'The Compensation is Changing the Future': A Reparative Approach to Redressing Human Rights Violations Experienced by People Living with Dementia in Long Term Care

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Abstract

This article presents findings of an empirical study of community perspectives on redressing human rights violations experienced by people with dementia in long term care institutions (LTC institutions). Research participants – including people with dementia – expressed strong preference for a redress approach providing recognition and validation of individuals' experiences of harm, affirming humanity of people with dementia, delivering accountability, and facilitating systems change. This can be understood as a 'reparative approach to redress' aligning with a human rights approach to redressing gross human rights violations; distinct from redress through domestic civil justice systems, which focuses on monetary payments and is often characterised as taking a corrective

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approach. This article contributes empirical insights to emerging human rights scholarship on disability and reparations and introduces a methodological approach to constructing conceptions and practices of redress centering experiences and perspectives of disabled people and those who advocate for them.

Keywords: Dementia; Disability; Reparations; Long Term Care; UN Convention on the Rights of Persons with Disabilities

1. Introduction

This article proposes a 'reparative approach' to redressing human rights violations experienced by people living with dementia (people with dementia) in long term care institutions (LTC institutions) to advance human rights to access to justice and independent living in the UN Convention on the Rights of Persons with Disabilities (CRPD)[1]. This approach aligns with the human rights approach to redressing gross human rights violations reflected in 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);[2] distinct to focus on monetary payments in domestic civil justice systems, which is characterised as a 'corrective approach' to redress.[3] The article contributes community perspectives to help guide future policy and research on redress for disabled people and a methodological approach to constructing conceptions and practices of redress centering experiences and perspectives of disabled people and those who advocate for them, rather than relying on assumptions of needs or what should be valued.

People with dementia experience wide-ranging harms in LTC institutions, including physical and sexual assault; neglect; restraint; and detention in segregated dementia units. Yet existing justice, regulatory, and political systems have failed to redress these harms, hold perpetrators accountable, or ensure transformative change of systems and structures enabling harm. These gaps in practice are compounded by a lack of

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[1] Convention on the Rights of Persons with Disabilities (2006) A/RES/61/106.

[2] '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' (adopted 21 March 2006) UNGA A/RES/60/147.

[3] Kathleen Daly and Juliet Davis, 'Money Justice' (2021) 54 Journal of Criminology 60, 62.

scholarship to guide development of redress for people with dementia in LTC institutions. Lack of redress practice and scholarship in the context of LTC institutions can be contrasted to the existence of redress and depth of academic and political engagement with the topic in relation to historical institutional abuse.

Limited existing research and practice provides a unique opportunity to develop greater empirical understanding of community perspectives on redress. This article presents empirical findings from an Australian project with people with dementia and their care partners, family members, and advocates who support them. We explored their understandings of redress based on personal and professional experiences of and perspectives on harm in LTC institutions. People with dementia were prioritised as leaders and participants in the research. However, we did not recruit as many people with dementia living in LTC institutions as was originally planned, and there is need for future redress research engaging specifically with that group.

People with dementia and their care partners, family members, and advocates who support them all expressed strong preferences for an approach to redress providing recognition of harm and validation of individuals' experiences of harm, affirming the humanity of people with dementia, delivering accountability, and facilitating systems change. Other publications from this project detail: the international human rights framework of the project, an overarching matrix for understanding the empirical findings, and reasons why redress is needed.[4] This article concentrates on a further aspect of the project: empirical insights on the specific approach to redress and what forms it should take.

We argue the empirical findings support a 'reparative approach' to redress because they foreground responding to past harm as a foundation for harm prevention and system transformation at individual and collective (community and national) scales, as demonstrated by the essential forms of redress identified by research participants: rehabilitation and removal from harm, truth-telling, apologies, systems reform, and monetary payments. While both corrective and reparative approaches to redress include monetary payments, the significance and purpose of monetary

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[4] Linda Steele and Kate Swaffer, 'Reparations for Harms Experienced in Residential Aged Care' (2022) 24 Health and Human Rights Journal 71; Linda Steele and Kate Swaffer, 'Disability Human Rights and Reparations for People with Dementia in Long Term Care Institutions: An Empirical Study' (2024) 26 Scandinavian Journal of Disability Research 423; Linda Steele and others, 'Reparations for People Living with Dementia: Recognition, Accountability, Change, Now!' (2023) 22 Dementia 1738.

payments differs between the two approaches. A corrective approach focuses on monetary payment to specific individuals commensurate to the impacts on them of the wrongdoing to rectify the impacts of that wrong in order to return the individual to a prior state. In contrast, in a reparative approach monetary payments are but one of a broader range of forms of redress that operate in relation to individual victim-survivors and collectively at community and national scales and are directed to rectifying past wrong in a context of transforming structural conditions to a better state than that prior to the wrongdoing.[5]

The article is relevant and important now for three reasons. First, the article's focus on redress broadens the scope of human rights scholarship on people with dementia in LTC institutions. Scholarship to date has focused on establishing human rights violations in LTC institutions rather than the subsequent question of how we respond to and move forward from those violations. Second, the article brings into conversation the Van Boven Principles with the CRPD, and human rights scholarship on reparations[6] with disability human rights scholarship on access to justice.[7] In doing so, the article contributes empirical insights to emerging human rights scholarship on disability and reparations.[8] Third, the article provides a human rights-oriented method for research informing design of redress that can be adapted for use in relation to other institutional abuse contexts.

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[5] Tina Minkowitz, 'Deinstitutionalization as Reparative Justice: A Commentary on the Guidelines on Deinstitutionalization, Including in Emergencies' (2024) 13 Laws.

[6] Jemima Garcia-Godos, 'Reparations' in Olivera Simić (ed), *An Introduction to Transitional Justice* (Routledge 2021); Luke Moffett, 'Transitional Justice and Reparations: Remedying the Past?' in Cheryl Lawther, Luke Moffett and Dov Jacobs (eds), *Research Handbook on Transitional Justice* (Edward Elgar Publishing 2017).

[7] Eilionóir Flynn, *Disabled Justice?* (Routledge 2016); Anna Lawson, 'Disabled People and Access to Justice: From Disablement to Enablement?' in Peter Blanck (ed), *Routledge Handbook of Disability Law and Human Rights* (Routledge 2016).

[8] Tina Minkowitz, 'Reparation for Psychiatric Violence: A Call to Justice' in Michael A Stein and others (eds), *Mental Health, Legal Capacity, and Human Rights* (CUP 2021); William Pons, Janet Lord and Michael Ashley Stein, 'Disability, Human Rights Violations, and Crimes Against Humanity' 116 American Journal of International Law 58; Steele and Swaffer (n 4); Steele and others, 'Recognition, Accountability, Change, Now!' (n 4).

2. Background: Dementia, Human Rights Violations and Reparations

A. Human Rights Violations in LTC Institutions

Public inquiries, media reports, civil society reports, and academic research all document harms taking place in LTC institutions across different countries, particularly with respect to people with dementia. These harms include physical and sexual violence, emotional abuse, neglect of personal care, use of restraints and non-consensual psychotropic medication, and denial of medical treatment and rehabilitation support.[9]

In Australia,[10] an estimated 39.2% of people in Australian LTC institutions experience neglect, emotional abuse or physical abuse[11] and

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[9] Hannah Flamm, '"They Want Docile": How Nursing Homes in the United States Overmedicate People with Dementia' (Human Rights Watch 2018) <https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia> accessed 22 October 2024; Caroline Emmer De Albuquerque Green, Anthea Tinker and Jill Manthorpe, 'Human Rights and Care Homes for Older People: A Typology of Approaches from Academic Literature as a Starting Point for Activist Scholarship in Human Rights and Institutional Care' (2022) 26 The International Journal of Human Rights 717; Nick Hardwick and others, 'Human Rights and Systemic Wrongs: National Preventive Mechanisms and the Monitoring of Care Homes for Older People' (2022) 14 Journal of Human Rights Practice 243; Maeve O'Rourke, *Human Rights and the Care of Older People: Dignity, Vulnerability, and the Anti- Torture Norm* (OUP 2024); Linda Steele and others, 'Segregation and Incarceration of People Living with Dementia in Care Homes: Critical Disability and Human Rights Approaches' in Richard Ward and Linn Sandberg (eds), *Critical Dementia Studies: An Introduction* (Routledge 2023).

[10] Deborah Parker, Jane Phillips and Michael Woods, 'We've Had 20 Aged Care Reviews in 20 Years – Will the Royal Commission Be Any Different?' (*The Conversation*, 20 September 2018) <http://theconversation.com/weve-had-20-aged-care-reviews-in-20-years-will-the-royal-commission-be-any-different-103347> accessed 16 February 2022; Royal Commission into Aged Care Quality and Safety, 'Final Report: Care, Dignity and Respect, Volume 1, Summary and Recommendations' (Commonwealth of Australia 2021); Royal Commission into Aged Care Quality and Safety, 'Final Report: Care, Dignity and Respect, Volume 2, The Current System' (Commonwealth of Australia 2021).

[11] Royal Commission into Aged Care Quality and Safety, 'Experimental Estimates of the Prevalence of Elder Abuse in Australian Aged Care Facilities' (Royal Commission into Aged Care Quality and Safety 2020) <https://agedcare.royalcommission.gov.au/sites/default/files/2020-12/research-paper-17-elder-abuse-prevalence-aged-care-facilities.pdf> accessed 16 February 2022.

per year there are 2,520 alleged incidents of unlawful sexual contact.[12] Levels of poor nutrition and low hydration are high in Australian LTC institution residents.[13] Incontinence is also associated with harm in Australian LTC institutions, including incontinence caused by 'indiscriminate use of laxatives and limited access to toileting assistance', rationing of incontinence pads, and 'working to a funding model that incentivises higher levels of incontinence'.[14] There are significant issues with medication in Australian LTC institutions, including low reporting of inappropriate use of antipsychotic agents especially regarding initial dose and excessive duration of treatment,[15] overuse of antipsychotics prescribed for people with dementia,[16] and deaths involving high-risk medications.[17] In its 2019 interim report titled *Neglect* the Royal Commission into Aged Care Quality and Safety observed LTC institution residents have their 'basic human rights denied. Their dignity is not respected, and their identity is ignored. It most certainly is not a full life. It is a shocking tale of neglect'.[18] In its final report, the Commission recognised 'the number of people who have experienced substandard care is inexcusably high'[19] and 'abuse is an extreme example of substandard care and reaches into the realm of criminal behaviour.'[20]

While these harms are widespread in LTC institutions and are not

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[12] Royal Commission into Aged Care Quality and Safety, 'Care, Dignity and Respect: Volume 1'(n 10) 140.

[13] Maree Bernoth, Jennie Dietsch and Carmel Davies, '"Two Dead Frankfurts and a Blob of Sauce": The Serendipity of Receiving Nutrition and Hydration in Australian Residential Aged Care' (2014) 21 Collegian 171.

[14] Joan Ostaszkiewicz, Beverly O'Connell and Trisha Dunning, 'Fear and Overprotection in Australian Residential Aged-Care Facilities: The Inadvertent Impact of Regulation on Quality Continence Care' (2016) 35 Australasian Journal on Ageing 119.

[15] Hee Young Shin and others, 'The Use of Antipsychotics among People Treated with Medications for Dementia in Residential Aged Care Facilities' (2016) 28 International Psychogeriatrics 977.

[16] Kaye Ervin and others, 'Time for Australia to Revisit Antipsychotic Use in Dementia in Residential Aged Care' (2019) 12 Australasian Medical Journal 138.

[17] Natali Jokanovic and others, 'A Review of Coronial Investigations into Medication-Related Deaths in Residential Aged Care' (2019) 15 Research in Social and Administrative Pharmacy 410.

[18] Royal Commission into Aged Care Quality and Safety, 'Interim Report: Neglect Volume 1' (Commonwealth of Australia 2019) 12 <https://agedcare.royalcommission.gov.au/publications/interim-report> accessed 28 January 2021.

[19] Royal Commission into Aged Care Quality and Safety, 'Care, Dignity and Respect: Volume 1' (n 10) 68.

[20] Royal Commission into Aged Care Quality and Safety, 'Care, Dignity and Respect, Volume 2' (n 10) 3.

dependent on dementia diagnosis, people with dementia are particularly at risk of these harms. Lack of capacity enables others to decide on entry to and detention in LTC institutions and use of psychotropic medication and restraint. People with dementia are segregated from the wider community, and additionally often detained in locked dementia units segregated from other residents. In these units people with dementia are denied the full range of social and environmental stimulation available to other residents, prevented from leaving, and denied control over all aspects of daily life. People with dementia might communicate in different ways and are less likely to be listened to or believed when they report harm, nor are they included in LTC institution feedback and reform processes.[21] Noting people with dementia are not a homogenous group, their relative targeting for and experiences of harm are shaped by other dynamics of oppression including sexism, ageism, racism, and heterosexism, as well as settler colonialism and globalisation.[22]

Harm experienced by people with dementia in LTC institutions has significant impacts. They experience deterioration in their physical and mental health, ongoing trauma, and sometimes even death. Care partners and family members who have witnessed harm and tried to intervene are often characterised as a problem in the process and experience vicarious trauma, distress, and anger. They can also experience guilt and moral injury from having been involved in circumstances giving rise to harm.[23]

While there is ample empirical evidence of harm in LTC institutions and its grave impacts, there is disagreement within scholarship about the scope of these harms, and there is a spectrum in terms of what harms are identified and the extent these are framed as human rights violations.[24] The role of LTC institutions themselves in creating or perpetuating this problem and the legitimacy of LTC institutions and their continued existence is also controversial and debated.

Some scholarship focuses on individual access to quality of personal and

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[21] Kristina Chelberg and Kate Swaffer, '"Missing Persons": Absent Voices of People with Dementia in the Australian Royal Commission into Aged Care' (2024) 30 Journal of Law and Medicine 761; Linda Steele and others, 'Human Rights and the Confinement of People Living with Dementia in Care Homes' (2020) 22 Health and Human Rights 1.

[22] James Rupert Fletcher, 'Globalising Dementia Research: Echoes of Racialisation and Colonialism' (2024) 1 Journal of Global Ageing 159; Linn Sandberg and Richard Ward, 'Introduction: Why Critical Dementia Studies and Why Now?' in Richard Ward and Linn Sandberg (eds), *Critical Dementia Studies: An Introduction* (Routledge 2023).

[23] Rosie Harding, *Duties to Care: Dementia, Relationality and Law* (CUP 2017); Steele and Swaffer, 'Reparations for Harms' (n 4).

[24] See Green, Tinker and Manthorpe (n 9).

medical care within LTC institutions and ensuring robust regulation of LTC institutions, including legal oversight of coercive interventions such as restraint and psychotropic medication and safeguarding individuals from harm.[25] Other scholars take a more expansive view. Pursuant to this view, harm – including harm that is legal under domestic law such as use of psychotropic medications and restraint and the institutional and segregated nature of LTC institutions – is understood as constituting human rights violations related to discrimination, legal capacity, violence, detention and torture.[26] In the expansive view, harm to people with dementia in LTC institutions is systemic and structural because it is 'facilitated by and sometimes embedded within the geography and architecture, political economy, legal and regulatory frameworks, and operation of aged care'.[27] This expansive view of harm is inextricably connected to the character of LTC institutions as 'total institutions'.[28]

This expansive view of harm might be provocative for those readers who agree many individuals with dementia are treated poorly and subjected to unnecessary restraints in LTC institutions but see a role for these sorts of interventions in some cases or are resigned to this being an inevitable experience associated with dementia. However, the expansive view of harm is explicitly aligned with international human rights developments over the past 15 years brought about by the CRPD. The CRPD applies to people with dementia on the basis they are disabled by reason of cognitive and other impairments. Historically, people with dementia have experienced lower levels of human rights recognition, reflecting their broader marginalisation.[29] Critical dementia scholarship highlights people with dementia are dehumanised and positioned as burdensome and disposable by falling short of ableist norms of capacity, self-sufficiency and productivity, and successful and healthy aging. This socio-cultural status enables and justifies a range of harms including coercive and violent interventions, neglect of personal and medical care, social isolation and

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[25] Laura Grenfell, Anita Mackay and Julie Debeljak, 'Human Rights Accountability and Redress for Systems of Ill-Treatment in Residential Aged-Care' (2021) 47 Monash University Law Review 57; Poland Lai, 'Longer View: Human Rights and Safeguards for Long-Term Care Residents' (2022) 43 Windsor Review of Legal and Social Issues 36.

[26] O'Rourke (n 9); Steele and others, 'Segregation and Incarceration' (n 9).

[27] Steele and Swaffer, 'Reparations for Harms' (n 4) 72.

[28] Kate Rossiter and Jen Rinaldi, *Institutional Violence and Disability: Punishing Conditions* (Routledge 2018).

[29] Suzanne Cahill, *Dementia and Human Rights* (Policy Press 2018).

segregation, and denial of voice and participation.[30] The coming into force of the CRPD reinforces universality of human rights. Being disabled – including cognitively disabled through dementia – is not a basis for a lower threshold of human rights; disabled people are entitled to full recognition of their autonomy, equality, and dignity, disability cannot be a basis for detention, restraint, segregation or institutionalisation, and governments should abolish substitute decision-making and have concrete plans for deinstitutionalisation.[31] Human rights apply irrespective of disability *and* irrespective age, and thus apply to people with dementia.[32]

Within this context, people with dementia who are harmed in LTC institutions can be understood as having their human rights violated. Some of these violations relate to conditions within institutions such as rights to liberty, non-discrimination, and freedom from torture under international instruments such as the International Covenant on Civil and Political Rights[33] and the Convention Against Torture.[34] Violations also extend to the CRPD. Specific rights violated include rights to freedom from violence and torture (Arts 15, 16), liberty (Art 14), personal integrity (Art 17), health (Art 25), rehabilitation (Art 26), legal capacity (Art 12), independent living (Art 19), and equality (Art 5). These human rights apply to a wide

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[30] Kristina Chelberg, ''Vulnerable Monsters': Constructions of Dementia in the Australian Royal Commission into Aged Care' (2023) 36 International Journal for the Semiotics of Law - Revue Internationale de Sémiotique Juridique 1557; Rachel Herron, Christine Kelly and Katie Aubrecht, 'A Conversation About Ageism: Time to Deinstitutionalize Long-Term Care?' (2021) 90 University of Toronto Quarterly 183; Claire Loughnan, 'The Scene and the Unseen: Neglect and Death in Immigration Detention and Aged Care' (2022) 3 Incarceration; Claire Spivakovsky and Linda Steele, 'Disability Law in a Pandemic: The Temporal Folds of Medico-Legal Violence' (2022) 31 Social & Legal Studies 175.

[31] Theresia Degener, 'Disability in a Human Rights Context' (2016) 5 Laws 35; UN Special Rapporteur on the rights of persons with disabilities, 'Older Persons with Disabilities)' (2019) A/74/186; Rosemary Kayess and Phillip French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 Human Rights Law Review 1; Gerard Quinn, 'Personhood & Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD Concept Paper' (2010) <http://www.fedvol.ie/_fileupload/Research/NDE%20Reading%20Lists/Harvard%20Legal%20Capacity%20gq%20draft%202%20Gerard%20Quinn%20Feb%202010.pdf> accessed 16 February 2022.

[32] Devandas (n 31); CPRD Committee, 'Guidelines on Deinstitutionalization, Including in Emergencies' (2022) CRPD/C/5; CRPD Committee, 'General Comment 5 on Article 19 Independent Living' (2017) CRPD/C/GC/5.

[33] International Covenant on Civil and Political Rights 1966 (adopted 16 December, entered into force 23 March 1976) 999 INTS 171.

[34] Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (adopted 10 December 1984, entry into force 26 June 1987) 1465 UNTS 85.

spectrum of harms within LTC institutions from restraint and detention[35] through to harms associated with routine personal care for some of the most basic needs such as inadequate continence management.[36] Being in an institutional setting *per se* – either non-consensually by reason of substitute decision-making or due to lack of resources and support to live in the community – gives rise to further human rights violations under the CRPD such as rights to legal capacity (Art 12), independent living (Art 19), and equality (Art 5).[37]

B. Access to Justice and Redress for Human Rights Violations in LTC Institutions

People with dementia have led advocacy for recognition of their human rights in LTC institutions.[38] But existing justice, regulatory, and political systems have failed to redress harm and related human rights violations, hold perpetrators accountable, and ensure transformative systemic and structural change to prevent further harm. These failures are evident in the Australian context.

Australian criminal justice systems recognise some harms in LTC institutions as unlawful, such as sexual assault and physical assault. There have been some instances of convictions for these harms.[39] However, there are systemic barriers to police reporting and investigation.[40] Australian civil

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[35] CRPD Committee, 'Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities: The Right to Liberty and Security of Persons with Disabilities' (2015) 18 <https://www.ohchr.org/Documents/HRBodies/CRPD/14thsession/GuidelinesOnArticle14.doc>.

[36] O'Rourke (n 9) 151–180.

[37] CPRD Committee, 'General Comment 5' (n 32); Devandas (n 31); Independent Expert on the enjoyment of all human rights by older persons, 'Older Persons Deprived of Liberty' (2022) A/HRC/51/27.

[38] Kate Swaffer, 'Human Rights, Disability and Dementia' (2018) 7 Australian Journal of Dementia Care 25.

[39] Liv Casben, 'Aged Care Worker Prakash Paudyal Jailed over Assault of Dementia Patient' (*ABC News*, 23 January 2019) <https://www.abc.net.au/news/2019-01-23/aged-care-worker-sentenced-for-assault-of-elderly-man/10743004> accessed 16 February 2022; Mazoe Ford, 'Sydney Aged Care Worker Avoids Jail for Assault on Dementia Patient' (*ABC News*, 20 September 2018) <https://www.abc.net.au/news/2018-09-20/sydney-nursing-home-dana-grey-assault-sentencing/10285024> accessed 22 October 2024.

[40] Older Persons Advocacy Network, 'Ready to Listen' <https://opan.org.au/education/training-for-aged-care-professionals/ready-to-listen/> accessed 24 January 2022; Daisy Smith and others, 'The Epidemiology of Sexual Assault of Older Female Nursing Home Residents, in Victoria Australia, between 2000 and 2015'

justice systems have been utilised by people with dementia and their families, including in the context of COVID-19.[41] However, civil litigation is expensive and lengthy and people with dementia are disadvantaged in compensation by reason of their age and disability.[42] Civil remedies are not available for all forms of harm in LTC institutions, particularly those that are legal, relate to guardians' substitute decisions and/or are attributable to design and operation of LTC systems.[43]

Complaint schemes operated by government agencies are sometimes seen as providing more affordable and efficient processes for dispute resolution. However, successive Australian Royal Commissions have illuminated complaint schemes are experienced as punitive, lacking transparency, not delivering meaningful outcomes, and exacerbating trauma.[44]

Australian public inquiries have not delivered widescale reform (including deinstitutionalisation and prohibition of restraints and non-consensual psychotropic medication) nor have they recommended measures for redressing harm in LTC institutions, even though these inquiries have recognised some harm in LTC institutions such as that arising from physical and sexual assault, neglect, and use of restraint.[45] Australian public inquiries into LTC institutions have not prompted justice system reforms or introduction of redress schemes like those for historical institutional abuse in relation to children.

(2019) 36 Legal Medicine 89; Sharon Wall, 'The Ultimate Betrayal: Sexual Assault of Older People in Residential Care' (2010) 100 Precedent 11; Mary Stathopoulos and others, 'Addressing Women's Victimisation Histories in Custodial Settings' (Australian Institute of Family Studies 2012).

[41] Kylie Burns, 'The Forgotten Injured: Can Tort Compensate for Public Regulatory Failure in Residential Aged and Disability Care?' (2024) 29 Torts Law Journal 99; Sara Dehm, Claire Loughnan and Linda Steele, 'COVID-19 and Sites of Confinement: Public Health, Disposable Lives and Legal Accountability in Immigration Detention and Aged Care' (2021) 44 University of New South Wales Law Journal 60.

[42] Kylie Burns, 'The Forgotten Injured: Recovery for Injuries in Aged Care' (*Griffith News*, 1 June 2021) <https://news.griffith.edu.au/2021/06/01/the-forgotten-injured-recovery-for-injuries-in-aged-care/> accessed 16 February 2022; Burns (n 41).

[43] Spivakovsky and Steele (n 30); Steele and Swaffer, 'Reparations for Harms' (n 4).

[44] Royal Commission into Aged Care Quality and Safety, 'Care, Dignity and Respect, Volume 2,(n 10); Dinesh Wadiwel, Claire Spivakovsky and Linda Steele, 'Complaint Mechanisms: Reporting Pathways for Violence, Abuse, Neglect and Exploitation' (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability 2022) <https://disability.royalcommission.gov.au/system/files/2023-02/Research%20Report%20-%20Complaint%20mechanisms%20Reporting%20pathways%20for%20violence%2C%20abuse%2C%20neglect%20and%20exploitation_0.pdf> accessed 16 February 2022.

[45] Steele and Swaffer, 'Reparations for Harms' (n 4).

Barriers to access to justice and redress mean people with dementia experience a further layer of human rights violation. Rights violated include access to justice (Art 13 CRPD), freedom from violence (Art 16 CRPD),[46] and remedy (Art 2, International Covenant on Civil and Political Rights; Art 14, Convention Against Torture).[47] Disability human rights scholarship on access to justice has largely focused on disabled people's participation in domestic justice systems and highlights importance of improving accessibility, staff knowledge and competency, and reasonable accommodations within those systems.[48] This work provides important strategies for addressing human rights violations in LTC institutions through reforms to civil and criminal justice systems and complaint schemes that could form one aspect of a broader human rights-based and comprehensive approach to reparations. There is also emerging engagement with alternative avenues for justice, as we discuss next.

C. Reparations and People with Dementia

Additional to requiring access to judicial remedies for human rights violations that are also illegal or justiciable under domestic law, international human rights law provides for redress of gross human rights violations in the form of 'reparations'.[49] Reparations refers to actions of making amends and righting wrongs in relation to systemic and widespread human rights violations. Reparations emerged as a response to widespread and state sanctioned harm against minorities incapable of being seen as wrongs under domestic law or unlikely to be pursued through courts because of systemic discrimination.[50] The Van Boven Principles have their origins in a study by Theo van Boven requested in 1989 by the UN Sub-Commission on Prevention of Discrimination and Protection of Minorities on 'the right to restitution, compensation and rehabilitation for

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[46] UN Special Rapporteur on the rights of persons with disabilities, 'International Principles and Guidelines on Access to Justice for Persons with Disabilities' (2020) <https://www.ohchr.org/Documents/Issues/Disability/SR_Disability/GoodPractices/Access-to-Justice-EN.pdf> accessed 22 October 2024.

[47] CAT Committee, 'General Comment No. 3: Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment: Implementation of Article 14 by States Parties' (2012) CAT/C/GC/3.

[48] Flynn (n 7); Lawson (n 7); Jonas Ruškus, 'Transformative Justice for Elimination of Barriers to Access to Justice for Persons with Psychosocial or Intellectual Disabilities' (2023) 12 Laws.

[49] Van Boven Principles (n 2).

[50] Marten Zwanenburg, 'The Van Boven/Bassiouni Principles: An Appraisal' (2006) 24 Netherlands Quarterly of Human Rights 641.

victims of gross violations of human rights and fundamental freedoms'.[51] A 1993 report by the Special Rapporteur of UN Sub-Commission on Prevention of Discrimination and Protection of Minorities included a set of proposed basic principles and guidelines on reparations, which was then subject to reworking and revision over the next 17 years in expert, non-governmental and inter-governmental spheres.[52] In 2000 the Independent Expert of the Commission on Human Rights M. Cherif Bassiouni contributed dimensions to the draft informed by international humanitarian law.[53] Throughout development of the draft, human rights NGOs played a key role as did increasing intergovernmental involvement including open ended consultations led by the Chile delegation to the Commission on Human Rights.[54] The Van Boven Principles were adopted on 15 December 2005 by UN General Assembly resolution 60/147.

The Van Boven Principles provide an international human rights framework for remedying gross violations of international human rights law and serious violations of international humanitarian law. The principles take a 'victim-oriented perspective' and recognise victims' rights 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'.[55] The Van Boven Principles are 'recommendations and do not bind States'. However, this 'does not preclude the possibility that the resolutions, which as such are merely recommendations, reiterate principles which are binding on the basis of other sources of law'.[56]

The Van Boven Principles approach reparations as taking multiple forms, rather than specifically being equated to monetary relief. These forms are organised in the principles into five categories: restitution, compensation, rehabilitation, satisfaction, and guarantees of non-repetition.[57] Restitution aims to restore victim-survivors to their prior situation and can include 'restoration of liberty, enjoyment of human rights, identity, family life and citizenship, return to one's place of

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[51] Theo van Boven and others, 'Victims' Rights to a Remedy and Reparation: The New UN Principles and Guidelines' in Carla Ferstman and Mariana Goetx (eds), *Reparations for Victims of Genocide, War Crimes and Crimes against Humanity: Systems in Place and Systems in the Making* (Brill Nijhoff 2009) 25.

[52] ibid.

[53] ibid.

[54] ibid 26.

[55] Zwanenburg (n 50) 646.

[56] ibid 652.

[57] Van Boven Principles (n 2).

residence, restoration of employment, and return of property'.[58] Compensation is provided for 'economically assessable damage, as appropriate and proportional to the gravity of the violation and the circumstances of each case'. Rehabilitation includes 'medical and psychological care as well as legal and social services'.[59] Satisfaction focuses on public recognition of human rights violations and includes truth-telling, commemoration, official declaration of the rights of victims, public apology, judicial and administrative sanctions against perpetrators, and public education.[60] Guarantees of non-repetition are actions directed towards addressing structural drivers of human rights violations and include reviewing and reforming laws and promoting 'observance of codes of conduct and ethical norms',[61] targeting judicial and legal, health, and education systems.[62]

Reparations take a 'two-track approach'.[63] They involve looking back and responding to impacts of harm on individuals and communities, as well as looking forward to address systemic measures to prevent further perpetration of harm and bringing about societal change directed towards ending cycles of oppression, violence, and discrimination.[64] The future orientation of reparations can make them a tool for worldmaking, i.e. for constructing more hopeful and just futures.[65] Reparations are not dependent on illegality or unlawfulness of harm under domestic law, but rather on whether harm gives rise to widespread and systemic violation of human rights. Indeed, reparations often apply in situations of legally or socially sanctioned violence or discrimination. While reparations are

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[58] ibid 7.

[59] ibid 8. See also Roger Duthie and Clara Ramirez-Barat, 'Education as Rehabilitation for Human Rights Violations' (2016) 5 International Human Rights Law Review 241, 250.

[60] Van Boven Principles (n 2) 8.

[61] ibid 8–9.

[62] Jeremy Sarkin, 'Towards a Greater Understanding of Guarantees of Non-Repetition (GNR) or Non-Recurrence of Human Rights Violations: How GNR Intersects Transitional Justice with Processes of State (Re)Building, the Rule of Law, Democratic Governance, Reconciliation, Nation Building, Social Cohesion and Human Rights Protection' (2021) 57 Stanford Journal of International Law 191, 206; Andrew Songa, Annah Moyo-Kupeta and Nomathansanqa Masiko-Mpaka, 'Reparations' in Hakeem O Yusuf and Hugo van der Merwe (eds), *Transitional Justice: Theories, Mechanisms and Debates* (Routledge 2021) 143, 147.

[63] Kent Roach, *Remedies for Human Rights Violations: A Two-Track Approach to Supra-National and National Law* (CUP 2021) 88.

[64] Frédéric Mégret, 'The Case for Collective Reparations Before International Criminal Court' in Jo-Anne M Wenmers (ed), *Reparation for Victims of Humanity: The Healing Role of Reparation* (Routledge 2014) 179–180.

[65] Olúfemi O Táíwò, *Reconsidering Reparations* (OUP 2022).

distinct to remedies under domestic law, as we discuss below our findings suggest a reparative *approach* which can guide development of new redress schemes and might also be capable of being utilised to transform existing justice systems.

Disability rights activists have long advocated for reparations for disabled people harmed in institutional settings.[66] However, human rights literature on reparations has not yet explored needs or experiences of people with dementia who experience harm in LTC institutions. There is emerging research specifically on reparations for disability-specific harm, such as in contexts of institutional settings and discrimination in the community.[67] The topic of reparations for disabled people is also emerging in the international human rights system. The CRPD Committee's guidelines on deinstitutionalisation stipulate systems of redress should be available recognising 'all forms of human rights violations caused by the institutionalisation of persons with disabilities' and 'go beyond financial compensation' to include formal apologies, restitution, habilitation and rehabilitation, and establishment of truth commissions.[68]

Additionally, there is scholarship on including disabled people in mainstream reparations processes in post-conflict and postcolonial contexts and international criminal law.[69] This coincides with recent developments in including disabled people in UN peace and security agendas.[70]

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[66] Simon Katterl and others, 'Not Before Time: Lived Experience-Led Justice and Repair' (2023) <https://static1.squarespace.com/static/64509ef54c074f6f4dfb7138/t/648ed6db5216c12186d165f3/1687082792810/Not+Before+Time+-+State+Acknowledgement+of+Harm+2023+FINAL+ADVICE.pdf> accessed 16 February 2022; Minkowitz (n 8); Hege Orefellen, 'Hege Orefellen on Reparations' (*Absolute Prohibition,* 2016) <https://absoluteprohibition.wordpress.com/2016/02/06/hege-orefellen-on-reparations/> accessed 12 January 2024.

[67] Regina Kline and others, 'Disability Reparations and the Modernization of the Community Reinvestment Act of 1977' 24 New York University Journal of Legislation and Public Policy 375; Steele and Swaffer, 'Reparations for Harms' (n 4).

[68] CPRD COmmittee, 'Guidelines on Deinstitutionalization' (n 32) 17. For detailed analysis see Minkowitz (n 5).

[69] Janine Natalya Clark, 'Where Are the Voices and Experiences of Persons with Disabilities/Disabled People in Transitional Justice Research and Practice?' (2023) 15 Journal of Human Rights Practice 595; William I Pons, Lord and Stein (n 8); Karen Soldatic and Dinesha Samararatne (eds), *Women with Disabilities as Agents of Peace, Change and Rights: Experiences from Sri Lanka* (Routledge 2020).

[70] UN Special Rapporteur on the rights of persons with disabilities, 'Peacebuilding and the Inclusion of Persons with Disabilities' (2023) A/78/174; UNSC Res 2475 (2019) S/RES/2475.

3. Methods: A Disability Human Rights and Dementia-Centered Approach

Limited existing research and practice on redressing harm experienced by people with dementia in LTC institutions provided the research team with a unique opportunity to develop an understanding of redress driven by the experiences and needs of people with dementia and care partners and family members.

We utilised a disability human rights methodology. This methodology involves research aiming to achieve concrete outcomes advancing human rights of disabled people.[71] A disability human rights methodology is similar to inclusive and participatory research approaches advocated by scholars across disability human rights, critical disability, and dementia human rights studies.[72] People with dementia were prioritised as leaders and participants in research through involvement as advisors in design of the project proposal for funding, project investigator, project expert advisory group members, focus group participants, co-author of research outputs, and presenters in project launch events. We focused on outcomes and outputs directed towards reform of legal and service systems to ensure tangible benefits to people with dementia, including a set of 25 Dementia Reparations Principles. The Dementia Reparations Principles provide a framework for the necessity, form, and processes of redress. They were developed based on our empirical research, as well as international human rights norms on access to justice for people with disability, and analysis of the design and operation of Australian redress schemes for survivors of institutional child sexual abuse and members of the Stolen Generations. The project report and principles are available online and accessible through an Easy-Read summary.[73]

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[71] Anna Arstein-Kerslake and others, 'Introducing a Human Rights-Based Disability Research Methodology' (2020) 20 Human Rights Law Review 412.

[72] Alicia Diaz-Gil and others, 'A Human Rights-Based Framework for Qualitative Dementia Research' (2023) 30 Nursing Ethics 1138; Karen Fisher and Rosemary Kayess, 'Collaborative Disability-Inclusive Research and Evaluation as a Practical Justice Process' in Peter Aggleton, Alex Broom and Jeremy Moss (eds), *Practical Justice: Principles, Practice and Social Change* (Routledge 2019); Alanna Veitch and Jen Rinaldi, 'Disability Research Principles: Lessons from a Speaker Series' (2024) 18 Critical Studies: An International and Interdisciplinary Journal.

[73] 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) <https://opus.lib.uts.edu.au/handle/10453/166674> accessed 12 February

A. Ethical Considerations

The primary research method was qualitative research involving two stages of focus groups with four populations. The project had ethics approval from University of Technology Sydney Human Research Ethics Committee (ETH21-6114). Consent was sought from participants for each focus group round. All participants were paid the research participation rate recommended by People with Disabilities Australia.

Accessibility was a key ethical consideration. Participation and consent information was available in Easy Read. Easy Read is a form of accessible written communication for people with cognitive impairments such as people with intellectual disability and dementia, using simplified language and pictorial references to convey the most important information in complex documents. Focus groups were structured to include regular breaks. Feedback on accessibility of focus groups was also taken from participants with dementia and integrated into subsequent focus groups. For example, slides used in Stage Two Focus Groups were revised to ensure clearer communication.

High importance was placed on maximising psychological safety during focus groups. There was a risk of people experiencing distress from sharing their personal stories of mistreatment, abuse or rights violations and risk of vicarious trauma from hearing others' stories. A trained counsellor supported focus groups where people with dementia and care partners and family members participated. The counsellor was present at focus groups and concentrated on monitoring general and individual mood and validating participants' contributions prior to each break. The counsellor was available during breaks and for 30 minutes after each focus group for individual consultation. The counsellor was also available to the researchers. Participants were provided with contact details for advocacy and legal organisations. Participant confidentiality was upheld through giving people the option of how they named themselves in Zoom and whether they turned their camera off. There was option of an interview for any confidentiality or psychological safety concerns.

2022; Linda Steele and Kate Swaffer, 'Reparations for Harm to People Living with Dementia in Residential Aged Care – Project Report' (University of Technology Sydney 2023) <https://opus.lib.uts.edu.au/handle/10453/166672> accessed 22 October 2023; Linda Steele, Kate Swaffer, and Council for Intellectual Disability, 'Reparations for People with Dementia in Aged Care: Easy Read Translation' (University of Technology Sydney 2023) <https://opus.lib.uts.edu.au/handle/10453/166675> accessed 22 October 2023.

B. Recruitment

People with dementia were the primary group whose perspectives were sought. ‘Needs’ and ‘voices’ of people with dementia are frequently represented by others such as family advocates or experts.[74] This project aimed to inform understandings of redress from perspectives of people with dementia themselves, not only by others. However, participation was not limited to people with dementia who currently live in LTC institutions or with personal experience of harm. We recruited any person who identified as having dementia because they could still draw on their experiences of discrimination within the community and perspectives on rights, accessibility and inclusion, and we anticipated difficulties of recruiting from within LTC institutions because of gatekeeping by LTC providers and staff which can make it difficult to promote research to people with dementia.

Care partners and family members of people with dementia who have been harmed in LTC institutions, volunteer advocates (individuals who, in an unpaid capacity, advocate for improved rights and quality of life for people with dementia and who generally have had experience as care partners and family members of people with dementia), and lawyers and advocates (individuals working in a paid capacity in legal and advocacy organisations supporting disability rights, older people’s rights, or human rights more broadly) were also invited to participate. These three other participant categories are involved in witnessing and advocating against harm to people with dementia. While participation of people with dementia was prioritised, involvement of these three other participant categories was valuable because of their connections to people with dementia harmed in LTC institutions who have since died and their personal experiences of complaints and justice processes.

Recruitment occurred through social media; disability, dementia, and care partner advocacy organisations; and StepUp for Dementia (an Australian dementia research participation service).[75] Participants in Stage One Focus Groups were invited to participate in Stage Two Focus Groups. However, participation in both was not mandatory and Table 1 indicates variation between participant categories in terms of participation across

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[74] Chelberg and Swaffer (n 21).

[75] Yun-Hee Jeon and others, ‘Early Implementation and Evaluation of StepUp for Dementia Research: An Australia-Wide Dementia Research Participation and Public Engagement Platform’ (2021) International Journal of Environmental Research and Public Health.

both stages. There was separate recruitment material for each group and people with dementia were provided with Easy-Read information and consent forms, with consent sought for each focus group stage. Table 1 explains final participant sample.

	Stage One Focus Groups participants	**Stage Two Focus Groups participants**		**Total participants across all categories**
		Total Stage Two participants	**Participants new to project (i.e., did not participate in a Stage One Focus Group)**	
People with dementia (PLWD)	6	9	6	12
Care partners and family members (CPFM)	13	11	5	18
Volunteer advocates (VA)	8	9	3	11
Professional advocates and lawyers (AL)	11	10	7	18
Total	38	39	21	59

Table 1: Research participants

Overall, recruitment was consistent with targets, with exception of lower numbers of people with dementia who participated in the study (1/5 of all participants). People with dementia who declined to participate indicated the project's topic was not considered personally relevant (for example they did not live in LTC institutions and did not have experience of harm). We considered low recruitment of people with dementia might also relate to the topic being confronting to them, including if they have themselves experienced harm or fear experiencing harm or they face the prospect of entering LTC institutions. Care partners and family members might have assumed the need to protect people with dementia from knowledge of this topic or that people with dementia are not able to contribute. In contrast, increase in Stage Two Focus Group participation may have been due to data collection at this stage concentrating on feedback on a policy document, and because it was thus understood as removed from direct personal experience.

C. Data Collection and Analysis

Two stages of data collection through focus groups were conducted between July 2021 and December 2022 in Australia.

Focus groups provide individuals '[i]ncreased control over level of participation since there is less pressure to contribute than in individual interviews' and can promote feeling 'supported and empowered in a group with others who share similar experiences'.[76] Focus groups were ideal because they enabled individuals to reflect on and apply personal and professional experiences to discuss redress, rather than provide detailed recounts of experiences. However, individuals were given the option of an interview and there was one interview with a family member participant. Choice of focus groups over interviews has positively affected findings in providing more opportunity for reflection on and extrapolation from direct experience, although it has meant data contains less context of individuals' specific experiences of harm.

A first stage of focus groups (Stage One Focus Groups) explored perspectives on what redress means in the context of people with dementia in LTC institutions, as well as possible forms of and processes for redress. Each Stage One Focus Group was single participant category, to maximise opportunities for participation and safety in sharing personal experiences in a context where mixed focus groups might result in power imbalances and marginalise some participants.[77]

Question	**Prompt**
Is it necessary to right the wrongs of abuse and neglect of people living with dementia in residential aged care?	Important for you? Important for people living with dementia? Important for care partners, family members and close friends of people living

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[76] Claire Bamford and Errolyn Bruce, 'Successes and Challenges in Using Focus Groups with Older People with Dementia' in Heather Wilkinson (ed), *The Perspectives of People with Dementia: Research Methods and Motivations* (Jessica Kingsley Publishers 2001) 141.

[77] There was one exception of a Stage One Focus Group that consisted of a volunteer advocate (VA08) and care partner (CPFM13) who were friends and had been involved in advocacy relating to the care partner's deceased husband who had dementia and experienced harm in LTC institutions.

	with dementia who have experienced abuse and neglect? Important for the broader community? Important for government?
What does it mean to redress or set right abuse and neglect in residential aged care? Let's start at the individual level.	What does 'fixing' or 'righting' abuse and neglect mean in relation to specific victims of abuse and neglect? What does 'fixing' or 'righting' abuse and neglect mean in relation to care partners, family members and close friends of specific victims of abuse and neglect, including if that victim is no longer alive?
Let's now consider how we fix abuse and neglect at the structural/community level.	What does 'fixing' or 'righting' abuse and neglect mean in relation to the broader dementia community?
How should we redress abuse and neglect of people living with dementia in residential aged care?	What does 'fixing' or 'righting' abuse and neglect mean in relation to the aged care sector? What does 'fixing' or 'righting' abuse and neglect mean in relation to the broader Australian community and nation?
Let's begin with the forms/methods redress should take.	What form should redress take for people who are abused or neglected? What form should redress take for care partners or family of people who are impacted by the abuse and neglect of someone living with dementia? What form should redress take at the structural/community level? What form should redress take in relation to historical instances of abuse and neglect – when victim is deceased, when took place years or decades earlier? What are we redressing? Are we only responding to loss to victims and families (e.g. physical/psychological injury, broader impacts on lives, etc), or are we also responding to gain to perpetrators and others (e.g. profit gained through low labour and other costs related to neglecting or restraining residents)?
What about the process through which redress occurs, and who is involved in this	Who administers redress?

process?	What is involvement of dementia community? What is involvement and financial contribution of State and aged care sector? How do we ensure redress is accessible and inclusive to people living with dementia? How do we involve the broader community in redress processes?
What should be the role of the legal profession and justice system in redress?	

Table 2: Stage One Focus Group Questions

Stage One Focus Group data were thematically analysed using a coding schema applied to identify dimensions of 'who', 'what', 'why', and 'how' of redress. Author Steele coded this data. A research assistant (Hope Siciliano) who was not involved in Stage One Focus Groups then coded all transcripts to ensure rigorous analysis, and regular meetings were held between Steele and Siciliano to identify any variations to coding schema and any differences in coding.

'Dementia Redress Principles' were then drafted based on Stage One Focus Groups and analysis of international human rights norms and guidance on access to justice and reparations, and analysis of design and lived experiences of Australian redress schemes such as the National Redress Scheme for institutional child sexual abuse survivors.

A second round of focus groups (Stage Two Focus Groups) workshopped the draft 'Dementia Redress Principles'. These focus groups explored participants' views on content and wording of each specific draft principle and identified gaps in the scope of each. There were a mixture of single-participant group and mixed participant group sessions. This approach was based on feedback of the project advisory group that it would be appropriate at this stage to give participants (particularly people with dementia) the choice of participating amongst a more diverse range of people because discussion concentrated on a policy-type document rather than people's direct experiences.

Discussion involved asking a series of questions in relation to each draft 'Dementia Redress Principle', seeking general views as well as specific feedback on wording, and any additional principles needed (see Table 3). Participants were sent draft 'Dementia Redress Principles' and an overview of questions for discussion, ahead of focus groups. There were a range of mixed and single participant Stage Two Focus Groups.

Questions
Do you disagree with any of the dementia redress principles?
Are any of the dementia redress principles unclear?
Is anything missing from the dementia redress principles?
Do the dementia redress principles adequately respond to the circumstances of people living with dementia?
Do the dementia redress principles adequately respond to the scope and impacts of harms in residential aged care?
What challenges or barriers might be encountered in implementing the dementia redress principles?

Table 3: Stage Two Focus Group Questions

Stage Two Focus Group data were thematically analysed using a coding schema structured by reference to each draft principle to identify themes that could inform changes to specific principles, using the same process from Stage One Focus Group data analysis. Feedback on draft principles was also gathered at two project advisory group meetings – one before and one after Stage Two Focus Groups – and from international human rights experts.

A final set of principles were produced, now termed 'Dementia Reparations Principles'.[78] The principles provide guidance to advocates and policymakers to advance work on redress, and this article offers critical and contextual reflection on key forms of redress identified in the principles.

D. Limitations

There are four key limitations in the empirical study.

First, only one participant with dementia lived in a LTC institution (participating at both Stage One and Stage Two). Others indicated connections to LTC institutions such as having toured LTC institution for future planning, having a spouse (without dementia) living in a LTC institution, or social and advocacy links with individuals in LTC institutions (although these details were not systematically collected). **Some potential reasons for difficulties in recruiting people within LTC institutions are discussed in preceding paragraphs. The majority of participants with dementia living outside of LTC institutions impacts the extent the study provides evidence of views of people currently living in LTC institutions.

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[78] Steele and Swaffer, 'Dementia Reparations Principle' (n 73).

Second, the participant population with dementia self-selected. There was no representative sampling of people with dementia in terms of different types and stages of dementia and length of time living with dementia, nor was this information asked of participants. As such, views of this population cannot be generalised to views or voices of people with dementia in general. Moreover, given some participants with dementia are involved in advocacy and have familiarity with human rights, self-selection means the study population may represent a particularly involved cohort with more developed views on redress informed by their broader engagement in advocacy.

Third, perspectives of care partners and family members and volunteer advocates (as former care partners and family members) on what people with dementia need or value can contradict views of people with dementia. While care partners and family members can be advocates for people with dementia, they can also be perpetrators of harm and complicit in harms perpetrated by others.[79] Care partners and family members self-selecting to participate are likely to be people who are not or do not see themselves as perpetrators of or complicit in harm.

Fourth, this project did not involve empirical research with other stakeholder groups whose interests will likely shape design and operation of redress such as government and LTC institution providers. This could restrict policy impact of the project because redress schemes are a public policy measure and thus dependent on competing stakeholder interests.[80]

4. Findings: Multi-Faceted Redress

This section reports findings on requisite forms of redress for human rights violations experienced by people with dementia in LTC institutions. It is based on analysis of Stage One and Stage Two Focus Group data on perspectives of people with dementia and their care partners, family members, and advocates. Overall, all participants supported redress for a variety of reasons centered on four themes: recognising harm experienced by people with dementia and its impacts on them and care partners and family members, ensuring accountability of perpetrators, bringing about meaningful change to prevent further harm, and prompt action in response to urgency for redress.

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[79] See similar tension in Katterl and others (n 66) 14.

[80] Stephen Winter, *Monetary Redress for Abuse in State Care* (CUP 2023).

Participants proposed multiple forms of redress: rehabilitation and removal from harm, systems reform, truth-telling, apologies, sanctions, and targeted monetary payments. While all believed monetary payments could serve specific purposes in a larger range of forms of redress, alone they would not sufficiently address reasons why redress was needed.

Three caveats are necessary to contextualise broader relevance of findings. First, our empirical study found support for a particular way of responding to the problem of redress among the study cohort. We did not test or evaluate particular approaches and thus the project cannot provide an evidence base for the right policy solution to the problem of redress. Second, our empirical study only includes perspectives of one person with dementia living in a LTC institution with majority of participants with dementia not currently living in that setting. It thus should be understood as providing valuable testimony about community values, to inform a more comprehensive approach to redress in LTC institutions. Third, the study focuses on a relatively limited sample of individuals living in Australia. It thus does not provide empirical insights into what redress forms might be appropriate in other countries, both in terms of lived experiences of people and varying legal and justice systems and LTC systems.

Discussion below orders forms of redress in priority given to them by participants. Systems reform and rehabilitation were considered priority forms of redress and monetary payments were deprioritised by participants. However, it is important to note there were some subtle differences between participant groups and within participant groups. There were differences between participants with dementia concerning systems reform and rehabilitation. The participant with dementia living in a LTC institution emphasised structural reform at the local level within LTC institutions, such as improved staff training and enhanced access to allied health services. In contrast people with dementia who lived in the community identified importance of staff training but also discussed education of broader communities and access to alternatives to LTC institutions or moving people to other LTC institutions. Participants with dementia not living in LTC institutions also framed their preferences in terms of addressing segregation and discrimination. By way of differences between participant groups, the majority of care partner, family member and volunteer advocate participants were concerned with improving current circumstances within LTC institutions in tangible ways, compared to professional advocate and lawyer participants who had a more abstract focus on reforming policy and laws and setting up systems for formal processes of apology, compensation and truth-telling in a wider context of human rights and legal rights.

In reporting data, participants were de-identified and allocated individual codes reflecting their participant category. Letter-based codes were PLWD: people living with dementia, CPFM: care partners and family members, VA: volunteer advocates, and AL: advocates and lawyer; and number-based codes reflected order of registration. For example, PLWD09 indicates the participant as a person with dementia who was the 9th person in that category to register project participation.

A. Rehabilitation and Removal from Harm

Participants identified forms of redress supporting recovery and wellbeing of people with dementia. Participants emphasised importance of attending to immediate and deeply personal needs of individuals.

Rehabilitation and removal from harm is the most tangible, direct, and immediate form of redress for people with dementia. Participants explained redress must include rehabilitation and restorative care, including resourced and coordinated support to move individuals to a safe environment in the community. Rehabilitation does not compensate for harm, but it can assist with support for resultant disablement or trauma and for moving people with dementia out of harmful environments. PLWD09 argued for rehabilitation within a restorative framework:

> *when the harm has happened for us, we're left with the feelings, not the facts. [...] 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. [...] it's about this restorative justice, restoring someone to a state comparable to what they had before. [...] I just want to be gone from where it happened because otherwise you're just living in a trigger [...] it's like [domestic violence] and staying with your partner, you're always going to be triggered and on edge.*

PLWD07, at the same Stage Two Focus Group session, agreed with PLWD09 and noted even if a harmed individual received hundreds of thousands of dollars in compensation, if they remain at the site of harm 'there's no escaping [...] it's still in your face'.

Care partners and family members can experience ongoing trauma from harms to people with dementia. PLWD05 noted importance of support for care partners and family members 'to help them emotionally to have to deal with' impacts on them of harm to people with dementia. VA11 emphasised value of counselling for care partners and family due to her experiences: '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. [...] some of these people will have died and there'll be a sense of grief and loss'.

B. Structural Reform

Participants identified reforming laws, systems, and practices as a distinct form of redress (as well as commitments to and action on change being designed into truth-telling and apologies). Participants emphasised important connections between changing the future and learning from the past to prevent further harm.

Reform can extend in immediate term to improved living arrangements benefitting all residents in LTC institutions. PLWD01, who lives in a LTC institution, spoke of redress extending to improved care: '[B]etter food and activities. [...] 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"'. CPFM13 said the highest priority was shifting how care is provided in LTC institutions: 'And number one is tender, loving care. [...] Not having them sitting in a room like this, because they get another load of drugs. Stop the regular drugs'.

Longer term, redress must include reforming LTC institution governance, laws, and practices. This reform must be led by people with dementia. AL02 referred to need to 'overhaul the system': '[R]eal redress means you really don't do it again [...] Change the system, overhaul the system because the current system leads to abuse.' AL17 asserted reforms need to be 'compatible with human rights' to prevent human rights violations in any redesigned system. Some participants explicitly identified such reform as extending to deinstitutionalisation and desegregation. CPFM10 stated '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'.

Systems reform should also be progressed through dementia training delivered to healthcare and legal students, LTC providers, and all LTC institution staff and board members. PLWD09 discussed training being co-designed with people with dementia because existing training 'hasn't been developed by a co-design process’ and is ‘pretty old world’. This training must include learning about dementia as a disability, human rights of people with dementia, and perspectives of people with dementia. PLWD05 and PLWD06 proposed staff education on dementia should be mandatory and should occur in a broader context of raising community awareness about dementia. CPFM15 noted specific importance of human rights training extending to supported decision-making and legal capacity because otherwise ‘they’re going to constantly be denied that choice and control, and that autonomy’.

Some participants raised concerns about limitations of training and education, given deeper cultures of LTC institutions. CPFM16 observed: ‘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’. VA11 suggested training would be limited unless it occurs within a broader strategy of ‘changing culture’ within LTC institutions, because of present cultural assumptions ‘human rights stop’ when a person enters a LTC institution.

C. Truth-telling

Participants identified truth-telling about wide-ranging impacts of harm as both an important end and as foundational to authenticity and efficacy of other forms of redress.

Participants suggested various models of truth-telling. PLWD10, CPFM09, and CPFM12 (reporting on an earlier discussion with his spouse PLWD04) all proposed a victim impact statement model. 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’. AL01 suggested a model of truth-telling involving a site of commemoration of deceased people with dementia.

Truth-telling was identified as important because redress must simultaneously look back to acknowledge and heal past harm and look forward to how those experiences can inform and shape a better future for people with dementia. Referring to CPFM13 (whose husband died in a LTC institution), VA08 noted the importance of validating people’s experiences. Validation must involve individuals seeing lessons learned from their stories reflected in changes to LTC institutions; otherwise, truth-telling is tokenistic: 'Is [CPFM13] able to walk into a facility [...] and feel that she has been heard because there are real changes that she can see'.

Truth-telling might be a form of redress more relevant to care partners and family members. PLWD09 explained truth-telling would not be relevant to her, as a person with dementia; instead, as discussed earlier, it would be more important to address her immediate material circumstances: 'truth-telling would be for everyone around me, who are shocked and need an opportunity to express that'. PLWD10 agreed truth-telling 'might be more relevant to the family'. CPFM08 spoke of needing recognition of impacts on her of harm to her grandmother, without erasing her grandmother's experience of harm: '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'.

The purpose of truth-telling and public education initiatives is fivefold. First, truth-telling processes humanise people with dementia. VA07 explained 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.' AL01 suggested marking lives of people with dementia who had died as a way of bringing 'out into the open' 'largely invisible suffering'.

Second, truth-telling can validate experiences of harm and its impacts on others. Validation is important in a context of people with dementia being ignored or not being believed, and care partners and family members being viewed as problematic when they seek to intervene or advocate for justice (sometimes for years) after the person dies. CPFM13 described her advocacy after her husband's death as: 'my lifetime work [...] it's going to be what I work for until the day I die'. VA08 captured importance of validation by reference to the concept of 'silencing': 'this is a system that tries to silence people, to prevent them from having to, in fact, confront these problems'. For VA08, the validating role of truth-telling is 'about feeling that you have been heard, you have been listened to, and there is change.' CPFM16 described speaking of traumatic experiences as useful by enabling 'people [...] 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.' Truth-telling can build solidarity and support, as VA11 said: '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.'

Third, truth-telling has a pedagogical function of educating people with dementia and others on what constitutes harm and the right of people with dementia to redress. AL05 drew on her experience as a lawyer for child clients to explain sometimes people do not conceptualise their experiences as wrong, particularly where violence is normalised:

> *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 [...]".*

CPFM09 proposed truth-telling would ensure definitions of harm are informed by people's lived experiences: 'We could also define [harm] because it's the truth, isn't it?' Truth-telling can be important to educating care partners and family members not yet involved with LTC institutions, as explained by AL16 who had personal experience as a family member of a person with dementia harmed in a LTC institution: '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 [...] can rightfully expect.' Truth-telling provides opportunities for public learning of harm as a foundation for change, as explained by AL02: 'it forces the broader community to understand perspectives that may not be familiar to them [...] So it has an educational function'.

Fourth, truth-telling provides transparency, enabling society to reckon with what has happened as a foundation for social repair. There is limited access to information about harm in LTC institutions. LTC institutions are closed settings and LTC providers have access to public relations and marketing expertise to control their public image and brand. CPFM02 noted LTC providers control their message and hide harm from public knowledge. PLWD12 suggested public transparency through truth-telling could result in accountability: 'Putting up some sort of shame list [...], but particularly for the for-profits that are actually financially profiting from all of this sort of stuff.' AL02 described truth-telling as contributing to an 'ecosystem of accountability'.

Fifth, truth-telling is about individuals being able to know their experiences and stories are heard and impact change. AL09 explained 'the carer or the family member needs to know, [...] 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'. AL11 spoke about people who share their story needing to see tangible actions by LTC providers and government, because inaction can undermine truth-telling experiences: 'if they feel that yeah, I'm sharing it, but that's still going to happen to other people and nothing's coming from it'.

D. Apologies

Public apologies by LTC providers, governments, and legal and health professionals, followed by concrete actions to prevent future harm are a further aspect of redress. Like truth-telling, an apology should be a starting point for action by those apologising and not an endpoint, otherwise it remains hollow and meaningless. PLWD05 argued a public apology from a LTC provider is an initial step followed by acknowledgement by government of the broader problem because 'the government has been overseeing these services for many years, so of course they have to take responsibility for what's going on'. PLWD05 referred to government apology as essential to 'moving forward'. Similarly, CPFM09 explained a public apology by government is a 'very powerful start', because no government to date has taken responsibility for such harms.

Some participants emphasised need for apology to extend beyond acceptance of responsibility that is backed up with substantive action. PLWD05 said apology must be accompanied by actions to 'make up' for harm. VA01 identified need 'not just to say sorry, but do something concrete [...] to mean it and change their ways'. CPFM13 powerfully communicated risk of apologies being empty if they are simply tokenistic and issued to placate or silence family members but not change: 'we've got to get action going. [...] Let's act on what's wrong and make it right'.

The public nature of an official apology is particularly important. PLWD06 was of the view a public apology at the local service level might be sufficient to change practices within that service because of reputational risks of making harm public. CPFM03 spoke of reputational impacts of public apology: 'That would put pressure on the organisation because if it's become national or statewide publicised, [...] that organisation would be hit hard, [...] and people would then find out what's going on and what's happening'.

E. Sanctions

Participants identified importance of redress encompassing sanctions options such as financial penalties, banning staff, deregistration of staff, and closing LTC institutions.

Sanctions can facilitate harm prevention because financial penalties detrimentally impact individuals and organisations responsible for harm and hence deter wrongs. CPFM10 explained sanctions would provide impetus for LTC providers to change practices: 'you need a bit of carrot and stick. [...] a financial penalty would be the stick'. Similarly, CPFM15 stated: '[T]hat's where to hit them, in that hip pocket [...] that's the only thing they absolutely understand'.

Sanctions can also facilitate harm prevention through stopping perpetrators from working in LTC institutions or stopping specific LTC institutions from operating. PLWD09 suggested having a 'fit and proper test' to regulate whether LTC institution staff who perpetrate harm can continue to be employed in LTC institutions, like that often used to determine an individual's suitability for corporate governance roles. However, careful consideration is needed of how to approach accountability of staff in lower paid or insecure roles who are not in any position of control and who lack choice in how they perform duties. While precarity and exploitation experienced by some LTC institution staff do not justify or excuse harm, they do present a unique challenge with accountability. These circumstances enliven networks of harm and violence connecting oppression of marginalised workers and people with dementia, and demand turning attention to powerful perpetrators, as reflected upon by AL02:

> *it's very easy to attribute blame and penalty to individual staff members. [...] but how do we hold the government and their regulatory body accountable? [...] they're the ones who are tasked with ensuring the system is safe. [...] So it's not just the nurse at the grassroots level who is having to juggle 80 residents on one shift by herself.*

AL18 agreed, noting: 'We do need to hold [managers and CEOs] to account as well, because this problem won't be solved [while] we just keep penalising individual [staff] members.'

F. Monetary Payments

Participants supported monetary payments as a form of redress, where they have specific roles in an overall redress framework including other forms of redress described in this section.

While money was recognised as serving functions (discussed below), participants were sceptical about efficacy of monetary payments in facilitating change. Some participants noted money cannot fix or change the past, particularly where people with dementia have since died. PLWD05 said 'no money makes up for what's happened or the abuse that's occurred, [...] 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'.

Some participants emphasised monetary payments must operate in the context of a broader commitment to and action on changing systems and preventing further harm. PLWD12 stated categorically 'money doesn't interest me. It's making sure the system works'. CPFM13 explained: 'We'll never be compensated for what's happened in the past. The compensation is changing the future [...] 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?"' CPFM02 stated they were 'not so much concerned about compensation' and were more concerned with 'Learning from problems so that you can prevent them recurring'.

While monetary payments were not prioritised by participants, there was acknowledgement such payments were still important and could serve four specific purposes interconnected with other forms of redress and an overarching focus in redress on recognition, accountability, and change.

One specific purpose of monetary payments is to provide symbolic recognition of harm to people with dementia who have experienced arbitrary denial of human rights through being dehumanised and devalued. Instead of human rights being accepted as universal, as they are for most other people, people with dementia need to fight for recognition. This is captured by PLWD03: 'what are the laws that will protect all of us? [...] 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'. PLWD05 spoke about lack of recognition of harm as linked to cultural attitudes towards dementia: '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"'. CPFM02 explained how harm experienced by people with dementia can be dismissed by LTC institutions and police as part of dementia: 'it's too easy for them to pass it off and [say "It's] part of their delusion or hallucination or imagination, that it's not real"'.

In such a context, monetary payments can provide symbolic recognition of harm. VA08 explained significance to CPFM13 of recognition through monetary payment, in the context of CPFM13 having requested her deceased husband's LTC provider repay fees she had paid: 'It is about recognising that people have been [...] hurt, have been dehumanised, have not been treated the right way, have not been cared for in a society that purports to care'. AL02 explained how a monetary payment can be symbolic recognition of value of people 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'. In a similar vein, AL05 noted possibility of realising equality of people with dementia through treating them equally to those under other redress schemes: 'it's what we're offering in other redress schemes and in recognition of other types of harm. [...] it would be appropriate for that reason'.

Second, monetary payments can reimburse fees paid to LTC institutions. Reimbursement can provide the financial means to individuals to access better support and services in a community setting, as noted by PLWD06: 'the family can use that money to find a better facility. [...] it may then encourage families to fund having that person back at home'. Participants rationalised reimbursement because individuals have at times experienced longer-term material impacts from wasting money on services that were promised but they did not receive. CPFM06 explained: 'You don't pay for abuse'. CPFM10 referred to consumer rights: 'You are paying for a service that you didn't get'.

Monetary payments as reimbursement can also facilitate LTC providers forgoing financial gain derived from provision of harmful services, thus having a punitive and deterrent effect. CPFM10 explained: 'I don't think it should be government paying money to individuals. [...] it should certainly be coming from people who profited from the system and that's the providers, both for-profit or not-for-profit.' Such monetary payments can impact LTC providers' overall financial gain and thus deter further perpetration of harm, as demonstrated by an 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.'*

Third, monetary payments can cover costs of rehabilitation and restorative and trauma-informed care, at an individual or structural level. PLWD09 suggested monetary payments should be used to fund restorative care because 'the whole point of redress is to put the person back in the position they were before the event'. CPFM08 spoke of specific (and very basic) improvements in her grandmother's care such as 'healthy food and not frozen nuggets' and 'an extra tissue box in the room and wipes'. Some participants spoke of monetary payments being better spent on improving LTC at a structural level. CPFM09 stated: 'money could be better spent on improving aged care, as opposed to recompensing us for all that sort of happened to us'.

Fourth, monetary payments can contribute to funding dementia advocacy. PLWD12 suggested in situations where no one is seeking reimbursement for LTC institution fees for a particular individual who has been harmed, that money should instead go to a common fund to support advocacy. AL04 proposed funding growth of dementia rights advocacy sector as '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'.

5. Discussion: A Reparative Approach to Redress

This article contributes community perspectives to help guide future policy and research on redress for disabled people. Findings establish strong support for redress for people with dementia who are harmed in LTC institutions. Emphasis participants placed on a range of forms of redress aligns with redress scholarship in relation to historical institutional abuse identifying a series of survivor priorities for justice exceeding equating justice with money and focus on recognition and validation, voice, accountability and change.[81]

Findings establish importance of careful consideration of the overarching approach taken to redress. Specifically, they suggest a *particular 'reparative' approach* to redress. In a technical sense, a reparative approach is reflected in forms of redress identified by participants aligning with categories of reparations in the Van Boven Principles: rehabilitation and removal from harm aligns with rehabilitation and restitution categories; structural reform aligns with guarantees of non-repetition category; truth-telling, apologies, and sanctions align with satisfaction category; and monetary payments align with compensation and restitution categories. The reparative approach to redress is also apparent in the overarching framing of redress emerging in findings, particularly importance of using past harm in LTC institutions as a lesson for transformative change to prevent further harm to people with dementia. This study suggests a corrective justice approach to redress – whether in existing civil court systems and complaint schemes or any new LTC institution redress initiatives – should not be the default approach moving forward.

This section discusses areas of further exploration arising from this reparative approach: redress as worldmaking, decentering money in redressing harm, reparative civil justice systems, and methodological considerations.

A. Reparative Redress as 'Worldmaking'

Emphasis on using redress as a foundation for change was consistent across all forms of redress discussed by participants. This suggests as well as being a source of rehabilitation and recognition, reparations in the context of LTC institutions are also a tool for 'worldmaking': using redress to construct more hopeful and just futures.[82] This future-oriented and transformative use of redress might be particularly relevant in the LTC institutions context because these continue to operate and are yet to be the subject of deinstitutionalisation policies. LTC institutions are not relegated to the past in the way largescale disability or child welfare institutions are thought to be, but are entrenched in contemporary societies, legal systems, and economies.

More research is needed to explore what is meant by 'change' in terms

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[81] Patricia Lundy, 'Pathways to Justice: Historical Institutional Child Abuse and the Role of Activist Research' (2022) 14 Journal of Human Rights Practice 535.

[82] Táíwò (n 65).

of cultural, legal, and material dimensions of a future world without harm of people with dementia, to advance the goal of transformation rather than simply replicating and further entrenching what already exists. International human rights commentary on the right to independent living in the CRPD suggests transformation will necessarily encapsulate deinstitutionalisation and desegregation and addressing dementia-related stigma and discrimination.[83] However, in our empirical study there was lack of clarity of the extent participants saw deinstitutionalisation as part of redress or as being realistic. Thus, further research could engage in the specific topic of barriers – including cultural and attitudinal – to deinstitutionalisation of LTC institutions.

In order to be transformative, a reparative approach to redress must involve deeper engagement by governments, perpetrators, and perpetrator organisations to 'increase their acknowledgement of and directly address structural injustices that pervade modern societies and reproduce harm and attitudes that gave rise to such historical abuses'.[84] In this context, monetary payments should not act as 'closure of claims regarding wrongs' but instead should communicate a commitment to engagement with victim-survivors.[85] Participants in our empirical study reflected Gallen's caution that redress must be sustained through concrete action for change or otherwise can be co-opted by states and ultimately avoid meaningful long-term change for short-term placation.[86]

Participants with dementia were familiar with human rights. However, this is not necessarily representative of all people with dementia, and lack of knowledge about human rights and legal rights will likely limit potential impact of redress. Thus, possibility of 'worldmaking' will depend in part on supporting development of rights consciousness of people with dementia. This is particularly necessary for people with dementia living in LTC institutions who, through experiences of institutionalisation, might have lowered their expectations of what they find reasonable and fair.

Worldmaking might not only focus on public worlds of LTC systems and legal and justice systems, but also challenging and re-making private worlds of families and intimate relationships. Perhaps because the setting of our empirical study is LTC institutions, there is an implicit assumption

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[83] CRPD Committee, 'General Comment 5' (n 32); CPRD Committee, 'Guidelines on Deinstitutionalization' (n 32).

[84] James Gallen, *Transitional Justice and the Historical Abuses of Church and State* (CUP 2023) 5, 6.

[85] ibid 21.

[86] Gallen (n 84).

in our findings that harm is perpetrated wholly or predominantly by LTC staff and providers, legal and medical professionals working in LTC, and by government regulatory and legal frameworks. However, harm can also be perpetrated by care partners and family members. As such findings provide only part of the picture when crafting a societal response to redress, which must be complemented by nuanced exploration of what redress means in contexts where care partners and family members are perpetrators of or 'implicated subjects' in harm.[87]

B. Decentering Money

Findings confirm importance of decentering monetary payments in redressing harm experienced by people with dementia in LTC institutions. This finding must be treated cautiously to prevent it becoming a justification to avoid *any* monetary element in redress, particularly noting the study's Australian LTC context. Money might be more necessary in nations with less publicly funded ageing, disability and health systems or for individuals and families who experience poverty. Looking beyond LTC to disability and redress more broadly, money might be more relevant to younger disabled people who experience institutional harm and require monetary support for longer in their lifecourse. These reflections on findings on monetary payments suggest importance of shaping redress – including monetary payments – around the impacted community's personal circumstances. That aligns with empirical studies with historical institutional abuse survivors that have found limitations of monetary payments when redress is co-designed around survivors' diverse justice interests.[88] A common theme in historical institutional abuse research in relation to victims/survivors' views on monetary payments is 'it's not the money that matters', but rather they be 'heard and believed', 'the abuse be recognised and acknowledged', and a monetary payment can be connected to these priorities.[89] Thus, victims/survivors may perceive or experience actual scope or delivery of monetary payments as incapable of recognising the enormity of injustice and its impacts, incapable of disrupting enduring social injustices associated with harm, a means to silence them and stop them from pursuing justice, not facilitating

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[87] Michael Rothberg, *The Implicated Subject: Beyond Victims and Perpetrators* (Stanford University Press 2019).

[88] Kathleen Daly, *Redressing Institutional Abuse of Children* (Palgrave Macmillan 2014); Daly and Davis (n 3); Winter (n 80).

[89] Daly (n 88) 186, 195.

accountability, and circumventing systemic and structural change.[90]

Findings confirm community perception that money has limited impact in facilitating meaningful recognition of harm and structural change. Indeed, repeated concern raised by participants in our empirical study that money cannot change the past resonates with the 'money justice paradox': 'Money is used ubiquitously as 'justice' for victims' and is often all the civil justice system can provide, but many victims and survivors say that money alone is not justice, financial compensation on its own, can never compensate, and money cannot make up for what was lost'.[91] These findings also align with similar observations in the context of monetary payments in reparations more broadly. Minow argues 'at the heart of reparations is the paradoxical search to repair the irreparable'. In particular, payment can be viewed as an act of finality preventing further discussion of harm, '[m]oney can never remedy nonmonetary loss', and money can trivialise harm.[92]

While findings establish money alone must not be embraced as the sole form of redress, individual and collective functions of money are still an important consideration. Daly and Davis specifically note monetary payments can represent concrete recognition of gross harm, even if payments can never fix or compensate for the harm itself.[93] Lundy suggests in the context of redressing historical institutional abuse that monetary payments can be 'a symbolic measure; a tangible acknowledgement of the seriousness of the wrongdoing and how the state and/or institutions had failed to deal with it'.[94] Similarly, in a broader reparations context, Minow observes how monetary payments within reparations can provide material recognition of loss and also be a 'symbolic gesture' giving 'victims a chance to reclaim their dignity and their history'.[95] The answer then is not to completely reject monetary payments but ask how they can align with particular victims' justice interests.[96]

Findings of our empirical study also indicate as well as being a dynamic of redress, money is also a core dynamic in *harm* of people with dementia

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[90] Daly (n 88) 179–182; Daly and Davis (n 3) 62; Winter (n 80) 246.

[91] Daly and Davis (n 3) 63.

[92] Martha Minow, 'Breaking the Cycles of Hatred' in Martha Minow (ed), *Breaking the Cycles of Hatred: Memory, Law, and Repair* (PUP 2002) 23.

[93] Kathleen Daly and Juliet Davis, 'Civil Justice and Redress Scheme Outcomes for Child Sexual Abuse by the Catholic Church' (2021) 33 Current Issues in Criminal Justice 438, 440.

[94] Lundy (n 81).

[95] Minow (n 92) 23.

[96] Daly and Davis (n 3) 71.

in LTC institutions. Further exploration of restitutionary dynamics of a reparative approach to redress – focused on responding to LTC providers' financial *gain* and government cost savings through harm – is essential. This is particularly so given financial gain is not merely an aspect of harm in institutions, but is central to the model of 'care' in LTC and other disability institutions *per se*.[97]

C. Reparative Civil Justice Systems

While this article's focus on reparations broadens disability human rights scholarship on access to justice beyond the focal point of the court, our findings on a reparative *approach* to redress leave open possibility of transforming existing civil justice systems and complaint schemes, irrespective of whether new redress schemes are also introduced. This is particularly important for two reasons. First, the human right to equal access to justice requires equal access to courts.[98] Second, there is a perverse risk new redress schemes could undermine accountability, as O'Donnell et al. raise in relation to redressing historical institutional abuse, flagging 'real danger that the language of transitional justice may be co-opted by the state to justify offering a "specialised", selective, and limited justice model that in fact stymies accountability by denying access to established "democratic" institutions such as the courts, the coroners' system, academic research, and cultural and artistic expression and participation'.[99] Noting Winter's observation on the political rather than judicial nature of redress, exploring potential risks and limitations of non-judicial redress is essential.[100]

The reparative approach to redress advanced in this article can be used to evaluate and transform civil justice systems and complaint schemes. This might identify tort law's current potential to operate in a reparative register. Damages through tort law might provide money to use towards

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[97] Megan Linton, 'Class Inaction' (*Briarpatch,* 1 November 2022) <https://briarpatchmagazine.com/articles/view/class-inaction> accessed 25 August 2023.

[98] Wadiwel, Spivakovsky and Steele (n 44) 21.

[99] Katherine O'Donnell, Maeve O'Rourke and James M Smith, 'Editors' Introduction: REDRESS: Ireland's Institutions and Transitional Justice' in Katherine O'Donnell, Maeve O'Rourke and James M Smith (eds), *REDRESS: Ireland's Institutions and Transitional Justice* (University College Press Dublin 2022) xiv. See also Maeve O'Rourke, 'State Responses to Historical Abuses in Ireland: "Vulnerability" and the Denial of Rights' in Katherine O'Donnell, Maeve O'Rourke and James M Smith (eds), *REDRESS: Ireland's Institutions and Transitional Justice* (University College Press Dublin 2022).

[100] Winter (n 89).

better quality care or community-based living. Damages awarded against organisations can impact insurance, in turn placing pressure on sectors to change practices, as has been demonstrated in the context of historical institutional abuse.[101] Court decisions can serve as public vindication of harm, as demonstrated by scholarship on importance of nominal damages in tort cases.[102] Indeed, there is a burgeoning literature in tort theory arguing tort law already has capacity to accomplish aspects of reparative practice, including meaningfully recognising harm and bringing about systemic change.[103] However, this literature must be read alongside scholarship on tort law's impact on marginalised communities and its relationship to social injustice[104] and ableism.[105]

In practical terms, reparative potential of existing civil justice systems and complaint schemes still butts up against fundamental challenges in the LTC context. One of these is that many harms are not justiciable because they are legal. Transformation of existing justice systems will need to be accompanied by abolition of laws for substitute decision making, restraint and forced mental health treatment. Settlements are another challenge. Civil procedure laws – notably those related to legal costs – incentivise early resolution of civil court matters through settlement. However, confidentiality agreements or non-disclosure clauses sometimes associated with settlements can repress the voices of victims/survivors and hinder public awareness of human rights violations associated with LTC institutions. Moreover, court settlement schemes have been critiqued for their harmful impacts on disabled people.[106] A third challenge is complexities of distributive justice in administration of damages or financial settlements where the person with dementia is still alive and is subject to substitute decisionmaking for their financial affairs. In such a

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[101] Timothy D Lytton, 'Tort Claims for the Coverup of Child Sexual Abuse: Private Litigation, Corporate Accountability, and Institutional Reform' (2022) 72 DePaul Law Review 289.

[102] Jason NE Varuhas, 'The Concept of "Vindication" in the Law of Torts: Rights, Interests and Damages' (2014) 34 Oxford Journal of Legal Studies 253.

[103] Scott Hershovitz, *Law Is a Moral Practice* (HUP 2023); Emmanuel Voyiakis, 'Rights, Social Justice and Responsibility in the Law of Tort' (2012) 35 University of New South Wales Law Journal 449.

[104] Martha Chamallas, 'Social Justice Tort Theory' (2021) 14 Journal of Tort Law 309.

[105] Fiona Kumari Campbell, *Contours of Ableism: The Production of Disability and Abledness* (Palgrave Macmillan 2009); Sagit Mor and others, 'The Meaning of Injury: A Disability Perspective', *Injury and Injustice: The Cultural Politics of Harm and Redress* (CUP 2018); Sagit Mor and Rina B Pikkel, 'Disability, Rights, and the Construction of Sexuality in Tort Claims' (2019) 53 Law & Society Review 1.

[106] Rossiter and Rinaldi (n 28); Linton (n 97).

context, money might not enable genuine restoration, but instead provide an opportunity for further (financial) abuse.

D. Methodological Considerations

Our findings have methodological implications for research on and design of redress. Findings illuminate importance of not taking existing models and forms of redress as a starting point. Instead, a methodological approach exploring meaning of harm at a deeper and more nuanced level and how to redress this harm will engage more directly with people's experiences and provide a wider range of possibilities. This aligns with research on designing historical institutional abuse redress schemes driven by survivors' justice interests as defined by them.[107] Further consideration could be given to how this methodological approach to redress which is focused on building something totally novel intersects with what Cooper refers to as 'prefigurative law reform'.[108] These intersections indicate the potential for our empirical study's methodological approach to provide a new framework for policy development on redress for disabled people. This framework moves beyond a menu of predefined options and instead facilitates opportunities for disabled people and those who support them to participate in 'worldmaking' and constructing more hopeful and just futures.[109]

6. Conclusion

This article contributes empirical insights into community perspectives on an approach to and forms of redress in response to human rights violations experienced by people with dementia in LTC institutions. It highlights necessity for and ambition of a nuanced and multi-faceted reparative approach to redress. Within such an approach, there is an overarching emphasis on meaningful change to systems to avoid repetition of harm, with a key role for recognising people's experiences of harm, recognising

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[107] Daly (n 88) 176; Lundy (n 81).

[108] Davina Cooper, 'Prefigurative Law Reform: Creating a New Research Methodology of Radical Change' (*Critical Legal Thinking*, 3 March 2023) <https://criticallegalthinking.com/2023/03/03/prefigurative-law-reform-creating-a-new-research-methodology-of-radical-change/> accessed 25 August 2023.

[109] Táíwò (n 63).

humanity and equality of people with dementia, and holding to account those responsible for human rights violations. These findings provide new directions for human rights scholars researching access to justice for people with dementia or disabled people more broadly, in terms of identifying new avenues for pursuing redress and a framework for transforming existing avenues in civil justice systems and complaint schemes. A necessary dimension of future research and advocacy on redress in LTC institutions is interrogating cultural and socio-legal dynamics preventing redress for human rights violations in LTC institutions. Emerging interest in disability and redress in the international human rights system coupled with the stark absence of redress in the context of LTC institutions in contrast to the existence of redress and depth of academic and political engagement with the topic in relation to historical institutional abuse (albeit fraught with problems in design and operation) provides a timely reason for research and advocacy on redress in relation to dementia and disability. If progress is made, government support for redress needs to be cautiously considered, and ensuring engagement is as Gallen has described, a deeper forgoing of power.[110]

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[110] Gallen (n 84).