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Dear Joint Standing Committee on Implementation of the National Redress Scheme

Re: Submission to Inquiry on the Operation of the National Redress Scheme

This is a submission to the Joint Standing Committee on Implementation of the National Redress Scheme's Inquiry on the Operation of the National Redress Scheme.

The submission calls for the Joint Standing Committee on Implementation of the National Redress Scheme to specifically explore the experiences of people living with dementia in the National Redress Scheme and make recommendations in relation to the accessibility and inclusivity of the National Redress Scheme for people living with dementia and the leadership of survivors who are also people living with dementia in the ongoing operation and monitoring of the National Redress Scheme.

People living with dementia are people with disability because dementia is recognised as a cause of disability. **Dementia is a major cause of disability in older people**, yet dementia is often overlooked in disability-focused inquiries and policy reforms.

This call for specific attention to people living with dementia is supported by the findings and evidence-base of the project 'Redressing Abuse and Neglect of People Living with Dementia in Residential Aged Care' ('Dementia Redress Project'). While this research did not specifically focus on the National Redress Scheme, it raises broader issues around the need for redress processes that are inclusive of and accessible to people living with dementia and advance their human rights.

About the Dementia Redress Project

Using Australia as a case study, the project researchers developed a set of 'Dementia Reparations Principles'. These principles were informed by international human rights norms, design and lived experiences of other Australian specialised redress schemes, and empirical data from focus groups with people living with dementia, care partners and family members of people with dementia who have been harmed in aged care, and advocates and lawyers. The Project Report draws on the empirical data to provide rich

detail of individuals' experiences of harm and its impacts, and their perspectives on reparations and redress.

The Dementia Redress Project found through empirical research that people living with dementia want reparations, redress and justice which is inclusive, accessible and advances their human rights. In response to this finding and to guide future work on reparations and redress, the Dementia Reparations Principles have been developed. **These principles provide an evidence-based framework for the reform of existing options for redress such as the National Redress Scheme**, and design and operation of new redress and reparations schemes.

The 'Dementia Redress Project' is relevant to the Joint Standing Committee on Implementation of the National Redress Scheme's full exploration of and comprehensive recommendations on the National Redress Scheme in relation to all people with disability.

In particular, the international human rights foundations articulated in the Dementia Redress Project apply to all people with disability, irrespective of diagnosis or age.

The Dementia Redress Project was led by Associate Professor Linda Steele in collaboration with associate investigator Kate Swaffer and organisational partners Dementia Alliance International and People with Disability Australia. The project operated July 2021-December 2022 and is funded by a Dementia Centre for Research Collaboration – Dementia Australia Research Foundation Pilot Grant.

The following documents on the Dementia Redress Project are provided in support of our call for recommendations on reparations and redress:

- **Project Report:** Linda Steele and Kate Swaffer, *Reparations for Harm to People Living with Dementia in Residential Aged Care – Project Report* (University of Technology, Sydney, 2023).
- **Executive Summary:** Linda Steele and Kate Swaffer, *Reparations for Harm to People Living with Dementia in Residential Aged Care – Executive Summary* (University of Technology, Sydney, 2023).
- **Dementia Reparations Principles:** Linda Steele and Kate Swaffer, *Reparations for Harm to People Living with Dementia in Residential Aged Care – Dementia Reparations Principles* (University of Technology, Sydney, 2023).
- **Journal Article:** Linda Steele and Kate Swaffer, 'Reparations for Harms Experienced in Residential Aged Care' (2022) 24(2) *Health and Human Rights: An International Journal* 71.
- An Easy Read translation of the Executive Summary is currently being finalised.

Further information about the Dementia Redress Project can also be found at:

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

Submission publication by the Joint Standing Committee on Implementation of the National Redress Scheme

This letter and the *Health and Human Rights* journal article can be published now on the Inquiry website.

However, we ask that the Joint Standing Committee on Implementation of the National Redress Scheme not publish the Project Report, Executive Summary and Dementia Reparations Principles because these documents are under embargo **until officially launched on 15 March 2023**. The pagination of the documents is settled and they can be quoted from and cited.

We are currently working with Council for Intellectual Disability to finalise an Easy Read translation of the Executive Summary and Dementia Reparations Principles. This document will enhance the accessibility of our submission.

We are available to discuss with the Joint Standing Committee on Implementation of the National Redress Scheme our submission and the Dementia Redress Project.

Thank you for considering this information.

Yours Sincerely,

Associate Professor Linda Steele

Kate Swaffer