survivors, their families and the wider community. Funded projects focused on oral histories, Aboriginal family and community histories, healing, arts and cultural activities, memorials and places of reflection, and preserving and making accessible documents that are important to survivors and their families.[220]

The purpose of truth-telling and public education initiatives is fourfold: humanising the person living with dementia, validation, transparency and public education, and change.

Humanising

Truth-telling can humanise the person living with dementia who has died. For example, VA07 stated that care partners and family members

> want recognition that the person was valuable and their life was valued, and even if at the end, that it ended so tragically, that the person was a human being. That’s all I wanted. I wanted her to be believed, that was all.

In proposing that truth-telling could take the form of a memorial or site of commemoration, AL01 emphasised the importance of marking the lives of people living with dementia who had died as a way of recognising suffering of people living with dementia:

> This is a largely invisible suffering, if we talk about it and bring it out into the open, then I think there’s some redress in that. In giving the respect to the victims of violence … when you’re marking tragedy, you’re thinking about places as well, you’re looking at commemoration … I don’t know specifically enough about the history of violence and abuse of people living with dementia, but there would have to be specific places that you could create commemoration to heal as a society, to acknowledge suffering and make it

> part of our history, when it's currently not written at all. It's not in the history books right now. Just marking it, putting it on the pages and creating places for us to recognise the suffering that's occurred.

AL02 agreed with AL01, stating: 'It has to be something living, something creative, something which is life affirming, but also that remembers everything that has gone on in the past.'

Validation

Truthful public accounts can validate experiences of harm, in a context of people living with dementia not being believed or ignored, and care partners and family members being viewed as problematic when they seek to intervene or realise justice (as discussed in Section 4.2.3). This role of truth-telling was summarised by VA08: 'It is about feeling that you have been heard, you have been listened to, and there is change.'

CPFM16 discussed the importance of being able to speak of traumatic experiences:

> The truth-telling, I think that's a really important way to go, that people are able to discuss the terrible pain that has been experienced in witnessing some of the nightmare, really, that has occurred to people suffering from dementia in the hands of institutions. It is truly traumatic.

An exploratory approach to truth-telling – one that resists arbitrary categories of victim and perpetrator that typically structure criminal and civil justice processes – might provide unique opportunities for care partners and family members to grapple with experiences of moral injury and implication (introduced in Section 3.2.2).[221]

Two ALs drew on their experiences in redress schemes to explain the importance of being listened to and validated:

> AL10: I'm thinking about the effect for many of our clients that we help with victim support schemes, like particularly those who suffered childhood sexual abuse and might be looking, say a redress scheme versus something that's more administrative. And often what I hear is they just want an outcome, and again, it's not about sometimes the amount of money, but it's about being believed. Having their story like that that opportunity to put the testimony, and

> just getting something in terms of seeing it through, particularly for kids have been out-of-home care and sort of suffered push back at a lot of levels … whether it's individuals or their family members feel that, 'Okay, there's already an acknowledgement that these harms occurred and do occur. And so we're going to accept what you say at face value to some point.'
>
> AL08*:* I think that's the point you make … is really important because it's a chronic fear of people who have suffered a form of abuse or harm is that they won't be believed. It's kind of like The Rime of the Ancient Mariner, that who tries to tell everyone who will listen, what has happened, what they've seen. And that's why concepts of bearing witness are so important in repairing human rights abuse.

VA08 emphasised the importance of listening to and hearing family members and care partners who are sidelined in residential aged care:

> So redress is not always about formal structures. It's also about attitudes. It's about listening. It's about hearing people. And wow, I mean, what's so obvious in [CPFM13's] story since [CPFM13's husband] died, right, is that they've just tried to get rid of her.

An exchange between two ALs emphasised the importance of truth-telling to repair abuse of trust:

> AL10: Beside any compensation element that there needs to be an avenue for involvement of family or other carers, because there's that level of trust that's placed in a facility like an aged care setting to care for that individual. So there's an abuse of that trust in a sense, but also in many cases there are family or whoever the carers are who have been advocating, trying to get an answer, or trying to get a— lodge [a] complaint, or get some sort of outcome, who still need access to something at the end of the day, whether that's an apology or recognition or a chance to tell that story.
>
> AL09: And with that opportunity, I think that person, the care or the family member needs to know, and this is why it's different from [the National Redress Scheme]. Again, how [is] that going to happen to the next person or the lady next door. So how is this particular aged care facility going to stop

> this from happening again, I think would help go some way to addressing the family members' experience.

Transparency and education

Truth-telling may provide transparency in relation to what occurs in residential aged care facilities. There is limited access to information about harm because of the secrecy associated with the closed nature of these institutions and the legal processes associated with people's detention and restriction within these spaces (e.g., guardianship tribunal decisions are not routinely published[222] and generally people are legally prohibited from speaking publicly about their experiences of being under guardianship[223]). Privacy laws might also prevent individuals living with dementia and their care partners and family members from easily accessing information to advance claims for redress and share this with the public. Moreover, settlement in litigation might be used by residential aged care providers to prevent public disclosure of the harm. Residential aged care providers also have access to public relations and marketing expertise to control their public image and brand. For example, CPFM02 noted the challenges of residential aged care providers being able to control the message and image of their residential aged care services and thus hide harm from public knowledge:

> It's lovely getting happy, happy newsletters with pictures of lots of residents. It would also be good to have that information publicly available in terms of what has gone wrong, what has been done to rectify it and prevent it from happening in the future. So some sort of accountability system that is shared more publicly.

PLWD12 stated that the public transparency through truth-telling can result in accountability:

> I like the shame ... Putting up some sort of shame list and a naughty list, but particularly for the for-profits that are actually financially profiting from all of this sort of stuff and even not-for-profits. I'll use the example of [charity residential aged care provider] here, they are a not-for-profit, but any profits that they do have come their way, goes into making more aged care facilities. So they're not totally part of the angel system either. I wonder about some of what they're doing too.

Truth-telling can also have an educative function. CPFM09 explained this in terms of truthful accounts actually defining the meaning of harm:

> Just going back to truth-telling point. And it crossed mind that is a powerful thing and it could be used to define what harm is, because if you ask all of the people who have participated in this study to tell their story about the harm that was inflicted, you'd probably get some themes coming through. And that gives people an understanding of where these harms lie. So, I don't know whether that's possible to do, and certainly I'd be more than happy to have mine published as a means to educating people about the harms that they commit. Just as my example, which is very subtle, physical and chemical restraint are pretty adverse, but my husband was a very dignified person who had his dignity stripped entirely from him by the time he passed away and that's the lasting impression I've been left with, is that, and I can't get over that. And you can't redress that in my mind. ... We could also define [harm] because it's the truth, isn't it?

AL05 drew on her experiences representing child clients to explain that sometimes people do not even appreciate that what they have experienced is wrong, particularly in contexts where violence is normalised. Thus, truth-telling might help to educate people living with dementia on what constitutes harm and the right of people living with dementia to reparations:

> And I think they might be thinking, 'This doesn't seem right or I'm not enjoying this. This doesn't seem good but I guess this is how it is for me now.' And it's so important to have those voices shared on a platform. And that recognition that a redress scheme would provide so that they can think, 'Oh, other people are experiencing this and it's not just me and it is wrong and it's not just me.' That's so valuable and important and a really important part of a redress scheme. Yeah. Giving a platform for them to feel recognised and heard.

AL16 spoke about the possibility of truthful accounts to educate family members who might be considering encouraging a person living with dementia into residential aged care:

> [T]o include something about how things should have been done? I'm thinking again about people who are only just embarking on this part of their lives as

> having dementia being the carers of people, care partners of people with dementia. Hearing or reading those stories. If there was something that stood alongside the stories that talked about what those people should have experienced, it might help those other people to understand what they should expect in care, and can rightfully expect.

Truth-telling can also educate residential aged care providers and staff, as PLWD10 stated:

> Redress, having to be involved in redress emphasises to them, ‘Well, this is not what I should be doing.’ It can actually look at more than just the redress at the corporate level, the supervisory level.

AL18 spoke of the need for truth-telling to extend to positive experiences and practices, so that learning can also inform the transformed system.

Reckoning and change

Third, truthful public accounts can provide the public with the opportunity to learn of harm as a foundation for change. AL02 spoke of the educative function of truth-telling:

> I think it forces the broader community to understand perspectives that may not be familiar to them, that may not be within their world. Because even though conditions like dementia, disability, while relatively common, may not impact people at a time when we need them to recognise this is a problem. So for younger people, if you have something like a redress scheme, it’s out there, people are talking about it. So it has an educational function, I think.

AL02 also described truth-telling as creating an ‘ecosystem of accountability’:

> Well, I think redress is very important. With redress comes reckoning and with reckoning comes truth-telling, and I think it is part of creating an ecosystem of accountability because at the moment there is none. No one wants to be accountable for the wrongs that have been perpetrated against older people in aged care, so I believe having a redress system is important. The question is how do we do it in a way which is meaningful and which has impact into the future?

Change is important not only in terms of ensuring prevention of further harm but also in terms of individuals’ experiences of truth-telling. Using the example of CPFM13 (whose husband died in residential aged care), VA08 noted that validation must equate to the individual who shares their story being able to see the lessons learned from that story reflected in changes to residential aged care; otherwise listening can be a tokenistic process:

> [R]edress for [CPFM13] would be a recognition that at least some of these things had been taken on board. In other words, it’s not all about compensating her personally for what she’s been through, but a sense that she has been able to have an impact on change. And I think that’s a very, very tricky one, but I think it’s also really important. Is [CPFM13] able to walk into a facility, or into [local public hospital where CPFM13’s husband was taken], or whatever, and feel that she has been heard because there are real changes that she can see. And how would she, in fact be involved in that going forward? We’re very big at the moment on anything in the dementia space, for instance, has got to have a little kind of steering committee with somebody living with dementia, or with a carer, or whatever, these kind of often quite tokenistic positions. But let’s take someone like [CPFM13]. I mean, what does it mean to engage the people who have actually had these experiences in the attempts to move forward? Because I have never heard of that as an agenda item for anyone. I was thinking about it just as [CPFM13] was talking about it, and of course, in the context of this discussion generally. And at least, if for instance, [residential aged care facility where CPFM13 was harmed] or [local public hospital where CPFM13 was taken], whatever, had a commitment to change, would someone like [CPFM13] be invited to be a part of those changes? Or would she simply be dismissed because she hasn’t got the status or the qualifications? And this brings me back to the lived experience as a qualification in itself, which is incredibly important. Incredibly important. So, and that brings me back, I suppose, to the circles, about recognition.

A similar point was made by AL11 about people who share their story needing to see tangible actions by those who have listened to it:

> [O]kay, it’s one to share and trust that the recipient of my story, and how they’re, and what they’re going to do with my story too. Like, what’s the outcome going to be from it? Like if they feel that yeah, I’m sharing it, but there’s still going to happen to other people and nothing’s coming from it.

AL01, who had experience representing people involved in the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, noted the importance of listening being linked to change, so that there are tangible consequences and people are not retraumatised by participating in a futile process:

> And what, I guess is frustrating and tiring to see, is the voices of people with disability and voices of older people, being used for systemic reform that may or may not go anywhere. They’re putting so much on the line and they’re being so self-sacrificing and brave in sharing their stories at personal cost, in a way that might open up trauma. They’re telling their stories and sometimes there’s very little policy reform that comes out of it … I think people deserve better than just policy promises. I think it’s immoral in a way, to just have, as a singular purpose, truth-telling, if they’re not going to do anything about that horrible truth that they’re uncovering. I think having a form of redress that focuses on individual harm is actually a true recognition of the harm that violence, abuse, and neglect of people living with dementia has on us as a society, that we could do that as well. To recognise the individual harm I think would be an important step in affirming the dignity of a sometimes overlooked community, who may not have the political voice to always get ... They’re not handed a megaphone very often, let’s just say that. So I think in terms of redress for people with disability and older people, it’s about not expecting them to be self-sacrificing all the time for the sake of the greater good, having some benefit for them in terms of telling their truth.

The importance of tangible outcomes from truth-telling has been the basis of some criticism of memorials in the context of the Stolen Generations reparations schemes. For example, the South Australian Stolen Generations Scheme Consultation found mixed views on memorials among Stolen Generations survivors, wider Aboriginal communities and Aboriginal support service workers and agencies. Some expressed positive views. One anonymous participant noted: ‘Memorials, done well, can be great educative tools.'[224] Another anonymous participant stated it would be beneficial to have 'Memorials that are interactive and Honour those who were STOLEN and continue to be Stolen'.[225] Others expressed scepticism. An anonymous participant noted that a memorial is positive 'if it is a priority of the members of the stolen generations'.[226] Still other anonymous participants had negative views, variously describing memorials as 'a waste of money',[227] having 'no practical benefit for Stolen Generations members'[228] and 'only to benefit the non-Stolen Generations … [and] deflect from the fact people living today are affected. Seems to infer it's past history'.[229]

4.2.10 Principle 10: Apologies

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

Reparations must also take the form of public apologies by residential aged care providers and governments. Public apologies are an important way to communicate recognition and accountability. However, similarly to truth-telling, an apology should be a starting point for action and not an endpoint. Thus, apologies must be connected to concrete action to prevent future harm by those apologising. Legal and medical professionals – including professional associations and unions – should also apologise for their role in harm.

Apologies are a well-established form of reparations. The van Boven Principles note that one form of reparations for gross human rights violations is '[p]ublic apology, including acknowledgement of the facts and acceptance of responsibility'.[230] Reparations can also extend to guarantees of non-repetition.[231]

In Australia, redress schemes apologies have operated at two levels. At one level, schemes offer individual apologies. The National Redress Scheme provides for 'direct personal responses' (e.g., an apology or acknowledgement of responsibility) from the relevant government or organisation. Some of the state and territory Stolen Generations reparations schemes have the option of a personal apology. For example, under the New South Wales Stolen Generations Reparations Scheme, individuals can request a personal apology from a government representative. The Territories Stolen Generations Reparations Scheme includes the option of a direct personal response, which involves an individual telling their personal story to a senior government person about the impact of removal. The story can be acknowledged face-to-face, through a personal letter or both. The Office of the Commonwealth Ombudsman's Restorative Engagement Program for serious abuse within the Australian Defence Force provides the opportunity for people who have experienced serious abuse to tell their story (in private) and have Defence acknowledge and respond to that story.[232] At another level, as a specialised collective recognition measure, there have been official, public apologies to the wider impacted group, such as national and state government apologies to members of the Stolen Generations and to survivors of institutional child sexual abuse.

Apology as a first step

PLWD05 noted that an apology needs to be the first (but not the only) step in reparations:

> [T]he first step needs to be a public apology from the provider. I think it needs to go further than that, and I believe it's important that overall the government really acknowledges more openly what's going on. That there was so much came out of the Royal Commission, and it's almost as if the government is just washing its hands of the whole thing and saying, yeah, well, these people are in the wrong and they've got to do it, but the government has been overseeing these services for many years so of course, they have to take responsibility for what's going on. And they need to fully acknowledge and really make it an open discussion.

PLWD05 later referred to apology as essential to 'move forward':

> So, I personally could only see public apology from the government and again, an acknowledgement of what has been. And until that really occurs, then there's no moving forward.

Similarly, CPFM09 explained that a public apology is a 'start':

> So I think a public apology would be a really good start. Saying sorry's very important as we've all seen before. Acknowledging it is actually taking responsibility for it. And I don't think that there's any government that's actually done that yet. So to me that's really important … certainly saying sorry would be very powerful start in my mind.

CPFM09 also spoke of the importance of governments apologising as a first step, including for their failure to take any concrete and focused action after the Aged Care Royal Commission:

> Well I think just acknowledging that the neglect has happened, I think making a commitment to changing the [*Aged Care Act 1997* (Cth)] and apologising for doing what they did to it in the first place in 1997 would be a good start. But governments need to acknowledge it. They've just not acknowledged it. They've, all they've done is throw a bit of money here and there in a vague sort of a way. It's not acceptable. And I would be just absolutely devastated to think that this Royal Commission goes nowhere. It would just truly, truly break my heart for that to happen. So I think a public apology from a government acknowledging the neglect that's happened in aged care and the ageist views that have been held up till now would be a really good start.

CPFM10 was of the view that residential aged care providers, governments and regulators should all apologise:

> I agree that an apology and acknowledgement needs to happen, but I don't think it should just be from government. I think it should also be from providers. There are a number of groups that speak to providers and after the [Aged Care Royal Commission] … And I think they need to come out publicly and acknowledge yes, that this happened on our watch as well. And the same with the regulator. I think it needs to be a sort of government regulator and provider apology.

Drawing on their professional experiences in relation to the National Redress Scheme, AL09 suggested that an apology can be an important form of recognition for family members to respond to the impacts of the harm on them, specifically 'to help them manage feelings of guilt and shame'.

Importance of public apology

The public nature of an official apology is particularly important. PLWD06 was of the view that an apology at the local service level might be sufficient to change practices within that service because of the reputational risks:

> [I]f someone's having an issue or has had an issue in the past with a facility, I'm trying to find the right word, that's polite, that if they raise that then it's acknowledged publicly that there has been an issue that they will look at, and then the redress is the next stage after that. But if that happens, I think the need for more of it to happen is probably going to be reduced because it's going to cover other things at the same time, and make it more public. Which is probably one of the biggest issues of not having anything, it's all hidden … And for, well, depending on the scale of the provider, from the facility that is in question, right through to the top of the corporate. So that it's really open rather than the top pleading ignorance because no one's told them what's happening below and vice versa … It should be public. The details may not have to be public, and I think again, each location should have that information that there has been, five, 10, 50 issues raised in whatever time period, covering a time period. So that's readily available to anyone in the community who may be interested in the place or just for background knowledge.

Similarly, CPFM03 spoke of the potential power of the reputational impacts of a public apology:

> So, what I would like them to redress is basically just some national apology, in which I think, you see it in the papers, some people just apologise, whatever. So just a national apology for the events or the event. And then, at the same time, some reassurance that it's not going to occur again. That would put pressure on the organisation because if it's become national or statewide publicised, they would have, that organisation would be hit hard, wide publicity, and people would then find out, what's going on and what's happening. So I think the crux of redress would be hitting at the board level, hitting at the CEO level.

Apology must be followed by action

Some research participants emphasised that apology went beyond acceptance of responsibility and needed to be backed up by action. For example, PLWD05 stated that an apology must be accompanied by actions to 'make up' for the harm:

> I think an apology is very well, but it's really easy to apologise, then I think the difficulty in getting anybody to apologise is, 'Okay, no, sorry. Yes, we're not going to do it again maybe, but how do we make up for what we did?' And that certainly needs looking at.

CPFM13 powerfully communicated the risk of apologies being words and no action if they are simply tokenistic and issued to placate or silence family members without change:

> Admit we've got it wrong. Let's start again … 'We are sorry we poisoned your husband. Just get on with it.' That doesn't cut it. That doesn't cut it. I wake up in the night … And we are sorry. And we've put all these in position. It's nothing to what was there before. It's just words. There's no action. There is no action. So we've got to get action going. That's what I would think redress is. Let's act on what's wrong and make it right.

VA01 referred to the need for 'something concrete':

> The people who were responsible not just to say sorry, but do something concrete or, if they say sorry, to mean it and change their ways.

While apologies are a key feature of specialised redress schemes (as mentioned earlier in this section), they have also proved to be problematic. For example, in its 2021 report, the National Redress Scheme Joint Select Committee found a lack of systems in place to ensure that direct personal responses are a safe and healing experience.[233] Similarly, the 2021 *Final Report of the Second Year Review of the National Redress Scheme* by Robyn Kruk ('2021 Kruk Report') stated 'Respondents to all three review surveys considered the direct personal response the most problematic redress element',[234] and some survivor submissions to the Review also said that they did not find the [direct personal response] meaningful.[235] While it is recognised that direct personal responses done well can be 'powerfully healing', with lives 'transformed for the better',[236] '[a]n ill-considered direct personal response has the potential to be more damaging than receiving no direct personal response at all'.[237] One survivor explained their traumatic experience:

> When there is no independent facilitator, no structure, no agenda, no preparation, no understanding of the expectations by either party nor a clear

> articulation of the needs and aspirations of the parties, then there is plenty that can and will go wrong. In my case, nothing was discussed beforehand … [This] is psychologically unsafe for survivors. In the absence of an independent facilitator or convener, who can prepare both sides for an open and honest communication, there is the potential for further suffering and retraumatisation.[238]

Specific inappropriate practices in the context of direct personal responses include survivors being asked to sign non-disparagement clauses as part of the direct personal response process.[239] One submission cited by the 2021 Kruk Report noted the lack of 'strict guidelines about how institutions conduct the DPR [direct personal response], or consistency in how they might operate' leading to 'real risks that the survivor could be re-traumatised or even re-abused and that this opportunity for an apology will have the opposite effect'.[240] Another submission cited in the 2021 Kruk Report noted the importance of direct personal responses that evolve 'from being trauma aware to becoming trauma informed'. The submission explained that:

> This requires … institutions to move beyond the understanding of 'damage' inflicted, towards designing practices and processes that emphasise openness, collaboration, levelling of power differences, maximising restorative opportunities and championing a sense of safety, security and support for survivors throughout the redress process.[241]

These lived experiences of apology are an important source of learning for reparations in the context of people living with dementia.

4.2.11 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.

The van Boven Principles identify monetary payments as a form of reparations for gross human rights violations in the specific forms of restitution and compensation. The van Boven principles provide that 'restitution':

> whenever possible, restore the victim to the original situation before the gross violations of international human rights law or serious violations of international humanitarian law occurred. Restitution includes, as appropriate: restoration of liberty, enjoyment of human rights, identity, family life and citizenship, return to one's place of residence, restoration of employment and return of property.[242]

The van Boven principles further provide that 'compensation':

> should be provided for any economically assessable damage, as appropriate and proportional to the gravity of the violation and the circumstances of each case, resulting from gross violations of international human rights law and serious violations of international humanitarian law, such as:
>
> (a) Physical or mental harm;
>
> (b) Lost opportunities, including employment, education and social benefits;
>
> (c) Material damages and loss of earnings, including loss of earning potential;
>
> (d) Moral damage;
>
> (e) Costs required for legal or expert assistance, medicine and medical services and psychological and social services.[243]

Principle 11 deliberately refrains from using the term 'compensation' as there are challenges with economic assessment of damage to older people to return them to a prior position, particularly because they are no longer working and might have pre-existing health conditions.[244] Specialised redress schemes use terms such as 'monetary payments' to reflect that the payment is not compensatory and is instead 'made in recognition of wrongs and perhaps their impact'.[245] 'Monetary payment' better reflects research participants' concerns with recognition and reimbursement as key purposes of payment. Monetary payments are a core feature of Australian specialised redress schemes. The National Redress Scheme provides for redress payments of up to $150,000 depending on the nature of the sexual abuse. State and territory Stolen Generations schemes also provide for monetary payments. For example, the New South Wales Stolen Generations Reparations Scheme provides access to ex gratia payments of $75,000, and the Territories Stolen Generations Redress Scheme provides access to redress payments of up to $75,000.

Ambivalence towards monetary payments

Reparations are often associated in broader society with compensation and other monetary payments. However, research participants expressed that money was not a priority in any reparations for harm to people living with dementia. Some research participants were ambivalent about the significance of monetary payments, noting that money cannot fix or change the past, particularly where the person living with dementia has since died. Thus, if they are available, monetary payments must operate in the context of a broader commitment to and action on changing systems and preventing future perpetration of harm, or used to provide support for people who are impacted by harm. Money is not necessarily the best or only way to ensure recognition and healing, nor will it bring about accountability, prevention and transformation at a structural level.

Similarly, CPFM10 spoke of the importance of recognition:

> I don’t agree that redress should be financial, but that’s my personal opinion. Or if it’s financial, it should only go to people who are directly impacted. My parents have passed away, I don’t see why I should get any money. But I would like some acknowledgement from both government and providers, that they dropped the ball big-time. That’s how I see the redress. And that’s what I feel the Royal Commission could have said, that there needs to be an apology of some sort.

Other research participants spoke in terms of prevention of harm. VA11 spoke of the importance of ‘improvement in the future’ over money:

> [A] lot of it was about, all of the things that I’ve seen, you couldn’t have paid me for the things that I’ve experienced with aged care. What motivated me to speak to the [Aged Care Royal Commission] and speak right now, is that it’s the improvement in the future. I don’t know if we say, should, is there an expectation that people come forward will get a payment? A lot of us just want a recognition or, that our person goes back to the level they were before.

Similarly, CPFM13 referred to ‘changing the future’:

> We’ll never be compensated for what’s happened in the past. The compensation is changing the future … That would be a good start at redressing what’s going on, but we will never be compensated for the past. We can’t be, because it’s done and over with, according to them, and there’s too many and too much happened. But if we make a big enough song and dance about it, we can change the future. And we’re in the future. Goodness knows what’s going to happen to you and me tomorrow. Even young dementia. If it’s our turn. So we have got to jump up and down, make a song and dance, tell people what’s going on, ask people, ‘How do we fix this? What’s going on?’

PLWD12 referred to ‘making sure the system works’:

> I think, when you start talking about money, money doesn’t interest me. It’s making sure the system works … I think we’ve got to get ... Unless there was an actual monetary loss that it ... Suffering and stuff like that. I think we all suffer, and I think we’ve got to get away from that and just sort of say, well, life’s a bitch, you just got to deal with what life throws at you and just try and make sure that life, that we try and make things better for those that follow us.

CPFM03 stated that the most important thing is to ensure the harm does not happen again:

> [I]t’s not the money. It’s just the fact that I would like to have assurance that these things are not going to happen again, have assurance that they’re going to fix it.

Similarly, CPFM02 emphasised the importance of prevention:

> I’m not so much concerned about compensation. I don’t think I need to worry about that. I’m sure other people might, but I am more concerned about preventing problems arising … Learning from problems so that you can prevent them recurring … I don’t think money and payment for problems that have arisen is going to fix it. It doesn’t make any difference to the situations that I’ve experienced. So it’s not about money and therefore it’s not even about an apology, which could be a hollow apology anyway, it’s more about, ‘Okay, what are we going to do to fix this’, and prevent it recurring.

While monetary payments were not prioritised by research participants, there was some acknowledgement that such payments could serve specific purposes: symbolic recognition, reimbursement, fund rehabilitation and fund advocacy.

Symbolic recognition

One purpose of monetary payments as a form of reparations is to provide symbolic recognition of harm to people living with dementia. Monetary payments send a strong signal to society, legal and health care professionals and residential aged care providers that harm has been done, and that people living with dementia matter, that they are valued and that the harm must stop.

Reparations in the form of monetary payments can provide symbolic recognition and validation of physical, psychological and moral harm experienced by people living with dementia. Reparations can also provide symbolic recognition and validation of psychological and moral harm experienced by care partners and family members from witnessing harm, advocating to stop harm and realise justice, and having their trust and hope in the residential aged care system destroyed.

VA08 explained the significance of monetary payment as recognition, in the context of CPFM13's experience of her husband dying in residential aged care. CPFM13 had requested her husband's residential aged care facility repay her $18,000 she had paid to them for his care:

> [I]t is about recognition. It is about recognising that people have been, let me loosely say something like hurt, have been dehumanised, have not been treated the right way, have not been cared for in a society that purports to care. And that recognition, which of course is a lot of what compensation is about. But I think that that gets lost in a society that can only think about people and redress and compensation in monetary terms. And so if you reduce this to, if you like, economic objects, it's like [organisation operating facility where CPFM13's husband was harmed] saying, 'Well, what do you want the $18,000 for? We provided the care.' The $18,000 is really not a real amount that recognises what [CPFM13 and her husband] went through. It's simply a symbol, but they won't even do that. Not in any instance have [organisation] been prepared to say, 'We got it wrong. And we are sorry for ...' Not 'We are sorry for your grief', but 'We are sorry for the grief we caused

> you.' Not, 'Oh, we are very, very sorry that you are grieving.' Yeah well, so what? … Because they've actually produced a lot of it and compounded it over time.

AL02 explained that a monetary payment can be a symbolic way of indicating the value of people living with dementia:

> [I]t signals to society that everybody matters, including people who are older, people with disability. Therefore, if you do not look after them, if you abuse them, there is a price to pay because they are valuable as well. Currently … we are all disposable, dispensable and completely not valued. Yeah, so I think a redress scheme will have that function of telling the community they are important, they are valued. Because they have been wronged, we have to recognise this and compensate them for their suffering.

In a similar vein, AL05 noted the possibility of realising equality of people living with dementia through symbolic recognition of monetary payment as treating them equally to those under other redress schemes:

> I do think that compensation is an important component in relation to some forms of harm. I think that it's what we're offering in other redress schemes and in recognition of other types of harm. So I do think it would be appropriate for that reason.

In their research on 'money justice', Daly and Davis note that monetary payments can represent concrete recognition of gross harm, even if these payments can never fix or compensate for the harm itself.[246] In its submission to the development of the NSW Stolen Generations Reparations Scheme, Legal Aid NSW observed that some Stolen Generations survivors see 'compensation as a form of respect and recognition' that they were wronged by the relevant government in being removed from family and community.[247] For example, a Stolen Generations survivor, 'Luke', was quoted in the submission as saying: 'The worst thing was being taken away from my family. It's real hard to talk about and to think about – too many bad memories. I think the Government should pay money, out of respect. I've still waited a long time.'[248] Thus, Legal Aid NSW proposed a monetary payment be termed 'recognition payment' for its 'symbolic value to the Aboriginal community in redressing historical injustice and in more accurately describing one of the legal remedies made available'.[249]

Reimbursement for aged care costs

Another purpose of monetary payments is to reimburse individuals for money spent on residential aged care where harm occurred. This is because the promise of care for which they paid was never realised and because individuals have at times experienced longer-term material impact in spending money on services they did not receive. As explained by CPFM06: 'You don't pay for abuse and you paid extraordinary amounts of money over and above their pensions because it's assets tested for this.' CPFM15 explained that care should be reimbursed where harm has occurred because residential aged care providers have not given the care that was paid for:

> In terms of the monetary payment, I think one of the things that's crucial is that these particularly private providers operate under the financial competition legislation as well. And I think it's imperative that people ... I guess the narrative around these things is very much moved between, 'We're a business' versus 'We're providing care'. And to me there should be that absolute right of having the fees refunded. I think that's an important part. I don't really care about compensation so much, but it's more that, 'Well, you didn't provide what you're meant to provide', it's the same as if I buy something that's dodgy from a retail store. And, if you are going to throw that business principles up time and time again, well then you should face those consequences.

Monetary payments that reimburse residential aged care services can provide financial support to individuals to access better support and services in a community setting, as noted by PLWD06:

> Maybe if the facility was forced to refund any of the costs that had been incurred normally during that period of abuse to the family, with the view that then the family can use that money to find a better facility. And then if the abuse has been going on for 10 years, it could be quite interesting to see what the outcome would be. So the cost involved would quite large and it may then encourage families to fund having that person back at home …

> [O]ne aspect too that would be important is that there’s financial penalties, if you leave the place to go somewhere else. And if all that money was refunded because of the poor quality, then that’s going to allow better choice of where you go, without having to, well, maybe for the family remortgage the house as it were for the next person.

Monetary payments for this purpose can also facilitate residential aged care providers having to forgo financial gain derived from provision of harmful services. CPFM10 framed the rationale for monetary payments for reimbursement in terms of consumer rights:

> You are paying for a service that you didn’t get. Especially at the moment, a lot of people are paying for— and especially people with dementia— are paying for extra services, like a glass of wine and newspaper and what have you, that often they cannot use. They might not be able to read the newspaper anymore, but they just get charged this fee for something, movies and that, that they can’t access. So I certainly think in those sort of things, they should be refunded because they can’t use that service and reform. And I do think that sometimes providers have to be hit in the hip pocket. So I wouldn’t like to necessarily see monetary payments come from the government, but I think certainly for individuals and if individual providers have been found to be at fault, there should be some sort of process of finding or whatever, because if they get hit in the hip pocket, they might take a bit more notice.

CPFM10 further elaborated on the importance of monetary payments hitting the ‘hip pocket’ of residential aged care providers:

> I think if we look at the [Royal Commission into Misconduct in the Banking, Superannuation and Financial Services Industry], banks were fined and that made them pull their head in. You know, I think sometimes you need to hit people in the hip pocket. I don’t think it should be government paying money to individuals. I think it should certainly be coming from people who profited from the system and that’s the providers, both for-profit or not-for-profit. You know, we all know that some of the church, the faith-based organisations have really profited from aged care as well.

Such monetary payments can impact the organisation’s overall profit margin and thus deter further perpetration of harm, notably that which is directly associated with cost-efficiency. This is demonstrated by the following exchange between PLWD06 and PLWD05:

> PLWD06: The financial aspect does put an incentive on the provider.
>
> PLWD05: Yeah. I see the money side as more of a punishment for the providers rather than a thing for the family carers.

Similarly, CPFM15 stated:

> [T]hat’s where to hit them, in that hip pocket, because I think that’s the only thing they absolutely understand.

Fund rehabilitation and restorative care

A third purpose is to cover cost of rehabilitation and restorative care, at an individual or structural level. PLWD09, who proposed restorative care (see Section 4.2.8), suggested that monetary payments should be used to fund restorative care:

> Because without that, it really looks like you’re getting hardship. You know that sort of feeling that you’re getting paid off because of your pain and suffering? But the whole point of redress is to put the person back in the position they were before the event.

CPFM08 spoke of the importance of specific improvements in care for her grandmother:

> [M]y mum would not want a bar of that money. She would just want basic service that’s missing from my grandma’s room. Even things like the size of the room. We cannot stand next to a wheelchair or a walking frame to support her. There’s not enough room. It’s not, I don’t even think it’s accessible, disability accessible at all. I don’t think it would meet a standard if there are standards to follow. So some of the things we’re after, it was like we’d love that money to just swap food. So it’s healthy food and not frozen nuggets. And have an extra tissue box in the room and wipes, so we didn’t have to bring all of that sort of stuff with us. So I think putting that money back into resources.

Some research participants spoke of monetary payments being better spent on improving the aged care system at a structural level. For example, CPFM09 stated:

> Monetising it in my mind, money could be better spent on improving aged care, as opposed to recompensing us for all that sort of happened to us. I would really rather see that money go, be handed forward … there's not much money available for aged care so it seems, so I'd like it to be used for the living in a positive way.

AL01 also supported money being redirected to improving care:

> [T]he fact there are people making literally millions of dollars out of systems that force people to live in poverty and situations that they wouldn't want any of their relatives to live in, is disgraceful. It's not like there isn't funding for aged care, it's just where is that funding going? It's going to the pockets of ... I mean, obviously there needs to be more funding, but where is the funding at the moment going? It's going to the pockets of private enterprise when … that should be redirected to providing better care, but also could be a potential source for the money required for redress.

Fund advocacy

A fourth potential purpose of monetary payments is to contribute to funding of advocacy organisations for people living with dementia. PLWD12 suggested that where there is no one seeking reimbursement for aged care fees, the funds should instead go to a common fund to support advocacy:

> [I]n [CPFM 13's] case, then she had to cough up money to actually get the people to actually do something, I think she should get compensated. But if we're just talking about something that comes up and something to make the particularly the for-profit people, to ... I believe that any money that goes, shouldn't go back to, should go to some sort of common fund, whether it goes to Dementia Alliance or whether it goes to Dementia Australia or some aged care system, but somebody who can actually use that money that then not for the government to turn around and say, okay, you've got this money from this fund. And we now going to take your budget fund away from that. I think that needs to be protected.

AL04 proposed funding the growth of the dementia rights advocacy sector:

> One other mechanism that might be useful is for compensation to go to the peak or representative groups as well. And maybe a portion of that is either always or can be done by the carer is sent to the peak. And that's part of building a better ecosystem where the voices of people with lived experience are better represented and hopefully prevent that happening in the future.

4.2.12 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 must also take the form of sanctions that hold accountable and bring detriment to the individuals and organisations responsible for the harm. This form of reparations is important to ensure recognition of wrong, deterrence of future wrong and prevention through stopping perpetrators from working in residential aged care or stopping specific residential aged care facilities from operating. Sanctions need to target every level – e.g., individual workers found to have harmed an individual living with dementia, residential aged care providers allowing poor care, poor food and low staff levels, and management and board members who have enabled facilities to be governed in a manner that such harm can occur. Sanctions must extend to public servants who are responsible for policies that enable harm or for administering ineffective regulatory frameworks. Legal and health professionals must also be subject to sanctions.

Larger residential aged care providers must be prevented from having strong ties to governments, as a way to both enhance accountability and prevent policies that are part of a system that allows harm to happen. Anti-corruption, antitrust and competition laws can be explored as potential tools to prevent influence of residential aged care providers on governments.

Sanctions reflect the inclusion in the van Boven Principles of reparations in the form of '[j]udicial and administrative sanctions against persons liable for the violations'.[250] Sanctions have not been a feature of Australian specialised redress schemes.

Indeed, it is arguable that within those schemes, perpetrators have been quite invisible and marginal.

VA08 emphasised the importance of specific forms of redress to hold residential aged care providers accountable as central to the overall success and meaningfulness of reparations:

> And the grief and the anger chews people up for years, years, and years. I mean, I’m talking to one woman whose husband died 14 years ago and is still carrying the anger. And a lot of that anger is about the helplessness that you are thrown into as it were. And that helplessness continues when you get this complete refusal. 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.

PLWD02 suggested that addressing issues at a staffing level at a local level when they occur might alleviate the need for compensation or other forms of redress.

> Well, I think it can be on different levels. So, it could start in the facility, like I said before, you could have, start at training level, you could start at warnings and dismissals and there’s ... It’s different levels, for different misdemeanours, so redress can occur at all different levels, going ... right up and to compensation … Because for a small misdemeanour, you don’t, I wouldn’t expect compensation for a small misdemeanour, where I think perhaps education could be the key.

PLWD09 suggested having a ‘fit and proper test’ to regulate staff who perpetrate harm:

> PLWD09: [A] suggestion that we apply a fit and proper standard … So, we have fit and proper for company directors that, that filters on down through to all staff, so that their fit and proper sits with their registration.
>
> Facilitator: [S]o would it be possible for people to be able to report, for individuals to be able to report to that registration body if they do?

> PLWD09: [O]r that it should be automatic when a complaint is lodged that, that information filters through to the registration when anyone is named.

CPFM10 explained that sanctions would provide impetus for aged care providers to change their practices:

> I kind of believe that you need a bit of carrot and stick. And at the moment, we have a lot of carrot and no stick. The financial— You know, a financial penalty would be the stick.

However, some raised concerns about the tension between holding individual staff accountable for their conduct and the precarious circumstances in which they work, as discussed in Section 3.2.3. Thus, 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.

4.2.13 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.

Reparations must include institutional reform – of aged care governance and practices, and of the broader laws that regulate aged care. A common thread throughout the preceding principles is that reparations must ultimately be about changing systems and preventing further harm. As well as commitments to and action on change being designed into reparations in the forms of truth-telling and apologies (as discussed in Sections 4.2.9 and 4.2.10), reforming laws and practices can itself be a distinct further form of reparations.

The van Boven Principles note that reparations can take the form of ‘Reviewing and reforming laws contributing to or allowing gross violations of international human rights law’.[251]

AL02 referred to the need to ‘overhaul the system’:

> I suppose it gets back to the point of, if we really want redress, we have to overhaul the system. So all of these individual stories, if you take a bird’s eye view of it, it just calls for systemic change. It calls for major policy changes.

AL02 elaborated:

> [R]eal redress means you really don't do it again, and you really need to overhaul the system and that's it, full stop. This is something that the whole community will have to get behind. So that's it, full stop. That's redress. Change the system, overhaul the system because the current system leads to abuse.

Reparations in the form of law reform must be done in a human rights framework. Otherwise, any reforms can simply continue to facilitate human rights violations in any redesigned system. For example, AL17 said that reforms to laws and practices need to be undertaken 'in a way that's compatible with human rights'.

On this basis, this form of reparations is likely to be (necessarily) considered quite confronting and challenging for governments, residential aged care providers, health and legal professionals and broader society because, as discussed in Section 3.2.5, international human rights law provides rights to independent living and to freedom from coercive interventions such as confinement, forced medical treatment and use of restrictive practices. Human rights law reforms, done properly, would require deinstitutionalisation of residential aged care and prohibition of many of the key practices within them, such as restrictive practices, including chemical and physical restraints. The regulatory frameworks and professional standards of health and legal professions must also be reformed to ensure health and legal professionals advance the human rights of people living with dementia in their provision of health and legal services, including by addressing their professional roles in facilitating institutionalisation and coercive interventions such as restrictive practices.

Some research participants explicitly identified the importance of reparations extending to deinstitutionalisation and desegregation (however different research participants might understand those concepts) and for learning from deinstitutionalisation in other contexts. CPFM10 argued for the specific need for deinstitutionalisation of residential aged care:

> Any redress, I still think does need an apology from a provider group, but I think we do want to look at deinstitutionalising aged care. I mean, aged care is the last place where we're putting in people in bigger and bigger facilities for

> residential aged care. Every other sector, mental health, disability have moved away from large institutions.

CPFM06, who was in the same focus group session as CPFM10, reflected on her decades of experience working in disability services during processes of deinstitutionalisation to argued for deinstitutionalisation of residential aged care:

> I came from where we institutionalised people and tied people's hands to a chair because we thought that was the right thing to do. At that point, I wasn't educated. I was young, I was in the disability sector and working in a place that we thought that was right. A redress can bring this stuff to the forefront. A redress will probably hope or educate, I expect, it would start to educate people on what is right and what is wrong. The disability sector now know full damn well, that is not the thing that we do anymore. We're much, much better in the way we treat people. The aged care is 30 years behind.

In a similar vein, CPFM09 stated:

> [T]here should be … a building standard applied to aged care facilities. There's just so much evidence to suggest that small house-like models of care are the most appropriate, really for anybody trying to live the rest of their life in a happy situation. But you know, there needs to be a mandated rule applied to designing these facilities. Otherwise they'll just keep building them because it's a supposedly economy of scale. People won't stop doing things unless they, there's some form of accountability unfortunately. It's just the way humans are.

4.2.14 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.

Reparations must extend to training of those currently working in residential aged care – facility staff, management and board members, and health and legal professionals who support residential aged care provision. This training should not be taught through a biomedical model and should include learning on dementia as a disability, human rights of people living with dementia and the perspectives of people living with dementia. Training should be co-designed with people living with dementia. Existing training courses should be redesigned where necessary. Healthcare and legal students in university and TAFE colleges should also receive education on dementia, disability and human rights as part of their courses, noting that many ideas are formed before health and legal professionals even begin their careers. Lived experiences of harm, including those from any truth-telling process, can be included in training.

Training as a component of reparations is supported by the van Boven Principles, which provide that reparations can take the form of ‘Providing, on a priority and continued basis, human rights and international humanitarian law education to all sectors of society.’[252] Moreover, the van Boven Principles identify reparations in the form of ‘Inclusion of an accurate account of the violations that occurred in international human rights law and international humanitarian law training and in educational material at all levels’.[253] The importance of a human rights-based approach to training is also supported by Article 8 of the CRPD on awareness-raising, which states:

> 1. States Parties undertake to adopt immediate, effective and appropriate measures:
>
> > a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
> >
> > b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
> >
> > c) To promote awareness of the capabilities and contributions of persons with disabilities.
>
> 2. Measures to this end include:
>
> > a) Initiating and maintaining effective public awareness campaigns designed:

> > i. To nurture receptiveness to the rights of persons with disabilities;
> >
> > ii. To promote positive perceptions and greater social awareness towards persons with disabilities;
> >
> > iii. To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;
>
> b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;
>
> c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;
>
> d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.[254]

PLWD05 and PLWD06 observed that staff education on dementia should be mandatory and should occur in a broader context of raising community awareness about dementia:

> PLWD05: [I]n most cases as we know there's not even basic dementia training. I'm talking about home care worker who comes, she's very willing, very kind, doesn't have clue about dementia, and of course every time she comes I give her education and tell her she will be educated if not for me, but for other people. But that's not always possible. It's not everyone's in the situation will turn, pass that information. Either they learn by experience or they don't learn, they don't understand what's happening. And the organisation offers minimal staff and have to do it in their own time, and they don't get very much in the first place and to ask them to do training in their own time, they're not motivated to do that. So, yeah, until there's different standards of training, different levels of training for different workplace things.

> PLWD06: But also to go with the training, there needs to be promotion of public awareness … So the community has got a better understanding of what's involved from both ends, and can have their expectations raised appropriately.

PLWD09 and PLWD07 discussed the importance of training being co-designed with people living with dementia:

> PLWD09: [I]f any of you have seen some of the dementia training that there is, it hasn't been developed by a co-design process. So it's pretty shit. So before we go racing to send everybody to go and get trained, you might want to look at, and again, it's side of scope, but the training's—
>
> PLWD07: Update of the content and type of training.
>
> PLWD09: Yeah. It's pretty old world. A lot of it.

CPFM09 also supported the need for training:

> [U]nless we have a redress scheme that actually has a result of the people that work in the sector, getting the appropriate training, I don't think things are going to look any more positive anytime soon.

Some research participants referred to the University of Tasmania Understanding Dementia MOOC (Massive Open Online Course). CPFM09 cited examples from overseas:

> In Scandinavian countries, and I think also in New Zealand, people have actually paid to do dementia-specific training. They're paid to do the training and then when they get the education, they're actually acknowledged by getting more money for it as well. So that system works well in those countries and the same needs to apply in Australia, so that people who work in aged care, do gain the respect that they deserve. But training has to be mandatory. It can't be, well, the training's available online and therefore you need to just go and get it. The problem won't go away until the workforce issues are addressed.

VA07 mentioned the importance of human rights training:

> And until people recognise the rights of aged people as human beings worthy of human rights, what are we going to do? I mean, that was my form of redress, that's all I asked for was rights recognition training. And I sincerely do believe that if we do have that, then a person will be respected, their personhood will be respected, and then we will get the kind of change that we need, and there will be more humane person-centred care within our facilities.

CPFM15 noted the specific importance of human rights training extending to supported decision-making and legal capacity:

> [O]ne critical thing would be training around capacity, supported decision-making and things like presumption of capacity. So that sort of thing, because if people are presumed to not have capacity without any sort of thought put into that, they're going to constantly be denied that choice and control, and that autonomy.

However, some research participants raised concerns about the possible limits of training and education, given the deeper culture of residential aged care. For example, CPFM16 observed:

> [I]'s very difficult to educate a system. You can educate the individuals in it, but to restructure and educate a system is incredibly difficult. Because you've basically got to throw out all the patterning and all the dysfunction that exist within a system, and create new patterns that are unconscious. A lot of that stuff is unconscious and there's an, 'It's okay to do this.' An, 'It's okay to do that.' All of that has got to be thrown out and a whole retraining and a rethinking of structures and the way they operate.

Similarly, VA02 noted that training would not be sufficient unless it was associated with systemic reform.

> You can do all the staff training you want but you're still going to put them in a system that wakes people up and puts their hands down their pants every two hours [to check their incontinence pads]. You're still going to put them into a system where it's really okay to have a fake library wall. You're still putting them in a system, no matter how good the training is, you're putting good people with supposed good training into that vortex.

VA11 suggested that training can be limited if it is not situated in a broader strategy of changing cultures within residential aged care, because human rights ‘stop’ when one enters residential aged care:

> But I was just thinking around the staff and board training, to me it’s also a cultural problem, and I don’t know if we can address that somehow in staff and board training about redress should include training. We’ve got training to the providers on human rights, I don’t know if there’s anything we can do about changing culture. I’m not sure if this is the right place, but to me it’s like aged care in general has this culture where this is acceptable. And it seems to be that human rights stop when you go into aged care or dementia care, it seems to me a big cultural problem.

VA11 noted the importance of including human rights training in the education of future residential aged care staff:

> I’m about changing the whole thing, and also not just changing it when people start working in aged care, but we want to change it as a part of their start training. Again, I’m not sure if this is the right place, but we know that if they do the Aged Care Certificate III that dementia’s an optional unit. It’s not a part of the Certificate III of Aged Care that people learn about dementia or human rights, or anything like that. But then what happens is they go off into aged care and no one’s got time to do training, and then we’re trying to add these things in. These should be grassroots training for people going into registered nursing, those certificates, or geriatrics or whatever. It’d be good if we can make it at the start … Because I know when I spoke to the [Aged Care Royal Commission], this is one of the things that I identified with my mum’s care was that staff just said they weren’t trained in understanding dementia and then to try to get staff to learn later on, it’s too late. And it’s cultural and they’ve already been exposed to a culture of aged care where we don’t care about human rights anymore, they’ve already disengaged from it. I’m just wondering if there’s some way we could change it from that level.

PLWD11 suggested the need for training of other people who lived in residential aged care:

> The training also needs to be of all the residents who are in that aged care complex as well.

VA10 suggested training and education on dementia in broader society, including in schools:

> [B]ecause it is a cultural thing, I think it should be extended to the children in schools and the community in general, we should all better understand dementia and the consequences and what it is for the families and the carers. It needs to be not just staff and board training, but community awareness and training, because we're all going to be affected by dementia in one way or another as our population is ageing and more people are suffering from dementia. So I think it should be a community awareness and training, and schools is the best place to start, with children going into dementia care units.

4.2.15 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.

As well as responding to past harm and preventing further harm associated with the existing low status of people living with dementia, reparations can go further and seek to empower people living with dementia and enhance their sociopolitical status and identity. Reparations of this nature can include specific measures directed towards provision of resources to support advocacy for greater recognition of human rights of people living with dementia as a group, such as greater resourcing of peak bodies for people living with dementia and people with disability to better represent the voices and experiences of people living with dementia. Measures to empower people living with dementia are important because people living with dementia are not always able or willing to speak up for their own rights in residential aged care, including because of fear of retaliation.

These measures are supported by international human rights norms in the CRPD on awareness-raising, independent living and community inclusion, and political participation.

However, resourcing advocacy must not place all the responsibility on people living with dementia to advocate their own way out of harm at the cost of accountability for perpetrators and prevention of harm. VA07 cautioned:

> It seems to me that the onus should be on the providers doing the rights recognition training, and not so much on the people with dementia being all skilled up on all of their rights and things. It's awfully difficult. It's going to be enormously difficult for someone to take an action, even if they can prove that harm was done.

4.2.16 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.

Individuals' needs to facilitate and maximise participation in reparations processes will differ based on their identities and their broader experiences of oppression.

There is scholarship and international human rights commentary on the importance of recognising intersectionality in reparations processes in relation to other marginalised groups, such as in relation to women.[255] A similar knowledge-base that additionally considers disability, older age and specifically dementia is yet to be developed, although there is broader literature on access to justice for people living with dementia, people with disability and older people.[256]

AL18 mentioned the importance of explicitly identifying specific groups who might have diverse needs:

> I think that also could be more expanded on and really named, 'Okay, who are those intersecting groups that experience those explicit forms of discrimination?' Because blanket statements sometimes might not capture all of those specificities of those groups, unless they're really clearly laid out, because that might add to that cycle of invisibility.

Similarly, AL17 stated:

> I’m wondering if that also speaks to the need for sort of acknowledged intersectionality, and even it could be spelled out a bit more clear that the recognising diversity is about recognising, making sure that the process is culturally safe for people, even sometimes just naming, LGBTIQ plus community, sometimes it’s helpful to say the intersections and the different aspects of people’s identity that need to be recognised and supported.

Reparations also need to recognise diversity through accommodating the individual needs of each person, including in terms of the specific form/s of reparations each person might need. For example, VA11 stated:

> [I]t needs to be individually focused. We talk about person-centric or person-centred. When it comes to redress, if I’m coming forward and it’s usually a really gutsy thing to come forward for these things. It’s going to be really focused on the individual, whatever the outcome is or the outcome that they want, not what is generally thought to be the best thing. And I guess that comes back to the monetary payments as well. It may not be suitable for me. For me, what I want is maybe something different. It’s got to be focused on what I want, not what generally we would give in these situations, because my thing might be that I want to be moved or that I definitely want to stay here. So then we need to accommodate that. It needs to be accommodating of what the individual actually wants. And that’s like that big picture thing, when you were just saying big picture, what does this need to consider? It’s just really got to be individually focused and absolutely counselling is absolutely hand in hand with all of this. It’s got to be immediate. It’s not like, okay, well, we refer you on somewhere. Obviously, you’ve recognised that by having [counsellor] here today [at the focus group], but ... even with the Aged Care Quality Royal Commission, they had counsellors available for us. To me, a lot of this is really quite, it is traumatic and having counselling available immediately. And as a priority is definitely a thing because watching your family member being bullied, harassed, tortured, whatever, is very confronting, and what happens usually.

4.2.17 Principle 17: Trauma-informed and cultural safety

Reparations processes must be trauma-informed and culturally safe.

Reparations must be trauma-informed. This is important in order to prevent reparations itself from becoming a source of harm to people living with dementia and care partners and family members. Trauma-informed processes are supported by the van Boven Principles, which state:

> Victims should be treated with humanity and respect for their dignity and human rights, and appropriate measures should be taken to ensure their safety, physical and psychological well-being and privacy, as well as those of their families. The State should ensure that its domestic laws, to the extent possible, provide that a victim who has suffered violence or trauma should benefit from special consideration and care to avoid his or her re-traumatization in the course of legal and administrative procedures designed to provide justice and reparation.[257]

The earlier UN Declaration of Basic Principles of Justice for Victims of Crime and Abuse of Power similarly provides that victims should be treated with compassion and respect for their dignity. [258]

The van Boven Principles also state in the context of reparations for human rights violations that by taking a victim-oriented perspective, 'the international community affirms its human solidarity with victims of violations'.[259] A victim-centred approach to redress can be a symbolic and material indication of solidarity with people living with dementia and their families, and go some way to addressing the fear and mistrust that people living with dementia and their families have developed through past experiences of lack of transparency, power imbalances and retaliation.

Trauma-informed practice[260] means there is a framework for service providers that is based on knowledge and understanding of how trauma affects their service needs and care and their broader lives. There are five guiding principles of trauma-informed care: safety, choice, collaboration, trustworthiness and empowerment. Trauma-informed services means services that do no harm, services that do not retraumatise or blame victims for their efforts to manage their traumatic reactions, and services that embrace a message of hope and optimism that recovery is possible.[261]

Taking a trauma-informed approach to reparations processes is particularly important in light of the poor experiences of internal and external complaint processes people living with dementia and their care partners and family members have had (as discussed in Sections 4.2.2 and 4.2.6).

Some research participants spoke of the trauma they were still experiencing from having witnessed harm to people living with dementia. VA10 stated:

> I just want to mention that this trauma-informed business it’s often the families that are feeling the trauma because when we see our loved one being harmed or not well cared for, we are feeling it. And we are feeling really disabled in a way, because we feel, if we make too much a noise about this, it will go against our poor mother or father. And so I think the trauma informed [approach] should be about the families who are involved with the person or that advocates, because we are traumatised by seeing.

Some research participants noted the trauma that people would come to the reparations process with. For example, VA11 drew on her own experiences to explain:

> But it’s definitely, as soon as this process is starting, that support is made available to whoever needs it. It might be staff also working on this because we know that us sharing these stories is quite traumatic as well, because often accessing counselling is really difficult, and especially now in COVID, I just feel that we are opening a real big box here, that, that support has to be available. And some of these people will have died and there’ll be a sense of grief and loss also when you are telling these stories.

CPFM10 stated:

> So there’s a big financial and emotional cost. Everybody who’s been through … when you’ve been through it and going over and over and over your story, which is where you get the ‘you don’t want to do further harm with redress’, it is retraumatising when you’re continually going over it.

AL04 mentioned the importance of foregrounding victims:

> I do think that when I look at how we right wrongs and some of the reasons why we have the wrongs is that the lived experience and leadership of people, of older Australians, it’s just completely absent in discussions I see. And so

> there's no institutional structures that I can see that are set up to give visibility to older Australians, their lived experience of being older. But then also their lived experience of going through these different systems and the issues. And when I look at the Royal Commission and the way that media has covered this stuff it's been very concentrated on the perspective of the sector. And I think that the sector has a conflict of interest in those conversations and that you have to have the voices with lived experience in particular, the critical ones who are critical of the system.

AL02 spoke of the importance of reparations processes not retraumatising people:

> I think the way the redress, if it happens, the way that it is processed, the way that it is done is very important that it not retraumatise the people like how it is retraumatising, the redress scheme for people who have been abused, who have been in care. It is just horrific and I think it's so important that it not happen that way if this actually were to get off the ground.

Similarly, AL05 referred to retraumatisation as a 'really big issue':

> I think retraumatisation is a really big issue in this space where a person needs to provide evidence and go through their story. So I think this is assuming that there was a redress scheme and then in the process of making that go ahead being really aware about retraumatisation, how difficult it is for people to talk about that. … I know that sometimes people have never spoken about the abuse before to anybody and it's kind of the first time that they ever even recognising to themselves that there was abuse or neglect or that happened to them. And they had that experience. So I think that's really essential so as to not cause further harm in trying to right the previous harm. ... And making avenues for them to receive the right support, counselling, the right advocates with training in dealing with this. Like I was saying about having people who have specific training for working with people who are living with dementia, I think is really important.

AL04 described trauma-informed processes as being about giving more agency to individuals in the reparations process:

> [T]here's just something in there about lacking agency through the process. And so things that are happening to you, which you say replicates the kind of experiences that people have of institutions. And so I don't know if it's like a deinstitutionalised approach to it or something, certainly that when I think of trauma-informed, it's that the person's in charge of the process, you know? And so maybe that can be clarified in some way or strengthened, that they have much more agency to navigate that process rather than it just happening to them.

Reparations processes must be guided by the perspectives, needs and experiences of people living with dementia and foster their self-determination and autonomy.

It is critical that reparations processes are also culturally safe. 'Cultural safety' has been defined as a policy of ensuring respect for cultural and social differences in the provision of health and education services.[262] It is more than having awareness of other cultures or of respecting others. Cultural safety in a workplace or system involves everyone examining their own cultural identities and attitudes and be open-minded and flexible in attitudes towards people from cultures other than their own. Laverty et al explain in the health care context:

> Cultural safety is an Indigenous-led model of care, with limited, but increasing, uptake, particularly in Australia, New Zealand and Canada. It acknowledges the barriers to clinical effectiveness arising from the inherent power imbalance between provider and patient, and moves to redress this dynamic by making the clinician's cultural underpinning a critical focus for reflection. Moreover, it invites practitioners to consider: "what do I bring to this encounter, what is going on for me?" Culturally safe care results where there is no inadvertent disempowering of the recipient, indeed where recipients are involved in the decision making and become part of a team effort to maximise the effectiveness of the care. The model pursues more effective practice through being aware of difference, decolonising, considering power relationships, implementing reflective practice, and by allowing the patient to determine what safety means.[263]

People living with dementia or their care partners and family members who experience intersecting forms of discrimination and associated structural violence, trauma and harm might experience reparations processes as unsafe or be particularly at risk of becoming distressed or harmed through the process.

The importance of trauma-informed and culturally safe reparations processes is supported by criticisms of the National Redress Scheme, which has not been trauma-informed. For example, Fiona Petersen from The Healing Foundation is quoted in the 2021 report of the National Redress Scheme Joint Select Committee as saying: ‘Unfortunately, our experience is that not all aspects of the [National Redress Scheme] redress process are survivor-focused, accessible, culturally safe and meet the needs of particularly vulnerable survivors.’[264] The 2021 Kruk Report observed that ‘Survivors and their support services highlighted the experience of participation in the [National Redress] Scheme as traumatising’.[265] Numerous victim-survivors and advocates described the National Redress Scheme itself as traumatising. For example, in the National Redress Scheme Joint Select Committee’s 2020 report, survivor Jennifer Biggs stated: ‘I wasn’t just a victim once; I was a victim twice. But really I feel like I was a victim a lot more since all this [engaging with the National Redress Scheme] has been going on.’[266] Submissions to and internal interviews cited in the 2021 Kruk Report suggest that ‘trauma-informed’ is not understood or applied by the National Redress Scheme.[267] Another survivor quoted in the 2020 report, Morris Pitt, referred to the National Redress Scheme as a dehumanising experience:

> Since I’ve been involved with the [National] Redress Scheme I’ve also felt that I am nothing more than a number and I was having dehumanising experiences brought upon me … I am not a number to be processed without care and consideration. This lack of understanding and empathy makes me feel that I am not worth anything and that I need to be gotten rid of as soon as possible.’[268]

The experiences of the National Redress Scheme indicate the importance of reparations, along with all services associated with it (e.g. legal, redress, counselling, wrapround, outreach) being culturally informed. First Nations survivors have had particularly traumatic experiences of the National Redress Scheme.[269] The National Redress Scheme Joint Select Committee’s 2021 report noted that knowmore, Victorian Aboriginal Child Care Agency (VACCA), and Relationships Australia all testified that the National Redress Scheme was not culturally informed or aware.[270] The 2021 Kruk Report found that the National Redress Scheme design 'has not considered the unique cultural differences needed to engage Aboriginal and Torres Strait Islander survivors'.[271]

In its submission on the development of the New South Wales Stolen Generations Reparations Scheme, Legal Aid NSW suggested a preventive approach to retraumatisation for First Nations people, submitting that, at its core, the scheme must recognise 'the potential that claimants who participate in the process may re-traumatised' and must therefore 'provide culturally appropriate psychosocial support throughout the application process'.[272] Legal Aid NSW further submitted: 'Adequate social and psychosocial supports, including counselling, must be provided to achieve full participation and minimise the retraumatisation of claimants to the greatest extent possible'.[273]

4.2.18 Principle 18: Disability inclusion and access

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

People living with dementia have experienced barriers to equal justice in relation to harm in residential aged care by reason of the disability inaccessibility of mainstream justice and complaints systems. Yet equal access to justice, equality and non-discrimination, accessibility and reasonable accommodations are all human rights, as provided in the CRPD.[274] More broadly, the van Boven Principles provide that victims have the right to 'equal and effective access to justice'.[275]

Importance of accessible processes

Processes of reparations should take account of and be responsive to people's dementia, or any other cause of disability. People living with dementia should have access to advocacy and legal assistance and counselling to support their participation in reparations processes, and resources and funding for supported decision-making (if needed). Information about reparations should be presented in ways that are accessible to people living with dementia (such as in Easy Read formats) and be disseminated widely through the services people living with dementia and their care partners and family, and other marginalised communities, often access. There should also be outreach to residential aged care facilities and development of specialist trauma-informed legal assistance co-designed by people living with dementia.

PLWD05 and PLWD06 emphasised the importance of accessible redress processes:

> PLWD05: It is just about public awareness, isn't it? So information needs to be produced and distributed widely through channels that are more accessible. It's through health, it's through organisations, DAI [Dementia Alliance International], Dementia Australia, well, so that it's ready and accessible, and in an understandable format for people with dementia.
>
> PLWD06: But there's going to be no means that's going be able to be accessible to everyone. And I think one thing that would be a big step forward is, if every facility had a mandatory notice board that had this information on it, so everyone visiting would be forcibly aware of it … Can you find those notice boards in some of those locations? And yeah, because I know places where the information is available but the average person dealing with it doesn't have access to the technology or know how to use the technology, et cetera.

Broader awareness raising about human rights, and what constitutes harm in the context of residential aged care, will assist people living with dementia to understand if and when they have experienced harm (as discussed in Section 4.2.20), particularly in a context in which this harm is legally and socially authorised and normalised and routinised through daily practice.

Foregrounding disability inclusion and access in the design and operation of reparations processes and associated legal and counselling support services is important given the observed failure of the National Redress Scheme to be accessible to and inclusive of people with disability. For example, AL13 stated:

> So, particularly rights to equal recognition and principles around accessibility. And they're definitely things that the National Redress Scheme would've benefited from a greater focus on. And even I was thinking about barriers for people with dementia, and we're having some issues with evidentiary requirements and memory loss and people having to basically recall the details of what happened to them and essentially seek to prove their credibility

> of that. And there are things, I think, processes that are just too difficult and don’t really factor in different people’s needs and they don’t necessarily have the support to be able to overcome those barriers.

Reflecting on the National Redress Scheme, AL12 noted the specific importance of an accessible evidentiary threshold for accessing redress:

> So, reasonable likelihood that a person experienced abuse in this institution. But we’re seeing the decision-makers asking sometimes for evidence and information, and not just us, the statutory second anniversary review into the NRS [National Redress Scheme] had some commentary around this issue as well and some recommendations around ways to make sure that this issue was addressed. But so I think it’s one thing to have the scheme set up in a certain way, but then the way it’s operationalised is obviously critical as well. And some decision-makers seem to be expecting an awful lot of recall from traumatised people who might have been abused at a very young age. And so we certainly wouldn’t want to see that same expectation for people living with dementia. I think that’ll be another key issue that is really important to address because there’s no point having a scheme if every second person is found not eligible, right?

Accessibility limitations in the National Redress Scheme are also observed in reports on the National Redress Scheme. The 2021 Kruk Report noted the lack of options for people with disability to apply to the National Redress Scheme:

> Submissions from interviews, support services, advocacy groups and survivors to the Review [of the National Redress Scheme] strongly suggest the operationalisation of the Scheme currently presents significant access barriers for survivors with disability, some of which are seen as insurmountable. These suggest the Scheme does not currently offer an adequate range of options for people with disability to apply to the Scheme. There are also not enough communication products or support services to include effectively all survivors with disability, and this is having a material impact on the number of applications … [despite t]he Royal Commission reveal[ing] that paedophiles targeted children with disability, [and the fact that] childhood sexual abuse is a significant contributing factor to psychosocial

> disability, [and] the common experience of disability amongst applicants, support services raised concerns the Scheme's design had not anticipated disability as a central issue.[276]

The 2021 Kruk Report suggested that to better accommodate applicants with disability, the National Redress Scheme needs to 'allow a variety of communication methods for people to record their experience of abuse' using 'a range of media, including in writing, over the phone and in a video or audio recording' and 'Auslan interpreters and symbol-based communication tools'.[277] The 2021 Kruk Report noted that the already difficult and traumatising process would be even more difficult for people with cognitive disability:

> Support services described the current application process as incredibly difficult for traumatised applicants to complete, and reflected it was likely that people with additional barriers such as cognitive disability would find the application process impossible. While survivors with disability might have strong communication skills, some are unaware of the language used to describe sex and sexual abuse. Interviews and submissions to the Review described the insufficiency of redress support services trained to accommodate the needs of people with disability.[278]

Reparations will also need to be accessible, to people living with dementia in relation to not excluding them on the basis of assumptions about their mental incapacity. Strategies can include provision of supports to facilitate exercise of legal capacity such as use of supported decision-making. Article 12 of the CRPD provides for the right to legal capacity, stating in part that:

> 1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
> 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
> 3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.[279]

Principle 1 of the International Principles on Access to Justice for Persons with Disabilities reiterates Article 12:

> All persons with disabilities have legal capacity and, therefore, no one shall be denied access to justice on the basis of disability.[280]

People with Disability Australia has raised concerns about requirements related to legal capacity operating to exclude some people with disability from full participation in the National Redress Scheme:

> PWDA [People with Disability Australia] is concerned that evidentiary standards applied by the Scheme may unfairly disadvantage some people with disability, including people who require communication aids or are non-verbal.
>
> Our understanding is that decision-makers may assume people in these groups do not have the capacity to engage in the redress process on the basis that they are not able to identify how the abuse impacted them, even where there is documentary evidence of the abuse.
>
> The Independent Review Report contains discussion about respecting and supporting the legal capacity of survivors engaging with the scheme, noting that disability advocacy groups raised concerns that:
>
> - the legal capacity of applicants 'may not always be respected or supported by redress support services and legal firms', and
> - substitute decision-making arrangements under the Scheme such as guardianship and nominee arrangements should be dismantled.[281]

People with Disability Australia thus recommended

> that the Scheme's legislative and policy frameworks be reviewed to establish amendments needed to make evidentiary standards and their application sufficiently flexible and tailored in order to protect and support the exercise of legal capacity by people with disability.[282]

Experienced workers

AL02, AL18 and AL17 spoke of the need for those working in reparations processes to have knowledge of working with people living with dementia. For example, AL02 stated:

> I think it'll be important to note then that the people running the redress scheme should have appropriate qualifications, and also have people with lived experience involved and all those principles.

AL18 stated:

> [W]hoever does run this redress scheme should have profound knowledge of people living with dementia.

Co-design and leadership

Reparations must be led by and co-designed with people living with dementia. Care partners and family members must also have a role in the development and operation of reparations. Importantly, the design and operation of reparations must not be led or influenced by those involved in perpetrating harm.

Participation of people living with dementia enables direct involvement by people who have been impacted by harm living in, or facing the possibility of living in residential aged care, which in turn reflects direct action by governments to validate and respond to their experiences. Involvement of people living with dementia more broadly enables reparations to be informed by their deep knowledge, expertise and experience of what works for people living with dementia. Often people living with dementia are excluded from involvement in policy and service design and implementation, or their inclusion is tokenistic, because they are considered to lack capacity. Their exclusion can reflect a paternalistic approach that assumes others know best (whether those others are care partners and family members, service providers, academics, legal and health professionals or public servants).

AL01 linked the failure to listen to and recognise harm to people living with dementia to the broader political marginalisation of people living with dementia:

> Yeah. I think because maybe due to capacity, or this is a very ignored politically, group, this is a minority group with not much voting power, and at the moment not a huge amount of allies to it, which is absolutely horrible to say, but every minority group needs, in a democracy, some kind of alliance built around it. If at the moment it's a group that there are barriers for them to be included in society in many ways, and that includes in the political conversation as well. So I think the fact that we don't listen to older people or

> people with early onset, in general, we don’t ... I feel horrible saying this, but as a society, we generally don’t listen to older people and the wisdom of older people.

Thus, co-design is one way to challenge paternalism towards people living with dementia and realise equality and self-determination.

Leadership and co-design are among the elements of the PANEL human rights-based approach discussed in Section 4.2.1. Leadership and co-design are also a central dimension of domestic implementation of the CRPD (as per Article 33 on national implementation and monitoring) and involvement of people living with dementia in policy development and public administration (as per Article 29 on participation in political and public life). Leadership and co-design are also implicit in the longer-term principle of the disability rights movement, as captured in the phrase ‘nothing about us, without us!’.

The importance of leadership and co-design by people living with dementia is supported by a key criticism of the National Redress Scheme – namely, that it has excluded survivors of institutional child sexual abuse from the design and operation of the scheme. For example, the 2021 Kruk Report recognised the urgent need to ‘ensure the survivor voice is embedded throughout the Scheme’.[283]

The unique situation of residential aged care is that many people living with dementia who have been harmed will have died before reparations are available. Therefore, care partners and family members can sometimes be the most direct connection to those individuals. Moreover, some care partners and family members have themselves been impacted by the harm to a person living with dementia, either by witnessing that harm or through their efforts to stop the harm or advocate for the individual living with dementia (see further discussion in Sections 4.2.2 and 4.2.3). After an individual living with dementia dies, a care partner or family member might continue to advocate for recognition and justice for that individual, or wider change in residential aged care. Thus, care partners and family members should also be involved in co-design, although this must be carefully managed so that the voice of people living with dementia remains the driving force in the design and operation of reparations.

AL04 proposed that, additional to any specific reparations measures, leadership and co-design could also be embedded in broader legal and political systems. Such an approach would then mean that beyond the involvement of people living with dementia in the design and operation of reparations, the power relations between people living with dementia and governments and residential aged care providers could be reconfigured, including through giving people living with dementia a legislated role in overseeing law and policy development that impacts them:

> Is there agreement making between the state and that group that changes the underlying conditions between those people? So for example … how policy is made and set and what are the checks and balances? Do they need approvals from these particular people? You can do agreements for non-repetition. That's pretty tricky, given the system's pretty shithouse right now, they can't really keep to that. But, you can make an agreement to change the underlying relationship between the state and the relevant citizens.

AL04 went on to explain that this could change the 'tyranny of powerlessness' experienced by people living with dementia.

However, co-design needs to be carefully structured to ensure the safety of the co-design process for people living with dementia, as noted by AL04 (see also discussion in Section 3.2.2):

> How does this space grapple with the fact that sometimes the care partners might be participating in elder abuse and the dynamics around that?

The importance of co-design and leadership in redress of survivors, rather than relying on the involvement of well-meaning advocates speaking and working on behalf of survivors, has been confirmed by criticisms that the National Redress Scheme has excluded survivors from its design and operation. For example, Robert (a survivor) is quoted in the National Redress Scheme Joint Select Committee's 2020 report: 'we have perfectly good people speaking on behalf of survivors, but they don't really know. Until that [direct survivor involvement in reforming the National Redress Scheme] happens, it won't get better.'[284] As noted above, the 2021 Kruk Report states that there is an urgent need to 'ensure the survivor voice is embedded throughout the Scheme'.[285] Survivor feedback cited in the 2021 Kruk Report suggests that the National Redress Scheme 'poorly understands the concepts of “survivor-focused”’, with that this principle ‘frequently absent’ in the operational aspects of the Scheme.[286]

First Nations self-determination also needs to be central to the design and operation of reparations. This has been noted in relation to state and territory Stolen Generations reparations schemes. In its submission on the development of the New South Wales Stolen Generations Reparations Scheme, Legal Aid NSW identified the ‘need for Aboriginal led decision-making when implementing any [Stolen Generations] reparations scheme’.[287] The South Australian report on its Stolen Generations Reparations Scheme noted the ‘[i]mportance of involvement of Aboriginal people and Aboriginal organisations in the design and implementation of projects and programs’.[288] An anonymous participant in the South Australian report stated:

> when a [Stolen Generations reparations] program is designed, it is important that a well-established, long standing Aboriginal organisation with good governance and management systems is involved in the implementation of the programs. Members of the Stolen Generation need to have confidence in the Aboriginal organisation helping them with this very important role. The Aboriginal organisation also needs to have a good track record and the confidence of the Aboriginal community to achieve the best outcomes.[289]

4.2.19 Principle 19: Inclusive, accessible and equitable

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

While people living with dementia are themselves a marginalised group, it is important to be attentive to intersectionality along other lines of oppression. Reparations processes must respond to the diverse circumstances of people living with dementia, and their family members and care partners. Processes must be accessible irrespective of circumstances, and equitable in outcome. As well as being inclusive of disability (see Section 4.2.18), reparations processes must also respond to other dimensions of individuals’ identity (Indigeneity, gender, sexuality, religion, cultural and linguistic background) and life history (histories of institutionalisation, violence, armed conflict). Reparations must also respond to diverse harm experienced in residential aged care and the nuances of their varying impacts on people living with dementia, including possible physical, emotional, financial and cultural impacts (as discussed in Section 4.2.2).

The importance of accessible reparations processes is supported by the van Boven Principles, which elaborate:

> Obligations arising under international law to secure the right to access justice and fair and impartial proceedings shall be reflected in domestic laws. To that end, States should:
>
> …
>
> d) Make available all appropriate legal, diplomatic and consular means to ensure that victims can exercise their rights to remedy for gross violations of international human rights law or serious violations of international humanitarian law.[290]

Inclusivity, equity and accessibility need to drive the design and operation of reparations. Rather than thinking of these concepts at an abstract level, these concepts can be grounded in the realities of the lives of some of the most marginalised people living with dementia in residential aged care. For example, AL02 suggested that reparations should be accessible to individuals living in residential aged care who have no family or social networks to assist them in accessing reparations:

> I feel that if I'm a family member or if I'm someone with dementia, I have the ability to report and to get some redress … there are some who have no family members while living alone in age care. There is nothing in that, that gives me any confidence. If I am a staff member that I can see what's happening to that person in age care, that I can report it and that person can hopefully get some redress for the wrong that's being done to them.

This was then further explored in an exchange between AL02 and AL18:

> AL02: I think the question I would ask myself is, how would this 85-year-old woman with no visitors and no English in this age care facility, how is she going to access this redress scheme? I'll start from that basis and structure my principles around that.

> AL18: I think that's a really, really, really important point. I'll underpin, underline, bold, strike, whatever I can do, fully support that … Something that is really, really important, I know that this is part of it, the co-design and how the actual consumer and how that older person in residential age care is going to access this information or how they're going to be part of this entire process is the most important thing.

Reparations processes must be simple and straightforward and avoid complexity. Online, paper and verbal application options must be available, as not everyone has access to internet or the literacy or physical ability to write. CPFM14 spoke of the need for a simple process:

> And also, I think the process needs to be well-designed for families, carers, guardians, those who are going to be involved in the redress process. I think it needs to be something that is hopefully very straightforward for them to be involved in.

Other redress schemes have highlighted the importance of inclusive and accessible processes. For example, the National Redress Scheme has seen issues related to non-citizens and people with criminal records being unable to claim redress through that scheme,[291] and this can impact on marginalised groups that are more likely not to be Australian citizens (e.g., people from culturally and linguistically diverse communities) or more likely to be incarcerated (e.g., people with disability, First Nations people).[292]

AL13, drawing on experience with clients in the National Redress Scheme, stated:

> I was thinking about the relevance of it in terms of how you design a process and a redress scheme. So particularly rights to equal recognition and principles around accessibility. And they're definitely things that the National Redress Scheme would've benefited from a greater focus on. And even I was thinking about barriers for people with dementia, and we're having some issues with evidentiary requirements and memory loss and people having to basically recall the details of what happened to them and essentially seek to prove their credibility of that. And there are things, I think, processes that are just too difficult and don't really factor in different people's needs and they don't necessarily have the support to be able to overcome those barriers.

To facilitate equitable engagement with reparations, survivors' immediate primary needs must first be met, since survivors cannot engage with reparations if they have immediate basic unmet needs.

Experiences of the National Redress Scheme have demonstrated the importance of recognising and addressing survivors' immediate primary socioeconomic needs to make possible engagement with redress and the related traumatic past experiences they will be discussing.[293] For example, People with Disability Australia has noted that people with disability in marginalised or unsafe communities may be experiencing violence in the present and face numerous barriers that prevent them from being able to engage with the National Redress Scheme.[294] People with Disability Australia notes that this can be compounded for those experiencing intersectional dynamics of oppression, including survivors with disability who are of Aboriginal or Torres Strait Islander descent, from culturally and linguistically diverse backgrounds, are homeless, have low literacy, live in rural or remote areas or are experiencing family or domestic violence.[295]

More broadly, experiences of the National Redress Scheme have highlighted the need to minimise complexity of all facets of a redress scheme. Complexity creates major barriers to engagement that disproportionately impact the most marginalised.[296]

The Tasmanian Stolen Generations Scheme has been noted as having an accessible application process because it is informal and the burden of accessing supporting information is not on applicants:

> [T]he Office of the Assessor ... obtain[ed] any necessary reports and documentation, rather than requiring applicants to provide these themselves, which may have been burdensome. In order to ensure potential applicants are not dissuaded from accessing the scheme, the informal nature of Tasmania's application process should be replicated at the Commonwealth level.[297]

4.2.20 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.

People must know about reparations in order for them to be accessed. Yet people's knowledge of reparations will be shaped by the extent of any promotion and outreach efforts, coupled with individuals' personal, language and literacy, and living circumstances, and the willingness of those around them (including gatekeepers of information) to facilitate access to information.

The importance of promoting reparations is supported by the van Boven Principles, which elaborate:

> Obligations arising under international law to secure the right to access justice and fair and impartial proceedings shall be reflected in domestic laws. To that end, States should:
>
> a) Disseminate, through public and private mechanisms, information about all available remedies for gross violations of international human rights law and serious violations of international humanitarian law;[298]

All residential aged care facilities must be required to publicise and provide information about reparations in multiple modes, including having a mandatory notice board and pamphlets in accessible forms (e.g., Easy Read formats and community languages). In addition to information on reparations processes, residential aged care facilities must also provide information in accessible forms about what constitutes harm in residential aged care and about legal and human rights. This information can support people living with dementia (and even their care partners and family members) in developing their understanding of their entitlement to reparations. Information must also be available in the community in order to reach care partners and family members. Reparations must also be promoted through outreach to residential aged care facilities and community forums, and through engaging health and legal professionals and those working in other service systems who provide support to people living with dementia.

The need to raise awareness of the right to reparations was supported by CPFM01, who noted that older people might be of a generation that is not accustomed to a human rights and justice approach and thus not familiar with their entitlement to reparations, or even aware that they have experienced a violation of their rights:

> My mum and dad were very polite people. My dad had lived in boarding school when he was very young. His mother had died when he was very, very young and he'd had a very difficult childhood, but with a loving father who wasn't very capable a lot of the time of looking after him well, but he'd been in institutional care for a time when he was young. Afterwards, he'd gone to university, which was very unusual for someone in his family, and his background, and his generation. He'd done very well in life, but it was like regressing back into that period of his life when things had been so terrible, but he'd been brought up to be very polite and to respect authority, to respect doctors, not to ever seek special treatment or to complain or anything like that. And my mum was the same. I hope our generation will be different, that we will acknowledge that we have rights, and that we will fight for those rights to the extent that we are capable of doing that until hopefully somebody, if we lose cognitive capacity, will be able to do that for us. But Mum and Dad didn't want to do that most of the time. And so once Dad was in this locked ward, Mum would fluctuate between trying to do what was best for him, trying to make that happen, and then submitting to authority and submitting to advice.

AL05 drew on her experiences representing child clients to explain that sometimes people do not even appreciate that what they have experienced is wrong. This can be particularly the case in contexts where violence is normalised:

> What comes up with my [children] clients a lot is that they don't even know that what happened to them was wrong. They've had a bad experience and often with my clients, I deal with a lot of where the police have done the wrong thing in arresting my clients and that kind of thing. So the client is being told you've done something wrong. And you deserve this and then they don't know that what's happened afterwards, the arrest or if the arrest was violent or they were falsely imprisoned or things like that, they just don't know that what happened is wrong until they come across the right information. So I think that this problem is probably rife within the population of people we're talking about here.

People living with dementia may rely upon family members and care partners for information. However, some may not have social support; thus, information must be provided in a way that is not reliant on family members and care partners (as discussed by AL02 in Section 4.2.19).

CPFM17 emphasised the importance of promoting reparations within residential aged care facilities:

> I think nursing homes, yes, I think that’s a great idea and they should have whatever they’ve got, brochures, pamphlets, information, whatever, there for the residents and the families to either pick up, look at, read, care and so on. A great number of older carers are older people who can’t access the internet, who can’t use the computer.

Residential aged care providers must not prevent or obstruct promotion of information about reparations. This risk was flagged by PLWD09, who stated:

> [I]f you have residential care that you have to have a complete poster, how to make a complaint, how to give feedback, so that’s publicly available and how to report something similar to what you’d see in a— you know, in day shelter, you’ll see signs and leaflets and stuff. Or in a hospital there’s leaflets with numbers that you can call, if you’re left in the waiting room for 12 hours. Something along those lines that would be legislated differently, but this type of disclosure of how to empower yourself so that advocates can come in and really boost and support the person to have a voice, is what I’d be thinking about in terms of how to address this power imbalance and essentially having an open access policy.

The importance of promotion is underscored by criticisms that the National Redress Scheme has failed to engage in sufficient promotion and outreach to people with disability. For example, through consultancies and interviews cited in the 2021 Kruk Report, it was found that there was little knowledge of the National Redress Scheme in the disability sector:

> The [National Redress] Scheme is little known and understood by people with disability and in the disability sector [and] does not have a pervasive public profile because it was deliberately under-promoted from the outset.[299]

Moreover, it was also noted there was little knowledge of the National Redress Scheme in the wider service systems and among the professions with which people with disability interact, as noted by Romola Hollywood from People with Disability Australia:

> [M]any helping professionals across the disability, health, housing and justice sectors are unaware of the scheme or have very limited information, and generally are not proactive in providing accessible information to people with disability about the scheme when disclosures of potentially relevant child sexual abuse are made.[300]

People with Disability Australia has elaborated on this criticism:

> The [People with Disability Australia] team shared information with 895 people from 286 organisations, and of those, only 21 people had even heard of the [National] Redress Scheme! As there is no general public advertising campaign, if health professionals and other services working with potential applicants don't know the Scheme exists, then it is highly unlikely these potential applicants will be able to apply. We wish to foreground the compounding effects of intersectionality here, and acknowledge that survivors with disability may also be of Aboriginal or Torres Strait Islander descent, or of CALD [culturally and linguistically diverse] backgrounds, or be homeless, or have low literacy, or may be living in rural or remote areas, or may be experiencing family or domestic violence. All of these cohorts, among others, traditionally face barriers to accessing Government services. We therefore ask that the government immediately and strenuously enacts the recommendations that speak of more assertive outreach to people with disability and other cohorts, and to make information about the Scheme, and the process itself, much more accessible.[301]

4.2.21 Principle 21: Collective applications

Reparations processes must include an option for collective applications.

The option of making a collective application – i.e., with other individuals who have been impacted by harm – is important to ensuring accessibility and safety of the reparations process. Collectives may need an advocate or a union to support them, and to ensure action is taken.

The option of collective reparations claims is supported by the van Boven Principles, which provide: ‘In addition to individual access to justice, States should endeavour to develop procedures to allow groups of victims to present claims for reparation and to receive reparation, as appropriate.’[302]

The opportunity to make collective applications for reparations is important both in ensuring the safety, accessibility, and inclusivity of the reparations process and delivering reparations outcomes that have greater possibility of bringing about structural change. The structural and systemic nature of harm experienced by people with dementia in residential care means that many will have similar experiences of harm. Seeking reparations as an individual can fragment what is a systemic issue needing structural reform and demanding the full scope of accountability and financial and reputational impact on residential aged care providers. There are significant power imbalances between individuals (i.e., people living with dementia and their care partners and family members) and residential aged care providers, governments, and health and legal professionals. Moreover, seeking reparations as an individual might be isolating and disempowering, and compound existing experiences of having been isolated, disbelieved and marginalised through internal and external complaint processes, whereas collectively, support is innately provided. People can then be discouraged from accessing justice, including because of being intimidated or worried about retaliation, the reality that staff are more likely to be believed than residents or their families, or being concerned about lack of transparency.

CPFM11 emphasised the importance of collective processes for reparations because of the power imbalances with residential aged care providers:

> I just feel like one person trying, it’s overwhelming to try and do it on your own. So if some sort of group that’s on it, yeah, that might be part of the redress, that there’s someone on your side, the consumers … You’re just fighting on your own, but there might be lots of other people like me that it’d be nice to have some sort of solidarity on trying to do it. Because I’ve said that to [the] Aged Care Quality and Safety Commission], there’s so much of a power imbalance.

CPFM13 similarly spoke of being outnumbered by residential aged care staff:

> This is where the advocate comes in. This is where a resident needs an advocate like ... or a union. You can call a union and say, ‘Look, we’ve got a problem here, we don’t know what’s going on. Can you find it for us?’ This is the residents are left like sitting ducks. But the nurses can do and say what they like, and they get backed up on it. And even if they’re wrong, and I know that when they’re wrong, the other nurse will back them up before they’ll back the resident up.

VA11 spoke positively of the option of collective applications, drawing on her own experience:

> [I]t’s that [retaliation] you feel, as a family member, you feel you’re up against an organisation, which is caring for someone that you love. You always fear that [retaliation] and it’s definitely a common thing that are known with other people. You don’t say anything, but if you could make a collective application that would probably give you some sense of security.

CPFM12 suggested an open and collective process of sharing information about harm in residential aged care, in order to develop strength in numbers:

> Why not make it an open book? … [E]veryone starts to share the information about what’s happening to them. ... I’ve often thought that if you a lodge complaint, a lot of people don’t know, someone else has got the same complaint or suffered the same thing. And maybe I was thinking something on the notice board.

AL12 and AL13 also supported the idea of collective applications, drawing on experiences with the Stolen Generations reparations schemes:

> AL12: We have some clients, for example, Stolen Generation survivors from particular institutions, who have participated in class actions. And I think it’s not always been a good process in terms of the trauma that legal processes can bring. But that collective acknowledgement and action has made it easier for other people to come forward. And contrasting actually to the redress scheme where it’s a very individual approach, we’ve heard from some organisations that support Stolen Generation survivors that it can actually harm that collective feeling that people have where they’re getting different

> redress outcomes or different amounts of money, even though they all resided in the same institution and they collectively feel that they went through the same harm. So yeah, I think it's something that we've heard is a benefit of those collective processes. …
>
> AL13: And thinking about also some of the particular issues of vulnerability for people with dementia, my general sort of feeling is that a collective process might help address or manage some of those. It's not just one person saying this or one person's experience. That collective, I think, probably adds, not that it should, but adds weight to and will, I think, help address some of those other issues we talked about earlier in terms of capacity and things like that.

4.2.22 Principle 22: Independent advocacy

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

Accessing reparations must not impose a financial cost on those who have been harmed. Everyone (regardless of financial status) must be able to access advocacy. Processes must be as simple as possible to prevent the need to engage lawyers. There must be free legal assistance, counselling and other supports available to those who do require support to access reparations. Independent advocacy is necessary because a person's agency and ability to self-advocate, the power to represent oneself, is lost in institutional settings, and access to advocates might be difficult. Moreover, some people living with dementia in residential aged care will be socially isolated and thus will require direct and easy pathways to access advocacy.

The van Boven Principles elaborate on advocacy:

> Obligations arising under international law to secure the right to access justice and fair and impartial proceedings shall be reflected in domestic laws. To that end, States should:
>
> …
>
> c) Provide proper assistance to victims seeking access to justice;
> d) Make available all appropriate legal, diplomatic and consular means to ensure that victims can exercise their rights to remedy for gross violations

> of international human rights law or serious violations of international humanitarian law.[303]

PLWD01 spoke of the importance of self and peer advocacy in the context of her own experience advocating within residential aged care:

> I think I would just like to add now that because the aged care facilities now, people are not coming into aged care until much further advanced in things. So, a lot of people are past the stage of speaking up. So that's why I probably get labelled ... Yes, I've got a big mouth and I'm a bit of a stirrer, but I feel that I am speaking up on my fellow residents here as well, because they are not able to speak up now. And I think this is where a lot of things are happening. That there's nobody in some of the facilities that is able to speak out, on behalf of our fellow residents.

Similarly, CPFM12 noted the inability of people living with dementia to advocate within the institutional context of residential aged care:

> I think when you go into an institution like that, you lose personal advocacy. Your power to represent yourself is lost.

VA04 emphasised the importance of free advocacy:

> [O]f course they have feelings about what they think happened in the nursing home, but everyone is always aware that if you don't have any money, your chances of getting anything legal done are pretty slim, especially if you're trying to fight this sort of battle on your own. And so therefore, perhaps again generally at looking at redress and particularly when the person is no longer alive, again, if there was some sort of legal facility available, independent legal facility that would allow people to do that, knowing that they weren't going to have to fork out hundreds of thousands of dollars to even get a voice. I just think that might, again, it might make nursing home management think about those sorts of things a little more.

Advocacy must be independent to ensure that there is no actual or perceived association of advocacy with residential aged care providers, the residential aged care industry or governments and to ensure the process is safe. Independence is important because existing complaints systems are perceived as serving the interests of residential aged care providers and governments (see further discussion in Sections 4.2.6 and 4.2.23) There are also power imbalances in residential aged care, gatekeeping of access to advocacy and risks of retaliation.

CPFM13 suggested a ‘union’ to address power imbalances:

> [M]y husband was so homesick and yet I couldn’t even take him out the place because I didn’t know which way he would go. And homesickness is a terrible, terrible illness on top of what they got. And one psychologist says to me, ‘Oh, but some staff don’t like some residents.’ And I looked at her and I thought ... I never said anything, because I have to think about it some time. And I thought, what about the poor resident that doesn’t like them? They’re stuck with it. It’s just not right. And also their nurses, they were hiding, they were out smoking altogether, leaving nobody. And not one of these residents touched us or any visitor that came, but yet they say they can’t have anybody in because they’ve got behaviours. And they’ve got a union to protect them. A patient is needing an advocate or a union. That’s my first thing. He or she needs somebody coming into nursing homes and believing the family and the patient. Number one. That’s what I picked up because it doesn’t matter what [husband] tried to do, it was his fault. His fault, no matter what. Oh, there was no this, there was no that, there wasn’t even around to see what happened. So that would be the first thing I’d like to see and advocate for the patients, don’t care about the nurses. They’ve got the union. We’re here for these residents and to see that they’re treated right.

Advocates must be experienced in working with people living with dementia, and must have knowledge of how to communicate with and support people living with dementia in a non-paternalistic way.

As noted by AL02 in Section 4.2.19, people who are socially isolated may require assistance to initiate reparations. Therefore, there must be clear referral mechanisms if residential aged care staff or other people wish to direct a person living with dementia to that assistance and support. Independent advocates can be particularly important for people living with dementia who do not have family members or friends to advocate for them, as AL18 noted:

> I think it’s also really important to mention those that might not have anyone or might not have any family members or are really socially isolated that can’t rely on either direct family members or someone caring for them. I think that would be a really good distinction to keep in there, because that’s also a huge issue and also a huge issue for inequity in accessing information at times as well.

Moreover, advocates must have easy access to residential aged care facilities and must not be denied or obstructed entry by residential aged care staff and management. For example, CPFM15 mentioned the importance of residential aged care providers being required to provide access to advocates:

> [T]he problem, most of the time, which I’ve found is that, providers don’t have to recognise advocates. They don’t have to let them through the door.

Advocacy is also important to sustain the quest for justice in the face of grief, exhaustion and disillusionment. For example, CPFM03 noted that

> unfortunately, the family members bury their loved ones are thinking, sigh of relief. Everything’s over, everyone’s at peace. And hence they don’t follow through. I’ve had so many family relatives that still catch up with me from time to time and show disbelief of what’s happened, but they just got to a point of ‘look it’s happened, I’m going to go quiet now’. At the time, they would’ve jumped up and down if they knew that there was some redress or some place they could go to, but there’s no help whatsoever.

A similar point was made by CPFM09, stating that an advocate would

> be able to help people through the process because they know that people sort of lose heart and feel really disempowered and they may not actually use this form for that reason. So having … someone like that to see them through the process, I think that’s helpful.

Free advocacy also helps prevent financial exploitation by for-profit advocates. AL12 raised the issue of risk of exploitation by for-profit lawyers and advocates in light of the National Redress Scheme:

> I think in terms of some of the behaviour we've seen from private law firms, I mean, there's going to be unscrupulous operators in any scheme, but I think there's a real absence of regulation in relation to that in the [National Redress Scheme] … And we've particularly seen that in people in prison, which is going to be less relevant in your context, but rural and remote communities and Aboriginal communities. So I would expect that those sorts of things would come up again … And it's also not just lawyers. It's, there are people who are not lawyers who are basically operating businesses, I guess referral businesses, so collecting survivor names and passing them onto law firms, particularly to assist with civil claims but also sometimes to assist with [the National Redress Scheme]. And of course, these people are not providing their services for free, so it ends up having a significant cost for survivors … So it would definitely be something that has to be made a priority, because our client group is vulnerable enough with things like age and literacy issues and disability. But I mean, when you're specifically talking about a group of people with dementia, the capacity issues are just going to, I think, make that 10 times worse.

4.2.23 Principle 23: Safe, timely, independent and transparent

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

In order to be safe and independent, reparations must take place outside the institution and be separate from residential aged care providers, the residential aged care industry and governments. Fear of retaliation, lack of independence and processes and outcomes favouring residential aged care providers have been common criticisms of existing complaints systems. Reparations processes must be transparent so that individuals have confidence in the process. Reparations must be delivered in a timely manner so that people both have the time they need to apply and do not experience further trauma and detriment waiting for an outcome.

The van Boven Principles state:

> Obligations arising under international law to secure the right to access justice and fair and impartial proceedings shall be reflected in domestic laws. To that end, States should:

> …
>
> b) Take measures to minimise the inconvenience to victims and their representatives, protect against unlawful interference with their privacy as appropriate and ensure their safety from intimidation and retaliation, as well as that of their families and witnesses, before, during and after judicial, administrative, or other proceedings that affect the interests of victims;[304]

Safe

Reparations processes must be safe, in that individuals are not fearful of retaliation. PLWD12 explained the importance of the process being safe from retaliation:

> I like the idea that it must be independent. It must be safe. It must be like a whistleblower sort of thing that you are not going to get. My wife is concerned that if I make too much noise, it's going to come back and hurt her because the staff are going to say ... 'You're a troublemaker', and therefore they take it out on her, you know? Well, as that I keep on saying, well blossom, I just can't accept any practices that are going to cause you problems. And I will make a noise and I will cause issues for the management, and the management have said to me, I will appreciate you saying this sort of thing, because I hear things that they don't, and I give them feedback.

The process must also be safe in terms of preventing exploitation by lawyers and advocates and family members who might be supporting an individual through the reparations process.

As noted in Section 4.2.22, the National Redress Scheme has seen predatory professional behaviours targeting marginalised survivors documented by many survivor support groups, including knowmore, Relationships Australia, People with Disability Australia and Bravehearts.[305] This behaviour most often involves private law firms but also includes survivor advocacy businesses. For example, in the 2021 National Redress Scheme Joint Select Committee report, People with Disability Australia is quoted as stating:

> Some child abuse survivors are particularly vulnerable to exploitation by private law firms wishing to profit from providing advice about and preparing

> redress applications, including people in prison and some people with intellectual, cognitive and psychosocial disability. Child abuse often produces intense and ongoing psychological impacts which intensify such vulnerability.[306]

In the same report, Fiona Petersen from The Healing Foundation noted that Stolen Generations survivors have been targeted by predatory lawyers in the context of the National Redress Scheme:

> Stolen Generation survivors have reported that private law firms have been proactively contacting them to promote their services in a predatory manner.[307]

The 2021 report quoted knowmore legal service as advising that some survivors are not being notified of free advocacy for survivors, thus resulting in use of expensive and predatory services:

> [M]any survivors are not being advised about the availability of free and specialist services or are being openly dissuaded from seeking help from such sources and, in some instances, are paying a high price for services that are objectively not of an appropriate professional standard.[308]

Reparations processes must also prevent exploitation by family members. For example, PLWD09 explained the importance of reparations being explicitly directed towards the needs of the individual living with dementia to avoid the risk of reparations ultimately benefiting others:

> Yeah, so you're supported to use it to restore yourself, not just left there with your, say you've got like some shitty son, or a shitty cousin that's just going to be like, 'Yahoo, 200K, yeah, party.' It's not, it can't be like that, a cash exchange. It's got to be facilitated.

AL16 also raised the risk of such exploitation:

> Is it possible, it sounds awful to even raise it, but do we need to think about the potential family members to abuse the redress system? So family members who have not had the best interests of the older person at heart to continue after that person dies and to take advantage of the redress system?

> ... And it’s hard because we try to encourage people in residential aged care to be alert to evidence of elder abuse by family members. And you can imagine a situation where there can be contestation between possibly staff members at residential aged care and family members, both accusing each other of abuse. And it’s just very difficult, but you’ve got to start somewhere, don’t you? I think.

The risks of exploitation by family members has been noted in the context of the National Redress Scheme. Amanda Whelan from knowmore legal service is quoted in the 2021 report of the National Redress Scheme Joint Select Committee:

> We’ve been hugely concerned around elder abuse as well and other kinds of stand-over tactics where we’re seeing the pressure that’s applied to people – emotional, physical or otherwise – about accessing their money.[309]

There is also the risk of financial exploitation being designed into the reparations system, in the sense of governments and residential aged care providers (who might be perpetrators of or complicit in the harm) benefiting from the payments. This risk will arise if payment of reparations impacts on income assessment for the purpose of government payments and residential aged care support. This has been an issue in relation to the National Redress Scheme, as noted by AL12:

> AL12: So we’ve got this issue with people who receive their redress payments who are living in residential aged care. Because they’ve received this lump sum of, say, up to $150,000, that then is basically included as an asset for the purpose of calculating their aged care fees. So we’ve had clients who have received this $150,000, and then in that first year after receiving it have basically paid up to 17 odd thousand of that back to the aged care facilities. And so, I guess the way we see that is that ... We wrote to the previous government about it, and their view was basically like, ‘Yes, people contribute to their aged care. So if they’ve got this money, why shouldn’t they?’
>
> Facilitator: Does that lower what the government contributes?
>
> AL12: Yes
>
> Facilitator: Or does that mean the aged care facility gets more?

> AL12: That's exactly the point is that it's really the government, well, or, I guess if it's a case, say it's a Commonwealth institution that's paid, that the person was abused in as a child, they, on the one hand, pay out this $150,000 and then take back some of it by asking the person to contribute more to their aged care. So there's some other issues that we've mainly been able to iron out, but, yeah, that one in particular, I think it's really, people can't, it's clearly not fair. It's not what the purpose of redress is. And there's, yeah, very much that sense that the government, again, is trying to claw back whatever money they can … And I'm obviously not across the details of the Aged Care Royal Commission generally, but I did look into some of its commentary around the means testing arrangements and basically the finding that they're not fair and they're particularly impacting on those people that have modest assets. And that's certainly the circumstances of most of our clients. They're just getting the full Age Pension, don't have anything else to their name. And then just get happen to get this one lump sum payment that is then eroded through aged care fees. Yeah, really just not right.

Timely

Reparations must be efficient, flexible and prompt enough to avoid lengthy delays, while also providing sufficiently lengthy application windows to ensure people have the opportunity to apply.

The van Boven Principles reflect these dual aspects of timeliness. The van Boven principles provide that victims have the right to 'prompt reparation for harm suffered'[310] while also stating that any domestic statutes of limitations should not be 'unduly restrictive'.[311]

Individuals must receive prompt, meaningful and personalised responses to their requests for information about or their applications for reparations, and the determination of their applications must not be prolonged. PLWD02 emphasised the importance of an immediate and efficient response:

> Just like an incident report has to be completed within 48 hours of an incident, so should redress. It should have a timeframe and it should be in a timely manner. And it needs to be, I think in quite a short timeframe, we know we

> don’t want things to drag on. And I think it’s really important that it’s done quite quickly, time for an investigation.

A prompt response is necessary for four reasons.

First, it is important to minimise harm to the individual and to try to intervene to move an individual if the harm is ongoing. An early response might also be more effective, as VA06 explained:

> One of the things that I bang on a bit about is getting in early. In respect to my own wife’s situation, if there’s something that I’m not impressed with or whatever, I go direct to the carer and have a talk about it. And the redress for me is when that carer acknowledges, ‘Okay, well, let’s do this a bit differently.’ That’s the end of it, it works. On occasion we’ve had to go beyond the carer, go through the RN, go to the management, but my experience has been positive in that if you get in early some of the heavy situations that could develop are stopped from happening.

Second, a prompt response can maximise recall of relevant information and prevent destruction of relevant documentation or data.

Third, a prompt response is important in recognition of the older age of many people living with dementia and the possibility that people living with dementia (and sometimes also older aged care partners and family members) will die waiting for reparations. For example, VA11 noted that timeliness is important because individuals who have been harmed might die while waiting for reparations (see Section 3.1.4).

Fourth, residential aged care providers might seek to strategically delay the process. For example, VA07 spoke of her mother’s experience:

> And they spin it out. Mum couldn’t get access to her own health files. I got them a week before she died. They prevaricate it for almost a year. They wouldn’t give me the information that I needed. And then when I said, where is this and that? And they said, her files have been lost. It was agency staff came in and her files have been lost. Honest to goodness. Every single thing they could possibly do to spin it out.

That's what will happen in aged care. My mother was nearly 91 when she died. They say, the longer we can put up obstacles ... The old lawyer's trick, we'll throw this in, we'll throw that in, we'll do something else ... and they'll either fall aside, or the person will die. And then we can shut it down, because that person didn't give you permission to apply for this. And she didn't do this and she didn't do that. And you can't apply for that because you are not the person.

On the other hand, reparations processes must be sufficiently flexible to account for the time it might take some people to come forward. Thus, there should not be limitation periods on applying for reparations. This is particularly important because in the immediate aftermath of a person living with dementia dying, care partners and families will be exhausted, grieving and busy with some having to remove the person's belongings from the aged care facility within 24 hours of the death, and with funeral and estate matters. It is also important in order to give proper recognition of the longstanding nature of this systemic and structural harm, and the ongoing and intergenerational impacts it can have on family members.

This issue of timeliness has been particularly pertinent in relation to the National Redress Scheme. Multiple reports have noted long delays in processing applications and undue time taken for applications to be finalised.[312] Survivors and their support services found 'that applications are taking too long to process'.[313] There was also poor communication with applicants about their applications.[314] Even though the National Redress Scheme relates to sexual abuse in child welfare institutions, the timeframe in which the abuse must have occurred means many claimants are now older people. Advocates have raised issues of people waiting years for redress, and even dying before they receive an outcome. For example, Anna Swain of knowmore is quoted in the National Redress Scheme Joint Select Committee's 2020 report as stating:

> A lot of people are concerned that they will pass away before a decision is made. In some way, communicating to a survivor that they haven't been forgotten and that their application is progressing and exactly what state it's at, and if an idea of a time frame could be provided, I think that would be a very helpful extra step.[315]

The trauma caused by long wait times was widely cited by survivors and support services.[316] For example, according to an anonymous survivor cited in the 2021 Kruk Report:

> I have no idea how much longer I have to wait or what is being assessed. I am feeling so judged and stressed. They were always able to tell me nothing except that I had to wait an indefinite period of time. I feel the whole process is traumatic, poorly resourced and poorly run.[317]

The 2021 Kruk Report stated:

> Submissions from support services report that many survivors interpret delays as a deliberate strategy by government of 'waiting for them to die' to reduce expenses.[318]

Some stakeholders recommended that the National Redress Scheme consider giving priority to those who are terminally ill, very old or facing hardship circumstances. For example, the National Redress Scheme Joint Select Committee noted that most stakeholders recommend advance payments for particularly vulnerable applicants.[319] Care Leavers Australia Network was cited in the National Redress Scheme Joint Select Committee's 2020 report as stating:

> [A]ll necessary precautions need to be taken to ensure our most vulnerable applicants will see some form of justice, acknowledgement and will get to utilise their redress payment and, at the very least, pay for their funerals.[320]

People with Disability Australia noted that early payment options can significantly improve all survivors' mental health, but particularly that of the most vulnerable, including people of advanced age, with disability and in ill health.[321]

First Nations people are also likely to uniquely benefit from advance payments. The Victorian Aboriginal Child Care Agency is quoted by the National Redress Scheme Joint Select Committee:

> The majority of clients Ngarra Jarra Noun [a Victorian Aboriginal Child Care Agency (VACCA) redress support service] are supporting have particular vulnerabilities, including living in poverty, homelessness, caring responsibilities for grandchildren, chronic health conditions, and advanced

> age. An advance payment could relieve some acute financial stress for these clients while they wait for a determination.[322]

Transparent and independent

Reparations must be organisationally, financially and legally separate from residential aged care facilities, the residential aged care industry and government departments that regulate and fund residential aged care facilities. Decision-making must be transparent, including through publicly available detailed guidance on how decisions are made and published outcomes of and reasons for decisions where agreed to by applicants.

PLWD03 noted the importance of independent processes in the context of the institutional setting of residential aged care:

> If it's already someone in residential [care], they have to be, have an independent person with a lawyer. They should be able to contact that person or the family member need to contact the person. And then they can have a out of that environment legal input. What are their rights? What happened? How to deal with the abuse? What level of abuse that is what's already happened? … I think it shouldn't be done in institution. It should be done out of. The client should have a right to have someone to be present, that resident with the family support. If there's no family support, there should be a support person, out of that facility. Taking that person out to talk to their legal representation so that they don't feel vulnerable where they're already living.

Similarly, PLWD06 emphasised the importance of an independent redress scheme:

> I think that there's need for an independent, for want of a better word, tribunal that at one level comprises some local legal representatives and whatever, so they could initially, I suppose, deal with the incident at that location if that's possible, but at the same time be able to escalate it throughout that business structure. And if that body is made up of independent people that have got a broad representation, it's more likely to be credible.

VA07 suggested an ombudsman model to ensure independence and transparency:

> I think an ombudsman is the perfect person to do something like that. They put a report in each year to say this, this, this, and this. And then because then that is divorced from government agencies. And it would be honest, you make the complaint to a completely independent ombudsman, and they have advocacy, people to help you, particularly if someone's living with dementia, help you in that process. And then they name and shame in a report each year.

Transparency must extend to access to information and documents held by the residential aged care provider that are relevant to an individual's reparations application (noting, for example, the challenges VA07 experienced in accessing her mother's files to facilitate a complaint, discussed above in the context of timeliness).

AL12 reflected on the need for independence and transparency in light of the National Redress Scheme experiences:

> So survivors, I think, generally very much feel that it's been designed to benefit institutions. And I think we even see that now with some decisions that are made that survivors perceive as being sort of intended to reduce the liability of institutions or to help institutions avoid paying. I wouldn't say that's the majority of cases. We see so many people accessing redress, and huge amounts of money have been paid out. But I think there's, yeah, that sense that institutions are not paying enough.

AL12's observations resonate with findings in the 2021 Kruk Report that 'lack of transparency in key areas of redress … facilitates a climate of mistrust, with few avenues for their resolution in circumstances where significant survivor mistrust of institutions already exists'.[323] It noted a 'common complaint in submissions that the Scheme and its processes are opaque and shrouded in secrecy'.[324] The 2020 report of the National Redress Scheme Joint Select Committee noted that the National Redress Scheme has been criticised for a lack of published guidelines around decision-making, which is said to make completing applications difficult.[325] The Women's Legal Service is quoted in the 2021 Kruk Report as submitting that the National Redress Scheme has failed to provide adequate reasons for determinations and the review process.[326]

4.2.24 Principle 24: Communication and enforcement of outcomes

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

Reparations will not be effective if reparations do not result in concrete action by perpetrators being held accountable for harm (as discussed in Sections 4.2.9 and 4.2.10). Concrete action entails not only forms of reparations that facilitate an initial commitment to action but also regular monitoring of what action has indeed been taken, and then enforcement processes if action is ultimately not taken.

The inclusion of enforcement in the reparations process would reflect similar aspects of enforcement of court judgments in the civil justice system, where there is recognition that the entire court process, and an eventual court judgment, could be undermined if the judgment is not followed.[327]

PLWD09 referred to this monitoring and enforcement in terms of a ‘loop’:

> [T]transparency aspect of that is really important, because if we were to use school bullies, for example. Your child is being bullied, you report it, but you never ever get to see if there are consequences, because that’s presumably the teacher will speak to that child privately. And we’re always expected to trust that that has happened, even though we have no idea of whether it has, or not. And that’s the system that we have at the minute, is that we have to trust that between the [Aged Care] Quality and Safety Commission and the organisation, something has happened. But we have no way of knowing and that trust can be misplaced. I think, transparency in that conversation is super important … So, it’s this accountability, but it’s a loop. And we are only first step in the loop. We make the complaint, but we don’t get the outcome. And sometimes, that’s enough, and sometimes that takes the position of acknowledgement for us. But unless it’s built in that the organisation is forced to be accountable, and this is what we’ve done to make sure it doesn’t happen again. And it’s put in those clear terms, because clarity and dementia friendly language is all very important in this and it’ll be in the supporting documents, I’m sure. But that 360 feedback is super important, from both whoever’s dealing with the complaint, and also, the institution … Because that’s the only way you’d get some closure.

VA11 spoke about the importance of holding residential aged care providers to account for what providers have undertaken to do through reparations, even years after reparations take place:

> [F]ive years ago, we are doing a redress for what happened five years ago, that it is recognised that the accreditors go in with their eyes open, knowing that this thing had happened. I guess you're talking about into the future as well. And this is something that in five years time, that this is in place for future problems. Just ensuring that it's all linked to those regulatory bodies. Because at the moment, the way that the Aged Care Quality Agency is working, I don't believe there is that link. I don't think that they're going out and they've got a list of names, people have mentioned as a part of the Royal Commission, but I think that when they go out and do their accreditation, that's all separate thing because that was the Royal Commission and there's no link. And I'd really love to see that link that, if they've been recognised or been reported, and this is about believing people that spoke in the Royal Commission and recognising those people that come forward and spent their time and went to court or sat with those people that some of these people have said, 'We know horrifying things, but nothing's come out of it.' And those aged care facilities are running the same and there's no link to what people have said. It would be really great to ensure that all of this links with that. And because at the moment, we're not hearing there's any investigations into any of those providers that people have spoken about. It's just making sure that all of that's linked together would be fabulous.

Some CPFMs spoke of the need for communication of outcomes of reparations to applicants. This related to care partners and family members having experiences of marginalisation in existing complaint processes, where they have received no notification of outcomes and thus no justice and closure. CPFM16 stated:

> I think having been through a process of making a complaint through the [state health department], and originally it was rejected. And then I made an appeal, and that was accepted. And it took nine months, and hell of a lot of paperwork, and a lot of evidence to be submitted. In the end, I had to ring and find out what's happened. And it was, 'Well, yes, something's happened.' And

> it's like, 'Well, yes. What is it?' 'Well, we can't tell you because that's private.' And it's like the doctor, you can say he's had a rap over the knuckles and it's like, 'Well, it's private.' And so what kind of, I guess, balance in the equation is that on our side, in terms of the right thing having been done, and not knowing really what the outcome is, other than the doctor got a rap over the knuckles. What exactly did they delineate, of all the many things, what it was that the doctor got a rap over the knuckles for has not been made clear. So I think that families should have the right to information about how the imbalance has been redressed and what action has been taken and what action is in place to avoid that situation from occurring again, to other people … I was just sent a very simple letter to say, 'It's been dealt with.' And it's like, 'Hello?' And it was speaking to a person who wasn't even in charge, but saying, 'Oh, look, I can't tell you because it's under privacy.' And how a doctor is dealt with is a private, that's a private situation. But he will get a rap over the knuckles. Now, what does that mean, is left to the imagination. And again, it's like the collaboration happening at the other end of the system where people are closing ranks to protect their own. And that happened many times. And I think we need greater transparency. We need to see what has occurred and we need to make sure that it doesn't occur again.

CPFM06 shared a similar experience:

> My apology came after the Aged Care Complaints went, contacted me and said, 'Oh, can we close it now?' I said, 'Well, I haven't heard from anybody.' 'Oh, sorry. They'll, meant to send you an apology.' And I got a letter which wasn't really even an apology. It was just ridiculous.

4.2.25 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.

Existence and availability of reparations should not be a substitute for accessing mainstream justice processes, including because these other options are not considered accessible, inclusive, affordable or efficient. Rather, the basis of the human right to equal access to justice, which has been discussed in Sections 1.1.3;

1.3 and 4.2.1, means that people living with dementia should have equal access to the courts, complaint systems and victim support schemes. Therefore, reforms to all systems are needed, including criminal and civil justice mechanisms and the aged care complaint systems. Dinesh Wadiwel, Claire Spivakovsky and Linda Steele have emphasised the need to balance any specialised justice pathways with access to mainstream justice and complaint systems in a research report for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability:

> A framework for complaint mechanisms for violence, abuse, neglect and exploitation of people with disability must advance rather than undermine rights to equality and access to justice. These human rights to equality and justice … will be undermined if people with disability are not given the same access to the police and courts as people without disability, including if courts and justice systems are not transformed to make them more inclusive and accessible. Further, rights to equal treatment and access to justice will be undermined if a complaint mechanism is designed with the intent that it be the primary or exclusive forum for responding to violence, abuse, neglect and exploitation of people with disability (including if such design becomes a justification for not transforming courts and justice systems). Indeed, this idea of people with disability being subject to 'second-class justice' has been more thoroughly explored in the context of people with disability as alleged offenders, where it is recognised that subjecting them to special hearings after a finding of unfitness, or to mental health courts on the basis of the special procedures and disposal options suited to their disability, is discriminatory.[328]

The expectation that people living with dementia should also be equally protected under the law was expressed by PLWD03:

> [W]hat crossed my mind is, it's a criminal behaviour from people. Where does the legal system come into this? Because it has to be linked.

Therefore, in addition to reparations, reforms to existing systems (including criminal and civil justice mechanisms, aged care complaint systems and victims support schemes) are needed to make them accessible, inclusive, affordable and efficient.

5. Next steps

This project is the first step in a longer-term pathway towards transformation in how harm in residential aged care is responded to and ultimately prevented. Specifically, it provides a strong evidence-base in favour of reparations and a principled framework for development of the policy and practice of reparations.

In moving forward to explore the translation of the Dementia Reparations Principles into policy and practice, it is important to consider how reparations might connect to existing frameworks in the Australian legal and policy landscape. These frameworks include:

- Royal Commissions: Recommendations of the Royal Commission into Aged Care Quality and Safety; Recommendations (once published) of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
- Regulatory frameworks: Charter of Aged Care Rights; existing sanctions; Serious Incidents Response Scheme; open disclosure under the *Aged Care Act 1997* (Cth) and the *Aged Care Quality and Safety Commission Act 2018* (Cth)
- Council of Elders
- Professional associations and societies, worker unions: Australian New Zealand Society of Geriatric Medicine; Australian Association of Gerontology; medical professional societies, law societies, nursing, health services unions
- Advocacy organisations' strategic priorities and campaigns
- Broader policy developments on violence prevention: National Action Plan to End Violence Against Women and Children
- International human rights developments: development of a human rights convention for older persons; CRPD Committee's work on deinstitutionalisation

There are six areas that have arisen in the research that should be prioritised for further exploration.

One area is the relationship between reparations and deinstitutionalisation of aged care system facilities. The recent Guidelines on Deinstitutionalization provide a useful framework for understanding reparations as one aspect of a transformative agenda of deinstitutionalising the aged care system and realising the right to independent living and community inclusion.

A second area is intersectionality. Research and practice on reparations in the field of transitional justice has highlighted the importance of intersectionality to understandings of experiences of harm, and to the design and operation of forms of reparations and reparations processes.

A third area is non-state-led reparations. This project focused on reparations designed into Australian law and policy. However, there is also scope for professional or community initiatives that are not dependent on a legal framework, and these may be more achievable if there is a lack of government willingness to pursue reparations. Examples include apologies by professional associations and governments (e.g., in the context of the role of psychological and social work professions in the Stolen Generations[329]), reparative approaches to professional education in universities (e.g., changes to university legal education related to Aboriginal people and the law and the legacies of colonialism and Residential Schools following the Canadian Truth and Reconciliation Commission[330]), and sites of conscience and place-based memory projects by survivors and their allies (e.g., sites of conscience related to places of former child welfare and Aboriginal child institutions[331]).

A fourth area is further exploration of the relationship of care partners and family members to harm of people living with dementia. Redress schemes in Australia have focused on harm in the ‘public sphere’, both harm outside the private realm of the family and harm that is perpetrated by individuals acting in public, commercial or charitable contexts. Yet, as discussed in Section 3.2.2, our focus groups made clear that family members can be perpetrators or implicated subjects in harm that occurs within residential aged care, and can also perpetrate harm in the family home and community.

A fifth area is cognitive impairment, legal capacity and reparations. The experiences and needs of people living with cognitive impairment have not been thoroughly addressed in Australian redress schemes in a way that aligns with Article 12 of the

CRPD, and the topics of legal capacity and supported decision-making are not fully explored in transitional justice reparations scholarship and practice.

A sixth area of exploration is reparations in relation to longer histories of harm in residential aged care. Our empirical research focused on the perspectives of people who have recent experiences of harm and its impacts. Moreover, the current harmful circumstances in residential aged care associated with profit-making and poor quality of care and support is often associated with the 1997 legislative reforms to the aged care system. However, institutions for older, disabled and poor people earlier in Australia's settler colonial history were also sites of harm.[332] Thus, further work can be done to trace longer histories of harm in institutional care, and explore relationships between this harm and settler colonial nation-building.

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