



# Safe and Just Futures for People Living with Dementia in Residential Aged Care



UNIVERSITY  
OF WOLLONGONG  
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# Realising human rights in everyday life & practice

## Background: Challenging Confinement & segregation

The 'Safe and Just Futures' project was a response to a variety of common aspects of the environmental design of residential aged care facilities (RACFs) that are detrimental to the quality of life and the exercise of human rights of people living with dementia. RACFs often house older people and people with disabilities (including people living with dementia) in large numbers separate from the rest of the community. Locked fences and doors commonly prevent residents from coming and going from RACFs.

RACFs generally include dementia care units that only house people living with dementia, therefore segregating them. Dementia care units are generally locked to prevent those inside from accessing other parts of the RACF and the community beyond the RACF.

These aspects of RACFs can give rise to discrimination, exclusion and injustice, yet they are often overlooked or taken for granted as the defining and natural features of RACFs. There has been a long focus in health and social science literature on 'quality' and 'safety' in aged care and this literature can be drawn on to question the impacts of these aspects of RACFs in relation to individual wellbeing. Yet, there has been little discussion across all academic disciplines of the social and political impacts on people living with dementia of common aspects of environmental design of RACFs.

People living with dementia and their international representative organisation 'Dementia Alliance International' have argued for many years that the environmental design of RACFs gives rise to confinement and segregation and constitutes human rights violations.

Historically, people living with dementia have not been considered as bearers of rights. However, the past decade has seen increased human rights recognition in the coming into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The CRPD requires people with disability (including people living with dementia) to enjoy the same rights as everyone else, including rights to autonomy in decision making, independent living and community inclusion, and liberty. Internationally, there is increasing pressure to recognise human and legal rights of people living with dementia, in part by reason of the advocacy of people living with dementia and their representative organisations and allies.

In an Australian context, there is emerging recognition of the human rights of people living with dementia in the context of law reform and policy discussions, as evidenced in the Royal Commission into Aged Care Quality and Safety and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Moreover, the new Aged Care Quality Standards – including through reference to dignity, respect, freedom from abuse, choice and independence – are encouraging shifts in service provision consistent with human rights.

The extent to which human rights are realised in practice and in everyday life depends not only on the willingness of politicians and policy makers to change legal and regulatory frameworks, but on the support from civil society for human rights – the attitudes and enthusiasm of community members, people living with dementia and those who provide advocacy and support.

## Aims of the Project

The aims of the project were to explore:

- current barriers to liberty and community access for people living with dementia in RACFs; and
- the possibilities and challenges of utilising a human rights framework to transform the living and support arrangements of people living with dementia in RACFs.

We sought to contribute to policy and law reform discussions around aged care, and raise awareness amongst lawyers, advocates, human rights practitioners and policy makers about human rights of people living with dementia.

The project researchers constituted an interdisciplinary team traversing law, public health, dementia design, and psychology, and included a leading international advocate on rights of persons living with dementia who herself has younger onset dementia.

The project was guided by an advisory group including people living with dementia, care partners, care home professionals, and lawyers and advocates for people living with dementia.

## Formative Research

The project ran in two stages.

**Stage 1** involved developing a framework for understanding segregation and confinement in residential aged care as a human rights issue. We drew on the human rights contained in the CRPD and the jurisprudence and work of the United Nations Committee on the Rights of Persons with Disabilities

**Stage 2** involved exploring perspectives of stakeholders in relation to the human rights framework. This included interviews and focus groups with:

- people living with dementia
- care partners
- care home workers
- lawyers and advocates.

Aged care regulatory officials did not respond to our invitation to participate.

Ethics approval was granted for the interviews and focus groups.

Following extensive recruitment efforts, our final sample of participants consisted of n=5 people living with dementia, n=19 care partners of people living with dementia, n=12 care home professionals, and n=9 lawyers and advocates. Overall, this was consistent with our targets, with the exception of the low numbers of people with dementia who took part.

## Interview & Focus Group Participants



## Findings

At Stage 1 of our project, we found that the CRPD can provide the basis for problematising confinement and segregation in RACFs as a violation of human rights of people living with dementia. The specific rights we identified are rights to:

- non-discrimination (Article 5);
- liberty and security of the person (Article 14);
- equality before the law (Article 12);
- accessibility (Article 9); and
- independent living and community inclusion (Article 19).

In developing the human rights framework, we found human rights are useful in highlighting what is currently harmful and unjust with current practice. In addition they also provide principles to guide transformation of the aged care system and our communities. This is critical to bring about meaningful alternatives and appropriate supports to make choices from a range of alternative residency and support options, end institutional-style aged care, and build communities that are free from ableism, ageism and other systems of oppression that contribute to confinement and segregation.

These results can be read in full in our academic publication 'Questioning Segregation of people with dementia: An International Human Rights Approach to Care Homes' available at: [www.mdpi.com/2075-471X/8/3/18/htm](http://www.mdpi.com/2075-471X/8/3/18/htm)

In Stage 2 we found support for human rights of people living with dementia in our key stakeholder groups but also identified a number of barriers that impede the practical and everyday realisation of these rights.

Contrary to our initial understanding of confinement and segregation as primarily driven by environmental design of RACFs we learnt that beyond locked doors and restrictive practices there are micro-level interrelated and compounding factors that contribute to human rights abuses of people living with dementia. These are related to limits on freedom of movement and community access that are, at times irrespective of the use of restrictive practices. They include:

- immobilisation and neglect of residents;
- limited and segregated recreational activities;
- concerns about duty of care and liability;
- apprehension of community exclusion;
- pathologisation of the responses of people with dementia to their circumstances; and
- subversion of the understandable resistance of people with dementia to the interventions, interactions and actions thrust upon them.

Overall, we also found that, across all participant groups, there was support at a general level for human rights for people living with dementia. Despite this, the overwhelming majority of participants identified barriers to realising human rights on a *practical* and *everyday* level. These barriers include:

- a lack of cohesive and supportive communities;
- the marketisation of aged care;
- perceived conflicts with safety and duty of care;
- the stigmatisation of people living with dementia, incapacity and epistemic negation;
- nihilism; and
- invisibility and dehumanisation.

Through these findings, we concluded that law and policy directed towards recognising human rights in RACFs must go beyond challenging environmental design and use of restrictive practices.

Critically, an effective response must also include issues relating to community access, social and recreational inclusion within and external to care homes, and physical mobility. On a related note, a human rights framework for addressing confinement and segregation should also embrace rights to participation in cultural life, recreation, leisure and sport (Art 30) and to habilitation and rehabilitation (Art 26).

In order to realise this broadened human rights framework, more attention must be given to changing cultural, economic and social drivers of ambivalence and resistance towards dementia and human rights within aged care and the broader community.

Engagement with human rights for people living with dementia must begin from the premise that people living with dementia are full humans, equal to everyone else. This is necessary in order to prevent the logics and ideas about dementia (which might be buried in seemingly apolitical and medical ideas about dementia) being transplanted into the way human rights are interpreted and applied on the ground. To this end, work needs to be done to improve aged care sector and community views about dementia and support the development of communities that are inclusive and supportive to people living with dementia.

Attention should be paid to the political economy of the aged care system and challenge the ways in which regulatory frameworks, funding and contractual arrangements prevent the realisation of human rights. It is vital to foreground the voices and experiences of people living with dementia in human rights scholarship and advocacy and support, and to amplify the work of consumer-led organisations such as Dementia Alliance International, and challenge the pathologization and subversion of their acts of resistance into further bases for confinement.



## Summit on Human Rights & People Living with Dementia

To help promote these findings community discourse around these critical issues, the project supported a Summit on Human Rights for people with dementia living in residential aged care. People living with dementia, care partners, advocates, lawyers, academics and other interested community members gathered at University of Technology Sydney on Friday 22 November 2019.

The summit provided an opportunity for knowledge translation in a number of key respects:

- to share our preliminary findings;
- to provide a forum to share other existing work on human rights; and
- to grow an Australian-based network to drive advocacy and change in this area.

The event was 'live scribed' by Devon Bunce of 'Digital Storytellers': [devon@digitalstorytellers.com.au](mailto:devon@digitalstorytellers.com.au).

The graphic recordings which capture key ideas and learnings from the Summit are contained below throughout our account of the summit.

The summit began with Linda Steele introducing the aims and preliminary findings of the 'Safe and Just Futures' project, pertaining to a human rights approach to segregation and confinement in residential aged care facilities.

Richard Fleming introduced some of the key developments relating to environmental design of residential aged care facilities.

Bobby Redman, Dennis Frost, Eileen Taylor, and Kate Swaffer offered insights from their personal experiences living with dementia. They expressed their deep concerns about going into aged care including losing their autonomy, dignity and freedom.

They called for the recognition of human rights of all people living with dementia including rights to equality, rehabilitation, and independent living. In their presentations care partners Lynda Henderson and Dubhglas Taylor supported these calls.



## Summit continued...

Yumi Lee (Older Women's Network NSW), Pauline Cramer (Val's LGBTI Ageing and Aged Care, La Trobe University) and Kate Kennedy (Senior Rights Service) emphasised the importance of taking an intersectional approach to understanding the identities, life histories, experiences and needs of people living with dementia.

Diana O'Neil (Flinders University) discussed the experiences and circumstances of diverse populations of people living with dementia including LGBT, public housing residents, care leavers, and older women (notably those who are homeless, in poverty or experiencing domestic violence), including circumstances of inequality, discrimination and violence they might experience across their life courses that then shape their journeys into aged care.

Hamish Robertson (University of Technology Sydney) offered some theoretical reflections on the social views about dementia, ageing and disability that contribute to the devaluing of people living with dementia and inform policies and practices that expose them to greater risk of harm and death.



Bethany Brown presented via Skype from New York on the recent Human Rights Watch report on chemical restraint in Australian nursing homes and the need for the Australian government to shift from regulating to prohibiting this practice. In a similar vein, Laura Grenfell (Law, University of Adelaide) argued that some harmful practices in residential aged care facilities might breach international human rights law relating to torture.

Lawyers Karen Williams (ADA), Sonia Di Mezza (ADACAS), Linda Rogers (private practitioner) and Rodney Lewis (private practitioner) discussed the possibilities for and barriers to realising legal rights for people living with dementia.

Leonie Sheedy and Stewart Quinn from Care Leavers Australasia Network spoke about the trauma care leavers (i.e. people who were in child welfare institutions, such as orphanages) have from their childhood and their fears of being institutionalised in aged care facilities – noting that many would choose suicide over aged care.



Kirsty Carr (Dementia Australia) suggested the current focus on aged care through the Royal Commission provides exciting opportunities for transformation of the aged care sector. Ingrid Fairlie (consultant working with UTS Faculty of Health) discussed the ways in which the new Aged Care standards are informed by human rights values of dignity and autonomy. Richard Fleming (University of Wollongong), Phillippa Carnemolla (University of Technology Sydney), and Claire Loughnan (University of Melbourne) offered academic reflections on the extent that we can achieve respect for dignity in aged care facilities through a facility's built environment and care practices.



## Resources & Other Outputs

Participants at the summit were invited to contribute to an anthology on human rights of people living with dementia.

The aim of the anthology is to showcase diverse perspectives in support of human rights of people living with dementia in order to communicate to law and policy makers and the wider community the growing support for recognising human rights of people living with dementia.

The team is currently developing submissions to the Royal Commission into Aged Care Quality and Safety and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

These submissions will also include the anthology to show the views of the research team form part of a broader Australian conversation about the importance of human rights for people living with dementia.

Stage 1 of the project is reported in an open access law journal:

Linda Steele, Kate Swaffer, Lyn Phillipson and Richard Fleming, 'Questioning Segregation of People Living with Dementia in Australia: An International Human Rights Approach to Care Homes.' *Laws* 2019, 8(3), 18  
doi.org/10.3390/laws8030018

<https://www.mdpi.com/2075-471X/8/3/18/htm>

Two articles on Stage 2 of the project are currently under development.

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- Lynda Henderson
- Elaine Pearson (Human Rights Watch)
- Bobby Redman
- Dubhglas Taylor
- Eileen Taylor
- Karen Williams (ADA).

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## Project Contact

Linda Steele

[linda.steele@uts.edu.au](mailto:linda.steele@uts.edu.au)