

### Issue 8: Human rights and confinement in residential care.

Welcome to Evidence at a Glance No 8.

In 2006 the United Nations Convention on the Rights of Persons with Disabilities<sup>1</sup> was signed by 165 countries. The purpose of the Convention *is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.*

People with dementia can face discrimination and treatment contravening their human rights for a variety of reasons including ageism, the stigma and discrimination associated with dementia, and the lack of capacity to challenge and report incidents that do occur.

This issue focuses on the findings from the Australian research *Human rights and the confinement of people living with dementia in care homes.*<sup>2</sup>

#### Methods

The research aimed to *deepen understanding of the drivers and facilitators of confinement in residential care with ultimate aim of enhancing the human rights of people living with dementia* (p.10).<sup>2</sup>

Methods of data collection included interviews and focus groups with 5 people living with dementia; 19 care partners; 12 care home professionals; and 9 lawyers and advocates. Individual interviews were by Zoom or phone call, the 2 focus groups were in-person.

Questions focused on access to the community, the full range of activities and social spaces usually found in aged care facilities, and what the participants knew about the ability to move around the homes.

The interview transcripts were analysed thematically.



<sup>1</sup> Retrieved from <http://www.un-documents.net/a61r106.htm>

<sup>2</sup>Steele, L., Carr, R., Swaffer, K., Phillipson, L., & Fleming, R. (2020). *Human rights and the confinement of people living with dementia in care homes*. Wollongong, Australia; Faculty of Business and Law – Papers, University of Wollongong.9. Retrieved from <https://ro.uow.edu.au/balpapers/9>

## Key Findings

Many care partners and health professionals were aware that people with dementia had limited or no access to community activities or spaces. But they did not perceive these limitations as confinement or restrictions on personal freedoms. The authors suggest *that those involved in the day-to-day support and advocacy of people living with dementia are largely oblivious to significant human rights violations* (p.12).<sup>2</sup>

Features that contribute to restricted freedom of movement including community access in residential settings were:

### *Locks and other material restraints of movement.*

- Restraints included locked doors, tray tables, and chemical restraint.
- Participants did identify restraints but usually only after they were asked about them. Visitor access was also controlled by locked doors.

### *Immobilization and neglect*

- The most common restriction was removal of means of mobility such as walking frames.
- People could also be deprived of the opportunity of physical exercise or other meaningful activity. They could also be put into common rooms or in their own room and left without the means of being able to move around.

### *Limited and segregated activities*

- Some respondents did speak positively about opportunities for family and friends to visit the home and nearby facilities such as cafes.
- Others noted that excursions were limited to pre-determined activities and destinations such as bus trips. One professional said that *bus trips go out, but the residents don't get off the bus* (p.13).<sup>2</sup>
- People with dementia did not always have access to the full range of community activities available to other residents, or to all areas of the residential facility.

### *Duty of care, risk, and liability*

- Respondents noted that staff were often quick to classify residents as at risk.
- Lawyers, advocates, and some care partners felt there was a narrow and arbitrary interpretation of duty of care. The focus was on physical safety, with little concern about emotional well-being and the duty to protect rights, freedoms and personhood.
- It was suggested that fear of litigation led to risk-adverse decisions. One lawyer described this as: *to really make sure that people are safe and not in danger, you completely remove risk, but when you do that you remove people's rights and the quality of their lives.*
- Health professionals noted that family members often placed a focus on physical safety rather than emotional wellbeing. They saw a need for community education to ensure that family saw the rights of the person with dementia as more than physical safety.

### *Pathologization and subversion of resistance*

- Some participants assumed people living with dementia lacked the capacity to know and express their views and needs. These assumptions supported care home decisions to limit freedom of movement and personal choice.
- Behaviours that are routine for a person can be seen by the home as attempts to escape or abscond.
- Behaviours that could be viewed as expressing distress or resisting limitations were pathologized as being challenging or a symptom of dementia. One care partner described this as *if you react with no, it's BPSD (behavioural and psychological symptoms of dementia), give you a shot, sit you in a chair with a lap belt, whatever.*(p16)<sup>2</sup>

### **Conclusion**

This Australian research concludes that aged care is risk adverse and dominated by procedures. *It is a sector that sustains a culture committed to minimizing risk, which is viewed through a narrow lens, at the expense of residents with dementia enjoying equality, autonomy, dignity, freedom, and other aspects integral to their physical and mental well-being* (p16). <sup>2</sup>

Concerns around the human rights of people with dementia are also raised in New Zealand reports. *This is not my home: A collection of perspectives on the provision of aged residential care without consent*<sup>3</sup> discusses issues with the legal and human rights protections for an estimated 5,000 New Zealanders living in secure residential dementia and psychogeriatric facilities.

### **Questions to discuss.**

How would you feel being confined to a building or a room?

Do you see any of the restrictive practices mentioned in this article in peoples' homes or community settings such as day programs?

- If so how can we safely enable, rather than disable, freedom of movement?
- How do we support rights, freedoms and personhood?
- How can we support emotional as well as physical wellbeing?

<sup>3</sup>Fisher, M., & Anderson-Bidois, J. (Eds). (2018). *This is not my home. A collection of perspectives on the provision of aged residential care without consent*. Auckland, New Zealand: Human Rights Commission.