

# Office of the Public Advocate

Submission in  
response to the  
*Future reform – an  
integrated care at  
home program to  
support older  
Australians*  
Discussion paper

August 2017

## Background

The Public Advocate was established by the *Guardianship and Administration Act 2000* (Qld) to undertake systemic advocacy on behalf of adults with impaired decision-making capacity in Queensland. The primary role of the Public Advocate is to promote and protect the rights, autonomy and participation of Queensland adults with impaired decision-making capacity in all aspects of community life.

More specifically, the Public Advocate has the following functions:

- promoting and protecting the rights of adults with impaired capacity for a matter;
- promoting the protection of the adults from neglect, exploitation or abuse;
- encouraging the development of programs to help the adults reach the greatest practicable degree of autonomy;
- promoting the provision of services and facilities for the adults; and
- monitoring and reviewing the delivery of services and facilities to the adults.<sup>1</sup>

## My interest in this issue

One of Australia's most significant social and demographic trends is its ageing population, described by the House of Representatives Standing Committee on Legal and Constitutional Affairs as "an inescapable demographic destiny".<sup>2</sup> While an ageing population is increasingly being interpreted positively,<sup>3</sup> growing numbers of older people will also increase the prevalence of age-related conditions such as dementia that may impact upon decision-making capacity and increase a person's vulnerability to elder abuse. The National President of Alzheimer's Australia commented that "dementia is without question the single biggest health issue facing Australia in the 21<sup>st</sup> century".<sup>4</sup> The number of people with dementia in Australia is expected to increase substantially from around 413,106 in 2017 to 1,100,890 by 2056.<sup>5</sup> Many people in this group will eventually experience the behavioural and psychological symptoms and challenging behaviours associated with dementia. This trend underpins my important work in advocating for this group.

I have a strong interest in the issue of care at home for older Australians. In my role as Public Advocate, I have observed the growing practice in Australian society of moving older people against their will from their homes and into residential aged care. This enforced relocation to institutional care often occurs at points in older people's lives when they are considered to be

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<sup>1</sup> *Guardianship and Administration Act 2000* (Qld) s 209.

<sup>2</sup> House of Representatives Standing Committee on Legal and Constitutional Affairs, The Parliament of the Commonwealth of Australia, *Older people and the law* (2007) vii.

<sup>3</sup> See, for example, European Centre for the Development of Vocational Training, *Working and Ageing: The Benefits of Investing in an Ageing Workforce* (2012, Office of the European Union) 1.

<sup>4</sup> Ita Buttrose, National President, Alzheimer's Australia as cited in Deloitte Access Economics, *Dementia Across Australia: 2011-2050* (9 September 2011) Alzheimer's Australia <<https://fightdementia.org.au/research-and-publications/reports-and-publications/access-economics-reports>> 7.

<sup>5</sup> Alzheimer's Australia, *Economic Cost of Dementia in Australia 2016-2056* (February 2017) 6.

failing in health and/or experiencing impaired decision-making capacity. These decisions are often made by family members and supported by medical professionals. I am aware of the many guardianship applications made by family members of older people or staff in Queensland Health to the Queensland Civil and Administrative Tribunal (QCAT) for the purpose of making the decision to move the person who is the subject of the application from hospital into residential aged care.

These decisions are often made on behalf of the older person without giving serious consideration to the possibility of the person remaining in their own home with appropriate support and services, even when the older person has indicated that is their preference. While family members may have genuine concerns for the health and safety of their aged relatives, some applications also appear to be driven by convenience, with family members wanting “things sorted out” so that they can be relieved of the responsibility and worry of their older relatives’ day-to-day care.

I have personally observed a case where a clearly competent elderly man, who was in hospital after experiencing a fall in his home, was reported by doctors to “lack insight” because he wanted to return to his home with support and did not want to discuss moving to residential aged care. This “lack of insight” was interpreted by the doctors as an early sign of dementia and indicative of a loss of decision-making capacity, and formed the basis of the guardianship application. Ultimately, QCAT did not make a guardianship order, but that outcome may not have been achieved without strong advocacy and representation from an advocacy and legal service.

In that particular case, neither the social workers at the hospital nor the man’s family were prepared to explore how he might be able to live in his home with support, even though this was the outcome he clearly wanted. This approach to the “care” of older people is often dictated by what is considered convenient for family and health services and involves the perceived lowest risk for the older person. It fails to recognise the rights of older people to make decisions with which others may not agree<sup>6</sup> and the rights of all people, especially older people, to self-determination and the dignity of risk.

My office is not certain of the policy basis for Queensland Health becoming involved in these matters, however I am concerned that its involvement may be driven by risk and/or cost management. The transfer of a patient into residential aged care shifts the person’s care and cost risks from Queensland Health to a residential aged care provider whereas allowing the person to return home does not. Further, if the older person has medical issues while living in residential aged care, they can receive treatment in the place they reside, reducing the likelihood of the person returning to hospital and the subsequent cost to the state health system. While these considerations are legitimate, they should not take precedence over the rights of older people to autonomy and, to the greatest extent possible, to make decisions for themselves. While there is a need to make timely and appropriate decisions about the care and accommodation of elderly patients, the law must, in the first instance, assume capacity and should respect the rights of older people to make their own decisions in respect of their

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<sup>6</sup> *Guardianship and Administration Act 2000* (Qld) s 5(b).

aged care and where they live, or be supported to make or participate in those decisions to the greatest extent possible.

Decisions about the living arrangements for older people that are made without taking the older persons' views and wishes into account and seeking to implement their desires breach their human rights. They also have significant cost impacts for the aged care system.

This submission should be considered within the context of these concerns.

## The future care at home program

I support the policy objectives for the program outlined in the Discussion paper, and in particular, the objectives of providing the greatest possible choice and control for consumers and encouraging independence and wellness as standard practice that is integrated into assessment practices and service delivery.

### A key policy to be considered in the future care at home program

If the program is to truly give consumers choice and control and encourage independence as standard practice in assessment practices, it is important that it is implemented in a way that ensures the views and wishes of the consumer are taken into account, irrespective of whether they have a capacity impairment. If the person indicates that they want to be supported to remain in their own home and there are services available that can achieve that outcome, that is what should be provided to the person.

In the final report for its inquiry into elder abuse in June 2017, the Australian Law Reform Commission (ALRC) recommended that:

The Australian Government should further consider Recommendation 6-2 of the ALRC Report No 124 *Equality, Capacity and Disability in Commonwealth Laws*, that aged care laws and legal frameworks should be amended consistently with the National Decision-Making Principles set out in that Report.<sup>7</sup>

In the Report *Equality, Capacity and Disability in Commonwealth Laws*, the ALRC recommended a set of four National Decision-Making Principles and accompanying guidelines to guide the reform of Commonwealth laws and review of State and Territory laws:

3.4 The emphasis is on the autonomy and independence of persons with disability who may require support in making decisions—their will and preferences must drive decisions that they are supported in making, and that others may make on their behalf. The National Decision-Making Principles provide a conceptual overlay, consistent with the CRPD, for a Commonwealth decision-making model that encourages supported decision-making.<sup>8</sup>

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<sup>7</sup> Australian Law Reform Commission, *Elder Abuse-A National Legal Response Final Report*, Report No 131 (2017) 147.

<sup>8</sup> Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Report No 124 (2014) 64.

The National Decision-Making Principles are that:

- Everyone has an equal rights to make decisions and to have their decisions respected;
- Persons who need support should be given access to the support they need in decision-making;
- A person's will and preferences must direct decisions that affect their lives; and
- There must be appropriate and effective safeguards in relation to interventions for persons who may require decision-making support.<sup>9</sup>

The ALRC's recommendations reflect increasing national and international recognition for people with impaired decision-making capacity to be treated equally under the law and exercise their right to make decisions for themselves. For the most part, this paradigm shift originates from the *Convention on the Rights of Persons with Disabilities*.<sup>10</sup>

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The ALRC's National Decision-Making Principles should be incorporated into the policy objectives of the care at home program.

Aged care assessment practices should require the determination and recording of the consumer's views and wishes, in terms of their preferred mode of care – in home or in residential aged care – and to the greatest extent possible offer a care package that supports the person's preferences.

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## Reform options

The comments in this section of the submission respond to the following sections of the discussion paper and associated questions:

- **Better meeting of consumer demand (4.3)** - Would you support the introduction of a new higher package level or other changes to the current package levels?
- **Using resources more effectively (4.6)** - How do we ensure that funding is being used effectively to maximise a person's ability to live in the community and to delay entry to residential aged care for as long as possible?

I broadly support the introduction of a new higher home care package level, on the basis that this would potentially support more older people to age with support in their own homes (if that was their preference), rather than them being transferred into residential aged care.

The discussion paper advises that the federal government manages the supply of home care packages by determining how many packages are released at each level to meet the overall target provision ratio for home care within the available expenditure. The paper examines changing the mix of home care packages available within the existing aged care budget in order to fund the higher package levels.

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<sup>9</sup> Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Report No 124 (2014) 64.

<sup>10</sup> United Nations, *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007 [2008] ATS 12 (entered into force 3 May 2008).

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In light of the potential number of older Australians being channelled into expensive residential aged care options (often against their will), consideration should be given to whether some of the funding for residential aged care could be transferred to the home care program funding to support higher level packages.

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In the absence of any higher package levels, those consumers would most likely have been accommodated in residential aged care. Presumably there is a significantly higher cost for residential aged care than the higher package levels, so there is also an argument that these packages should be fully reimbursed to the home care program from the residential aged care funding envelope.

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Consideration should be given to placing Aged Care Assessment Team (ACAT) assessors within state and territory hospitals, or at least having a formal point of contact to ensure they are involved in the assessment of the consumer for the appropriate care package and take account of the consumers' views and wishes, at the earliest possible time.

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The federal government should ensure that ACAT assessors are trained in the rights of aged care consumers, the National Decision-Making Principles and the Australian government's obligations to respect older people's rights to autonomy and to live the most independent lives that they can.

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## Concluding comment

Thank you for the opportunity to provide feedback on the *Future reform – an integrated care at home program to support older Australians* Discussion Paper. I welcome reforms that will provide greater opportunity for older Australians to be appropriately supported in their own homes.

I trust that the future care at home program will respect the right of older Australians, regardless of any impairment that they may have, to make decisions affecting their life to the fullest extent of their capacity.

Should the opportunity arise, I would be pleased to be part of further discussions in relation to these matters or any other issues raised in my submission.

Yours sincerely



Mary Burgess  
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