

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

7th April 2016

Dear Sir/Madam

Submission: Inquiry into the 'Indefinite detention of people with cognitive and psychiatric impairment in Australia'

Focus of Submission

This submission focuses on indefinite detention as it pertains to individuals with dementia in aged care facilities. We request that the Committee consider the specific circumstances of people with dementia and the physical strategies through which they are subjected to indefinite detention. In particular we recommend:

- include in review situations of detention of people with dementia
- better built environment
- training of staff
- clear articulation of legal rights of people with dementia and legal procedures for their detention
- consult with people with dementia, including those currently in aged care facilities and subjected to restraint??

Relevant terms of reference

- (a) the prevalence of imprisonment and indefinite detention of individuals with cognitive and psychiatric impairment within Australia;
- (c) the differing needs of individuals with various types of cognitive and psychiatric impairments such as foetal alcohol syndrome, intellectual disability or acquired brain injury and mental health disorders;
- (e) compliance with Australia's human rights obligations;
- (f) the capacity of various Commonwealth, state and territory systems, including assessment and early intervention, appropriate accommodation, treatment evaluation, training and personnel and specialist support and programs;

Dementia

Dementia is a disorder characterized by problems with memory and at least one other cognitive function (learning, reasoning, language, spatial ability and orientation, and handling complex tasks) that are severe enough to interfere with activities of daily living. Cognitive impairment is central to the diagnosis of dementia and to the lived experience of people with dementia.

- There are more than 353,800 Australians living with dementia [1]
- This number is expected to increase to 400,000 in less than five years [1]
- Without a medical breakthrough, the number of people with dementia is expected to be almost 900,000 by 2050 [1]

Dementia, residential aged care and indefinite detention of people with cognitive impairment.

More than 50% of residents in Australian Government-subsidised aged care facilities have dementia (85,227 out of 164,116 permanent residents with an ACFI assessment at 30 June, 2011) [1] and almost half (44%) of permanent residents with dementia also had a diagnosis of a mental illness[2].

The confusion which accompanies dementia determines the need for a variety of safety features to be built into the environment. Among other things, they often include the provision of a secure perimeter [3] and/or the establishment of locked dementia specific units which effectively confine the residents to one area.

It is therefore recommended that this Senate Inquiry includes the number of people with dementia in these units when they consider the prevalence of indefinite detention of individuals with cognitive and psychiatric impairment within Australia.

It is important to understand that residents may respond negatively to a safety or security measure if it obviously impedes their freedom [4, 5]. The presence of dementia does not result in a lack of awareness of detention until the final stages of the disease. As a result many residents feel imprisoned and attempt to escape because the environment and care practices do not meet their need to feel free.

Australia ratified the United Nations *Convention on the Rights of Persons with Disabilities* (UNCRPD) on 17 July 2008 and the treaty entered into force, internationally, on 16 August 2008. Australia has since ratified the Optional Protocol, meaning that enforcement measures with respect to the Convention apply in Australia. The Convention is applicable to the care of persons with dementia as dementia falls within the definition of a 'disability'. Article 14 of the Convention requires that people with disabilities are:

“... not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.”

The President of the Guardianship and Administration Board of Tasmania has observed

“Residential Aged Care Facilities continue to systematically detain people with dementia without clear authority to do so and in circumstances where the establishment of a requirement to do so under their duty of care might be questionable, or in other words, in circumstances where the defence of necessity to a charge or claim of unlawful detention might not exist or, at best, be limited. It seems that most facilities are prepared to ‘risk it’ that no-one will bring criminal or civil proceedings in relation to unlawful detention.” [6]

This observation is consistent with the views of the signatories to this submission. However, depending on the absence of will to bring criminal or civil proceedings may be becoming foolhardy as the voice of people with dementia is making itself heard. The welcome rise of organisations such as Dementia Alliance International (<http://www.dementiaallianceinternational.org/>) and the contributions made to the conduct of research and the development of policy by the Alzheimer’s Australia Consumer Dementia Research Network, and the work of the Alzheimer’s Australia Dementia Advisory Committee, a group exclusive to people with dementia, clearly show that it is time to take seriously the needs and wishes of people with dementia to have their freedom and their inherent dignity. It is time to accept the responsibility of striving to meet their needs in a humane, moral and ethical manner. The Convention may provide support to those who wish to bring this about through the courts, as suggested by the President of the Guardianship and Administration Board of Tasmania.

“Until now, Australian Aged Care facilities have relied upon the possible but uncertain common law defence of necessity. The application of that defence may now be watered down by the effects of ratifying the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)”.[6]

The capacity of the aged care system to meet the need (and right) of people with dementia for their freedom is limited by prevailing negative attitudes towards people with dementia, a fear of what might happen if people with dementia ‘get out’, a misunderstanding of duty of care which emphasises the provision of high security rather than genuine safety and a hyper-sensitivity to the possibility of litigation should anything happen to someone who has ‘escaped’. It is also limited by the nature of the buildings themselves. They have, by and large, been designed with security in mind. Not understanding that obvious security produces agitation and aggression in some and apathy and depression in others, nor understanding that a safe and secure environment, when and if needed, can be provided by ensuring that the safety features are unobtrusive [7-9].

It is suggested that the capacity of the aged care system to provide appropriate care to people with dementia could be increased by the delivery of education to managers and staff on human rights and the care of people with dementia and by increasing the emphasis placed by the Department of Health on the provision of suitably designed environments to accommodate those people with dementia who have a real need for secure accommodation. Both of these activities could be undertaken by the Department of Health funded Dementia Training Study Centres.

In summary it is the opinion of the signatories that it is time for the tens of thousands of people with dementia who are locked up in dementia units across Australia to enjoy a better balance between their rights to freedom of movement and from arbitrary detention on one hand and the need for detention perceived by many in the aged care industry on the other.

Yours sincerely

Professor Richard Fleming,
University of Wollongong.

Kate Swaffer,
Honorary Associate Fellow,
Faculty of Science, Medicine and Health,
University of Wollongong;
Chair, CEO and co-founder, Dementia
Alliance International.

Dr. Lyn Phillipson,
NHMRC-ARC Dementia Fellow,
Australian Health Services Research Institute,
University of Wollongong.

Dr. Linda Steele,
Lecturer,
School of Law,
University of Wollongong.

References

1. AIHW, *Dementia in Australia*, 2012, Australian Institute of Health and Welfare, Commonwealth of Australia: Canberra.
2. AIHW, *Residential aged care in Australia 2010–11: a statistical overview in Aged care statistics series 2012*, Australian Institute of Health and Welfare: Canberra.
3. Rosewarne, R., et al., *Care Needs of People with Dementia and Challenging Behaviour Living in Residential Facilities*, 1997, Commonwealth Dept. of Health and Family Services: Canberra.
4. Low, L.F., B. Draper, and H. Brodaty, *The relationship between self-destructive behaviour and nursing home environment*. *Aging & Mental Health*, 2004. **8**(1): p. 29-33.
5. Torrington, J., *What has architecture got to do with dementia care? Explorations of the relationship between quality of life and building design in two EQUAL projects*. *Quality in Ageing*, 2006. **7**(1): p. 34.
6. Smith, A. *Detention of People with Dementia in Secure Facilities in State Care in Tasmania*, . no date [31/3/2016]; Available from: http://www.guardianship.tas.gov.au/data/assets/pdf_file/0009/203967/Detention_of_people_with_dementia_in_secure_facilities.doc 31.7.12.pdf.
7. Zeisel, J., et al., *Environmental correlates to behavioral health outcomes in Alzheimer's special care units*. *The Gerontologist*, 2003. **43**(5): p. 697.
8. Annerstedt, L., *Group-living care: An alternative for the demented elderly*. *Dementia and Geriatric Cognitive Disorders*, 1997. **8**(2): p. 136-142.
9. Fleming, R., et al., *The relationship between the quality of the built environment and the quality of life of people with dementia in residential care*. *Dementia*, 2014