Aged Care Quality and Safety in Australia

Submission to the Royal Commission on Aged Care Quality and Safety

April 2019

The Public Advocate

Influencing change to empower lives

Contents

Introduction

The position of Public Advocate is established under the *Guardianship and Administration Act 2000* (Qld). 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 (the adults) 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.[1]

Many users of aged care services have, or will develop, impaired decision-making capacity as a result of a range of circumstances and conditions, not the least of which is dementia. It is estimated that in 2018, there were 436,366 Australians living with dementia. Without new medical discoveries and interventions, this number is expected to increase to 589,807 in 2028 and almost 1.1 million by 2058.[2]

In 2015, more than half of people who permanently resided in residential aged care had a diagnosis of dementia.[3] This proportion is expected to increase over time as the number of people living with dementia increases as a proportion of the population.[4] In light of this, it is likely that a significant proportion of aged care recipients will experience impaired decision-making capacity at some point during their engagement with the aged care system.

The Public Advocate welcomes the opportunity to make a submission to the Royal Commission into Aged Care Quality and Safety.

As the Royal Commission commences its work, it is important that we acknowledge that old age is the future for us all. We are all ageing, and many Australians will experience impaired decision-making capacity due to age-related conditions. The issues the Royal Commission is investigating about the quality of aged care, will eventually, and for some of us sooner rather than later, be very relevant in our own lives. Ultimately, it is in all of our interests that these sensitive issues are explored with compassion and respect, to ensure that the Australian aged care system delivers the best possible health and quality-of-care outcomes, and protects the rights and interests of some of the most vulnerable people in our community.

The use of restrictive practices in residential aged care

The Royal Commission has received evidence about the use of restrictive practices in residential aged care facilities from a number of perspectives. Evidence to date has focussed primarily on the experience of aged care residents who have been subjected to restraint or other restrictive practices (particularly chemical restraint in the form of anti-psychotic medications used as a form of sedative to manage the challenging behaviours of residents) and the consequent impact these treatments have had on those residents and their families and supporters.

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[1] *Guardianship and Administration Act 2000* (Qld) s 209.
[2] Dementia Australia, *Dementia Prevalence Data 2018-2058*, cited in *Dementia Australia, Key Facts and Statistics* (November 2018), Dementia Australia https://www.dementia.org.au/statistics>. Accessed online April 2019.
[3] Australian Institute of Health and Welfare, *Australia's Health 2016*, Commonwealth Government, 109 <https://www.aihw.gov.au/getmedia/9844cefb-7745-4dd8-9ee2-f4d1c3d6a727/19787-AH16.pdf.aspx?inline=true>. Accessed online January 2019.
[4] Ibid 108.

The Commission has heard evidence from:

- Medical professionals including Associate Professor Strivens, a geriatrician and President of the Australia and New Zealand Society for Geriatric Medicine, and Dr Bartone, the President of the Australian Medical Association;
- Ms Glenys Beauchamp PSM, Secretary of the Commonwealth Department of Health;
- Ms Maree Mcabe, the CEO of Dementia Australia, a peak advocacy body for people living with dementia, their families and carers; and
- Mr Mersiades, the CEO of Catholic Health Australia and Mr Rooney, the CEO of Leading Age Services Australia.

While the evidence of these witnesses has explored issues related to policy and clinical practice for restraint use in residential aged care facilities, the Commission has not, to date, heard any evidence addressing the law relating to the use of restrictive practices and the various legal and human rights issues associated with their use.

The use of restrictive practices to manage the challenging behaviours of people in the aged and disability sectors has become a key human rights issue in Australia.[5] Detention, seclusion, restricted access to objects, physical, chemical and mechanical restraint (as well as electronic forms of restraint such as tracking bracelets, camera surveillance, or restrictions on electronic devices)[6] are all types of restrictive practice currently employed across the aged care sector.

Restrictive practices are used in these settings despite studies indicating that their use may result in negative physical and psychological effects on the person being restrained[7] and may also constitute a breach of law and human rights.[8]

While some jurisdictions in Australia regulate the use of restrictive practices in the disability and/or mental health sectors,[9] the law governing these practices in residential aged care is unclear and, for the most part, non-existent.[10] At present, the *Aged Care Act 1997* (Cth) does not formally regulate the use of restrictive practices in residential aged care facilities.

This is concerning for a number of reasons. As noted, the number of people living with dementia is expected to increase substantially, and many people with dementia will eventually experience the behavioural and psychological symptoms (such as challenging behaviours) associated with the condition. There is a growing body of research indicating that dementia-related behaviours are

[5] Australian Law Reform Commission, Equality, Capacity and Disability in Commonwealth Laws, Report No 124 (2014) 243.
[6] Alistair R. Niemeijer et al, 'Ethical and practical concerns of surveillance technologies in residential care for people with dementia or intellectual disabilities: An overview of the literature' (2010) 22(7) *International Psychogeriatrics* 1129, 1136.
[7] Sarah Mott, Julia Poole and Marita Kenrick, 'Physical and chemical restraints in acute care: Their potential impact on the rehabilitation of older people' (2005) 11 *International Journal of Nursing Practice* 95, 96; Jenny Gowan and Louis Roller, 'Chemical restraint or pharmacological treatment for abnormal behaviours' (2012) 93 *The Australian Journal of Pharmacy* 58, 60; Jeffrey Chan, Janice LeBel and Lynne Webber, 'The dollars and sense of restraints and seclusion' (2012) 20(1) *Journal of Law and Medicine* 73, 74.
[8] Donal Griffith, 'Substituted decision making: Part 1 When are restraints off the rails?' (2014) 17(2) *Retirement & Estate Planning Bulletin* 1, 1; *Universal Declaration of Human Rights,* GA Res 217A (III), UN GAOR, 3rd sess, 183rd mtg, UN Doc A/810 (10 December 1948); Juan E. Mendez, 'Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment' (A/HRC/22/53, 1 February 2013); The potential for human rights breaches in relation to the use of restrictive practices has been reinforced by the United Nations Committee on the Rights of Persons with Disabilities, which expressed concerns about the use of unregulated restrictive practices in its concluding observations on Australia's initial report under the *Convention on the Rights of Persons With Disabilities*. See Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of Australia* (adopted by the Committee at its tenth session 2-13 September 2013) 5.
[9] See, for example, *Disability Services Act 2006* (Qld) pt 6; *Mental Health Act 2016* (Qld) ch 8.
[10] Michael Williams, John Chesterman and Richard Laufer, 'Consent versus scrutiny: Restricting liberties in post-Bournewood Victoria' (2014) 21(3) *Journal of Law and Medicine* 641, 644; Judy Allen and Tamara Tulich, "I want to go home now': Restraint decisions for dementia patients in Western Australia' (2015) 33(2) *Law in Context* 1, 4.

often being managed by unregulated restrictive practices,[11] and that restrictive interventions are in widespread use in both formal and informal aged care settings.[12]

Evidence also suggests that some residential aged care staff do not have the knowledge and/or skills to manage behaviours appropriately,[13] and that the wellbeing of the person being restrained may be negatively affected as a result.[14] It is concerning that the inappropriate use of restraints in aged care facilities in Australia has been a factor in the deaths of some people upon whom the restraints were used.[15]

A study led by Professor Joseph Ibrahim from Monash University in Victoria in 2015 investigated the nature and extent of physical restraint deaths reported to coroners in Australia over a 13 year period (2000-2013)[16]. The study found that five deaths due to physical restraint were recorded in this period, with neck compression and entrapment being the mechanism of harm in all cases, resulting in asphyxia and mechanical asphyxia.

Further research undertaken by Professor Ibrahim and others in 2017 involved an epidemiological analysis of premature deaths of nursing home residents.[17] This study examined the causes of death among residents of accredited Australian nursing homes, whose deaths were reported to coroners between 1 July 2000 and 30 June 2013, and were determined to have resulted from external causes. This study found that the incidence of premature and potentially preventable deaths of nursing home residents has increased over the past decade, particularly deaths associated with falls and choking. Over the period of the study, there were 2,679 deaths associated with resident falls and a further 261 caused by choking. Given there is a direct correlation between the use of psychotropic drugs as a form of chemical restraint and fall risks[18] the increase in fall incidents leading to premature deaths in nursing homes over the last decade may be related to the use of unregulated chemical restraint in these facilities.

Research undertaken as far back as 2014 for Alzheimer's Australia indicated that around half of all people living in residential aged care, and up to 80 per cent of those with dementia were receiving psychotropic medications.[19] Analysis of Pharmaceutical Benefits Scheme prescription data in 2013 also suggested a high level of inappropriate prescribing of antipsychotics in older people, raising

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[11] Sally Borbasi et al, 'A Nurse Practitioner Model of Service Delivery in Caring for People with Dementia' (2010) 36(1-2) Contemporary Nurse: A Journal for the Australian Nursing Profession (Supplementary Advances in Contemporary Nursing: Workforce and Workplaces) 49-60; Tanya Davison et al, 'Non-Pharmacological Approaches to Managing Challenging Behaviours Associated with Dementia in Aged Care' (2010) 32(5) InPsych.

[12] See, for example, Janet Timmins, 'Compliance with best practice: implementing the best available evidence in the use of physical restraint in residential aged care' (2008) 6(3) *International Journal of Evidence-Based Healthcare* 345, 345; Cath Roper, Bernadette McSherry and Lisa Brophy, 'Defining seclusion and restraint: Legal and policy definitions versus consumer and carer perspectives' (2015) 23(2) *Journal of Law and Medicine* 297, 298; Sarah N. Hilmer and Danijela Gnjidic, 'Rethinking psychotropics in nursing homes' (2013) 198(2) *Medical Journal of Australia* 77, 77Office of the Public Advocate (SA), 'Annual Report 2012-2013' (2013) 46; Mary Courtney et al, 'Benchmarking clinical indicators of quality for Australian residential aged care facilities' (2010) 34(1) *Australian Health Review* 93, 98. Additionally, in a study of family carers of people with dementia, the use of psychotropic medications was the second most commonly used strategy for managing behavioural and psychological symptoms of dementia. See Kirsten Moore et al 'How do Family Carers Respond to Behavioural and Psychological Symptoms of Dementia?' (2013) 25(5) *International Psychogeriatrics* 743-753.

[13] See Sally Borbasi et al, above n 12.

[14] Nicholas G Castle, 'Mental Health Outcomes and Physical Restraint Use in Nursing Homes {Private}' (2006) 33(6) *Administration and Policy in Mental Health and Mental Health Services Research* 696-704; K Cubit et al, 'Behaviours of Concern in Dementia: A Survey of the Frequency and Impact of Behaviours of Concern in Dementia on Residential Aged Care Staff' (2007) 26(2*) Australasian Journal on Ageing* 64-70.

[15] See, for example, *Plover v McIndoe* (2000) 2 VR 385; Sarah Farnsworth, *Woman dies of heart attack while strapped to toilet* (17 August 2011) ABC News <http://www.abc.net.au/news/2011-08-17/seymour-health/2843252>. Accessed online April 2019.

[16] Ibrahim et al (2017), *Physical Restraint deaths in a 13-year national cohort of nursing home residents,* Age and Ageing 2017; 46:688-693 <www.https\\10.1093/ageing/afw246>. Accessed online January 2019.

[17] Ibrahim, Joseph et al, Premature deaths of nursing home residents: an epidemiological analysis, *Medical Journal of Australia* 206 (10), 5 June 2017, Australia.

[18] Westbury et al, RedUSe: reducing antipsychotic and benzodiazepine prescribing in residential aged care facilities, *Medical Journal of Australia* 208 (9), 21 May 2018, 398.

[19] Assoc Prof Carmelle Peisah and Dr Ellen Skladzien, *The use of restraints and psychotropic medications in people with dementia: A report for Alzheimer's* Australia, Paper 38, March 2014.

growing concern that antipsychotics and similar medicines were being overprescribed to people with dementia as a first response to managing behaviour.[20]
A series of newspaper articles in *The Australian*[21] over the past 2 years have also highlighted individual stories and reports about the use of psychotropic medications as chemical restraint in aged care facilities. One of these articles[22] referred to a study conducted by the University of Tasmania[23] that found nearly two in three aged care residents are given psychiatric medication every day, mostly inappropriately prescribed, which are linked to death or falls and seizures. The then President of the Royal Australian College of General Practitioners, Professor Bastien Seidel, was quoted in the article confirming that aged care homes could no longer be assumed to be safe places, and stating:

> *[M]edical sedation is a foul compromise for inadequate nursing care. People think they're in a safe place in residential care and everything (will) be fine, but the reality is what's being reflected in the research.*[24]

The increasing number of people with dementia and the potential harm (or worse) that may occur as a result of ad hoc or poorly applied restrictive practices[25] suggest an urgent need to clarify the legality of the use of restrictive practices in the Australian aged care system. Further, restrictive practices should be regulated to achieve a more consistent, evidence-and rights-based approach to responding to dementia-related behaviours.

The legislative framework

As noted above, while some jurisdictions in Australia regulate the use of restrictive practices in the disability and/or mental health sectors,[26] the law governing these practices in residential aged care is unclear and, for the most part, non-existent.[27] The *Aged Care Act 1997* (Cth) does not formally regulate the use of restrictive practices such as chemical, physical and mechanical restraint in residential aged care.

Under section 96-1, the Minister for Health can create user rights, principles and standards which are reflected in the *Quality of Care Principles 2014* (Cth). These principles outline standards that may be used to protect residents who are vulnerable to restrictive practices, for example, the requirements to manage challenging behaviours effectively; provide a safe living environment; or to respect residents' independence, dignity, choice, and decision-making.[28]

Section 65-1 of the Act further states that if an aged care provider breaches any of its responsibilities under the Act (including its responsibility to act consistently with the care

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[20] National Prescribing Service (2013), 'Antipsychotic overuse in dementia — is there a problem', *Health News and Evidence*.
[21] Magarey, Joel, 'Aged care homes' drug use slammed as 'elder abuse'', *The Australian*, August 14, 2018 < https://www.theaustralian.com.au/national-affairs/health/agedcare-homes-drug-use-slammed-as-elder-abuse/news-story/8101e54e5dc89a8bfcdecf5663be727a>. Dowling, Jason, *'My Dad was given drugs 'like potato chips'*: how the elderly are being restrained, The Age 18 February 2016 <https://www.theage.com.au/national/victoria/my-dad-was-given-drugs-like-potato-chips-how-the-elderly-are-being-restrained-20160218-gmxc3o.html>.
<https://www.theguardian.com/society/2018/apr/21/dementia-patients-dehumanised-hospital-restraint-techniques>. Accessed online December 2018.
[22] Magarey, Joel, 'Aged care homes' drug use slammed as 'elder abuse'', *The Australian*, August 14, 2018. < https://www.theaustralian.com.au/national-affairs/health/agedcare-homes-drug-use-slammed-as-elder-abuse/news-story/8101e54e5dc89a8bfcdecf5663be727a>. Accessed online December 2018.
[23] Westbury et al, 'RedUSe: reducing antipsychotic and benzodiazepine prescribing in residential aged care facilities, *Medical Journal of Australia* (MJA) 208 (9), 21 May 2018, p.398-403
[24] See footnote 22.
[25] For example, behaviour driven by undiagnosed pain may be misinterpreted as a behavioural or psychological symptom of dementia and subsequently 'treated' with inappropriate administration of psychotropic drugs which can lead to complications such as falls, fractures, impaired cognition, and increased risk of death. See Edwin Tan et al, 'Analgesic Use, Pain and Daytime Sedation in People With and Without Dementia in Aged Care Facilities: A Cross-Sectional, Multisite, Epidemiological Study Protocol' (2014) 4(6) *BMJ Open*.
[26] See, for example, *Disability Services Act 2006* (Qld) pt 6; *Mental Health Act 2016* (Qld) ch 8.
[27] Michael Williams, John Chesterman and Richard Laufer, 'Consent versus scrutiny: Restricting liberties in post-Bournewood Victoria' (2014) 21(3) *Journal of Law and Medicine* 641, 644; Judy Allen and Tamara Tulich, "I want to go home now': Restraint decisions for dementia patients in Western Australia' (2015) 33(2) *Law in Context* 1, 4.
[28] *Quality of Care Principles 2014* (Cth), sch 2 pt 2 items 2.13, 4.4, 3.5, 3.6 and 3.9.

principles)[29], the Secretary of the Department of Health may impose sanctions that include the removal of funding or license to operate.

In the case of *Saitta Pty Ltd v Secretary, Department of Health and Ageing*[30] the use of restrictive practices were found to be a breach of the care principles.

> ***Saitta Pty Ltd v Secretary, Department of Health and Ageing.*** *The Administrative Appeals Tribunal upheld the Department of Health and Ageing's imposition of severe sanctions that led to the closure of the Belvedere Park Nursing Home in Melbourne, following an assessment that residents' safety was at severe and immediate risk. The tribunal described an incident where an unattended resident had been restrained to a chair with a lap-belt an hour after it should have been removed. This was considered a breach of the principle for the right to dignity, for residents to be assisted to achieve maximum independence, and for management to actively work in providing a safe and comfortable environment consistent with the residents' needs. However, there was no further discussion of restrictive practices as the matter focussed on many other serious incidents that led to the finding of severe immediate risk, including poor infection control; poor sanitation; inadequate incontinence management etc.*

While these provisions are available to be used to enforce standards in residential aged care facilities, the need to pursue cases in courts or tribunals to establish breaches and define what is included in the care principles and what would amount to a breach, means that the legislation lacks clarity in relation to restrictive practices. This needs to be remedied.

Reports and reviews

Aged care inquiries and reviews that have explored the issue of restrictive practice use in residential aged care are numerous, with three reports released in the last three years alone that make recommendations for legislative change in this area.

In its June 2016 *Elder Abuse Issues* Paper, the Australian Law Reform Commission (ALRC) recognised that some restrictive practices can constitute elder abuse, deprive people of their basic legal and human rights and be classified as assault, false imprisonment and/or other civil or criminal acts.[31]

In May 2017, the ALRC published the final report for the Elder Abuse Inquiry – *Elder Abuse: A National Legal Response*. In that report, the Commission recommended that aged care legislation should regulate the use of restrictive practices in residential aged care:

> **Recommendation 4–10** Aged care legislation should regulate the use of restrictive practices in residential aged care. Any restrictive practice should be the least restrictive and used only:
>
> (a) as a last resort, after alternative strategies have been considered, to prevent serious physical harm;
> (b) to the extent necessary and proportionate to the risk of harm;
> (c) with the approval of a person authorised by statute to make this decision;
> (d) as prescribed by a person's behaviour support plan; and
> (e) when subject to regular review.
>
> **Recommendation 4–11** The Commonwealth Government should consider further safeguards in relation to the use of restrictive practices in residential aged care, including:

[29] *Aged Care Act 1997 (Cth)* s 56–1(m).
[30] *Saitta Pty Ltd v Secretary, Department of Health and Ageing* (2008) 105 ALD 55.
[31] Australian Law Reform Commission, *Elder Abuse Issues Paper* (IP 47) (June 2016) 238.

(a) establishing an independent Senior Practitioner for aged care, to provide expert leadership on and oversight of the use of restrictive practices;
(b) requiring aged care providers to record and report the use of restrictive practices in residential aged care; and
(c) consistently regulating the use of restrictive practices in aged care and the National Disability Insurance Scheme.[32]

The 2017 independent review of the national aged care quality regulatory processes, conducted by Ms Kate Carnell and Professor Ron Paterson[33] also recognised this gap in the legislation, making a recommendation to government to legislate to regulate the use of restrictive practices as follows;

7. Aged care standards will limit the use of restrictive practices in residential aged care
    i. Any restrictive practice should be the least restrictive and used only:
        a. as a last resort, after alternative strategies have been considered, to prevent serious physical harm;
        b. to the extent necessary and proportionate to the risk of harm;
        c. with the approval of a person authorised by statute to make this decision;
        d. as prescribed by a person's behaviour support plan; and
        e. when subject to regular review.
    ii. Approved providers must record and report the use of restrictive practices in residential aged care to the Aged Care Commission
    iii. Accreditation reviews will review the use of psychotropic agents
    iv. Chief Clinical Advisor must approve the use of antipsychotic medications for aged care residents.[34]

More recently (October 2018), the Standing Committee on Health, Aged Care and Sport released its *Report on the inquiry into the Quality of Care in Residential Aged Care Facilities in Australia*.[35] That report also recommended the Australian Government amend the *Aged Care Act 1997* to legislate for the use of restrictive practices in residential aged care facilities.

International comparisons

On 15 June 2017, World Elder Abuse Awareness Day, my office released the paper *Legal frameworks for the use of restrictive practices in residential aged care: An analysis of Australian and international jurisdictions*.[36] The paper explored the existing laws, policies and practices in Australia and other international jurisdictions. The paper found that, unlike Australia, New Zealand, the United Kingdom, Scotland, the United States of America and most provinces of Canada have formal legal frameworks regulating the use of restrictive practices in residential aged care.

The key features of these systems include:
- the implementation of legislation, standards, regulations and/or safeguards that outline best-practice, evidence-based requirements regarding the use of restrictive practices;
- establishing principles that underpin the framework – for example, that restrictive practices may only be used in instances where a person is at risk and when all other less restrictive measures have been attempted;
- prohibiting the use of medication as a form of chemical restraint;
- a rigorous system of auditing for restrictive practices;
- substantial penalties for non-compliance with aged care services and restrictive practice standards;
- ensuring that state and national restrictive practice frameworks are congruent; and
- encouraging the judiciary to promote the freedoms and independence of older people.

[32] Australian Law Reform Commission, *Elder Abuse-A National Legal Response*, Report No 131 (2017) 11.
[33] Carnell, Kate AO and Paterson, Ron ONZM, *Review of National Aged Care Quality Regulatory Processes*, October 2017.
[34] *Ibid*, Recommendation 7, p xii.
[35] Standing Committee on Health, *Aged Care and Sport, Report on the Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia* (October 2018), Canberra Australia.
[36] Office of the Public Advocate, *Legal frameworks for the use of restrictive practices in residential aged care: An analysis of Australian and international jurisdictions* (June 2017). <https://www.justice.qld.gov.au/__data/assets/pdf_file/0005/524426/restrictive-practices-in-aged-care-final.pdf>. Accessed online December 2018.

The Australian Government's response

Following some particularly disturbing media reports about the misuse of restrictive practices in residential aged care, the Commonwealth Minister for Indigenous Health, Minister for Senior Australians and Aged Care, The Honourable Ken Wyatt AM, MP recently committed to improved regulation of chemical and physical restraint in aged care facilities.[37] The Minister outlined the Government's response to the issue as follows:

- The new Aged Care Quality Standards that come into force on 1 July 2019 'stipulate best-practice clinical care to minimise the use of chemical and physical restraint';
- The Department of Health has provided all aged care homes with the *Guiding principles for medication management in residential aged care facilities* to assist managers and staff to practice quality use and safe management of medicines;
- The Department of Health has also provided the *Decision-Making Tool Kit – Supporting a restraint free environment in Residential Aged Care* to residential aged care homes; and
- The Government has invested $4.1M in two separate research projects – the RedUSe Project and the HALT Project – to reduce the use of sedative and antipsychotic medications in residential aged care (see further comment about these projects below).

More recently, the Minister foreshadowed further 'regulatory changes', setting out specific provider responsibilities in relation to the use of physical and chemical restraint in aged care facilities to apply from 1 July 2019.[38] These proposed actions by the government and their likely legal and practical impacts will be considered in turn.

The Aged Care Quality Standards

The new Aged Care Quality Standards are contained in the *Quality of Care Amendment (Single Quality Framework) Principles 2018*.[39] The relevant section of the Aged Care Quality Standards is Standard 8 — Organisational Governance which provides:

> *Consumer outcome*
> (1) I am confident the organisation is well run. I can partner in improving the delivery of care and services
>
> *Organisation statement*
> (2) The organisation's governing body is accountable for the delivery of safe and quality care and services
>
> *Requirements*
> (3) The organisation demonstrates the following:
> (a) consumers are engaged in the development, delivery and evaluation of care and services are supported in that engagement;
> (b) the organisation's governing body promotes a culture of safe, inclusive and quality care and services and is accountable for their delivery;
> (c) effective organisation wide governance systems relating to the following;
> (i) information management;
> (ii) continuous improvement;
> (iii) financial governance;
> (iv) workforce governance, including the assignment of clear responsibilities and accountabilities;
> (v) regulatory compliance;
> (vi) feedback and complaints;
> (d) effective risk management systems and practice, including but not limited to the following;
> (i) managing high impact or high prevalence risks associated with the care of consumers;
> (ii) identifying and responding to abuse and neglect of consumers;
> (iii) supporting consumers to live the best life they can;
> (e) where clinical care is provided – a clinical governance framework, including but not limited to the following;
> (i) antimicrobial stewardship;
> (ii) **minimising the use of restraint;** [emphasis added]

[37] Ken Wyatt AM MP (Minister for Indigenous Health, Senior Australians and Aged Care), *Aged Care Restraint Regulations to Protect Senior Australians*, Parliament House, Canberra, 17 January 2019.

[38] Ken Wyatt AM MP (Minister for Indigenous Health, Senior Australians and Aged Care), *Stronger Restraint Regulations to Protect Senior Australians*, Parliament House, Canberra, 30 March 2019.

[39] *Quality of Care Amendment (Single Quality Framework) Principles 2018* (Cth).

(iii) open disclosure.

In terms of setting standards and an appropriate and accountable regulatory framework for the use of physical or chemical restraint, Quality Standard 8 is wholly inadequate. Quality Standard 8 provides a minimal reference to the use of physical or chemical restraint by merely requiring the clinical governance framework include minimising the use of restraint. Because the standard is so vague in its requirements around minimising the use of restraint, it is likely that it would be relatively easy for an aged care provider to satisfy this requirement with very little detail in any clinical governance framework, but the Quality Standard would be unlikely to achieve much in terms of reducing or eliminating the use of restraint or any other positive outcomes for aged care residents in terms of responding to challenging behaviours.

Residential aged care providers will be required to report under this standard, in accordance with the reporting requirements specified in the National Aged Care Quality Indicator Program, which will be a mandatory reporting program from 1 July 2019 (the program was previously voluntary). (See further discussion of the National Aged Care Quality Indicator Program and its adequacy, in terms of aged care service provider accountability, below.)

Aged care regulations

On 3 April 2019, the Minister released the amendment to the *Quality of Care Principles 2014,* making specific provision for the use of physical and chemical restraint. While any tightening of the standards of care around the use of physical and chemical restraint are supported, this amendment does not adopt many of the fundamental features of an accountable and transparent restrictive practices regulatory framework as recommended by the ALRC.

Some of the key features missing from the Australian Government's proposed new scheme include:

- the proposed scheme does not provide for the appointment of a formal independent decision-maker who is at arms-length from the provision of care to the person subject to the restrictive practice;
- there is no appeal process;
- there is no requirement that there should be regular reviews of the use of restrictive practices;
- there is no requirement that providers develop a behaviour support plan for the person which would guide the care provided to the person and decision-making and ensure the focus is on reducing and eliminating the use of restrictive practices;
- there is no requirement that the restrictive practices be applied for the least time necessary;
- there is no requirement that the restrictive practices used be proportionate to the risk of harm; and
- the proposed regime only requires that the consumer pose 'a risk of harm' which is a much lower threshold than the ALRC's recommendation that restrictive practices only be used to 'prevent serious physical harm'.

It is extremely concerning that the proposed regime provides for a doctor (most often a general practitioner), nurse practitioner or registered nurse to make decisions in relation to the use of restrictive practices, when most of these health practitioners will not have any formal training or recognised specialty in relation to the provision of clinical care in aged care or positive behaviour management.

This concern is further compounded by the fact that the health practitioners making the decisions also have an interest in the outcome of the decision, in terms of the management of the resident, the workloads of staff and the operation of the facility (because they also work there or provide services to the residents through an arrangement with the service provider). Decisions to prescribe medication to 'manage' residents who are displaying challenging behaviours will necessarily be influenced by considerations other than the rights of the residents and the immediate risk of harm to them or others. Those other considerations may include the views of management, the availability/numbers of staff and their skills in dealing with challenging residents, and convenience.

When decisions are being made to use chemical or other restraints on aged care residents by people who are not sufficiently independent of the provision of services, or trained in this type of decision-making, there is a risk that the decisions to use the restrictive practices may give too much

weight to certain considerations or may take other, irrelevant, considerations into account, which will ultimately affect the quality and validity of the decision.

Another key legal issue that arises from the proposed new Quality of Care Principles is that they make provision for the provider to obtain 'the informed consent of the consumer or the consumer's representative' to the use of restraint. (This consent is not required by the Principles in relation to the use of chemical restraint, apparently because it is a 'clinical' decision. Concerns relating to this approach will be discussed further below.)

Across the country, the law is unclear about whether a person's guardian or formal decision-maker can consent to the use of restrictive practices on a person for whom they are appointed.

> … absent specific legislative authorisation either through restrictive practices or coercive powers provisions in the legislation, questions remain about authorising restrictive practices through the guardianship system. This is despite the apparent widespread reliance on it, including with some apparent endorsement of this position by guardianship bodies.[40]

It is particularly concerning that the Australian Government is proposing an approach to correct the current inadequacies of the law around the use of restrictive practices in residential aged care that relies on the consent of guardians and other substitute decision-makers when the law is uncertain about whether guardians can lawfully consent to these practices. Instead of providing legal clarity to protect the rights and interests of aged care consumers and those who would be giving consent to restrictive practices, the Minister's new changes to chemical and physical restraint only raise further legal questions and leave residents, substitute decision-makers and staff in a legal limbo.

The problems associated with representatives' consent to the use of restrictive practices is compounded by the very informal 'representation' arrangements that are provided for under the *Aged Care Act 1997*. Under section 5 of the *Quality of Care Principles 2014,* other than under an enduring power of attorney or guardianship appointment, the following representative arrangements can be made:

- the consumer can nominate 'a person to be told about matters affecting the consumer';
- a person can nominate themselves to be 'a person to be told about matters affecting a consumer' and the approved provider 'is satisfied the person has a connection with the consumer' and is concerned for that person's safety, health and well-being;
- the person can be 'a partner, close relation or other relative of the consumer'; or
- it can be as relaxed as 'the person represents the consumer in dealings with the approved provider.'

It is unclear who can make the determination that the person can be regarded as the consumers' representative. However, again it seems wholly inappropriate that a person accepted as a 'representative' in most of the circumstances outlined under section 5 of the Principles, should also be the authority for providers to physically restrain a person in aged care or be the person notified about the use of chemical restraint. It is difficult to envisage how most ordinary people trying to fulfil such a role could provide 'informed consent' to the use of restraint on the aged care consumer they are supporting.

The 'use of chemical restraint' provisions under the Principles also raises significant concerns. This term is not commonly used in general medicine, is not evidence-based, is poorly understood and is unclear in meaning. It is therefore concerning to see the term enshrined in a legislative instrument, particularly, as it amounts to an acknowledgement and endorsement of a particular medical intervention (namely the use of medication as a chemical restraint to control behaviour) which is not generally considered to be good medical practice within the profession. It is also concerning that a government policy document is apparently dictating medical practice in aged care facilities in this way, particularly when there is no clear endorsement of this approach by the medical profession or the relevant specialist college.

[40] Kim Chandler, Ben White and Lindy Willmott, 'What role for adult guardianship in authorising restrictive practices?' (2017), *Monash University Law Review,* (Vol 43, No 2) p 496.

This approach could create difficulties for professional and disciplinary bodies when seeking to discipline a doctor for poor prescribing and medical practice where they have inappropriately prescribed antipsychotic medication as chemical restraint without a formal medical diagnosis. The government standards appear to be actively promoting a medical practice that should be discouraged.

The fundamental issue associated with the Australian Government's approach to chemical restraint in the new regulations is that it appears ill-informed and confused. The drafting suggests that decisions about chemically-based restrictive practices are clinical, however legislative instruments are being used to dictate the clinical approach.

The approach that the Australian Government has taken to the issue of regulation of restrictive practices in residential aged care demonstrates a complete lack of knowledge and understanding of three key issues:

- the previous reviews and recommendations about restrictive practices in aged care, such as the ALRC Elder Abuse Report and the Carnell-Patterson review and the general approaches and characteristics of legal frameworks for the regulation of restrictive practices;
- the law that applies to the use of restrictive practices and an understanding of basic legal and human rights; and
- the principles of positive behaviour support which should underpin any approach to restrictive practices, to ensure that they are focused on minimisation and elimination, are completely absent from the *Aged Care Act 1997*, the Principles and Standards, and all of the supporting resource material provided by government.

National Aged Care Quality Indicator Program - Resources

The resource manual[41] accompanying the National Aged Care Quality Indicator Program is extensive. However, it has not been updated to reflect the recent amendment to the Quality of Care Principles associated with chemical restraint. Accordingly, the resource manual provides no guidance on this issue. However, it provides considerable detail in relation to the use of physical restraint, what constitutes physical restraint and how to count instances of it in 'Chapter 5 Quality Indicator 2: Use of physical restraint'.

In this chapter, the resource manual notes that there are a number of adverse clinical events associated with physical restraint, including death, mental health decline, depression, social isolation, development of pressure injuries, falls, confusion, aggression and pain. The manual also provides additional key facts and other useful, but confusing information for aged care staff looking for guidance about how to make a decision about using physical restraint.

Those key facts include the following statements:

- Physical restraint is an infringement of the individual's right to freedom, dignity and autonomy.
- A family member and legal representatives do not have the legal right to request that a resident be restrained.
- There are many reasons why physical restraint is used but there is no evidence that demonstrates any benefit of its use to aged care residents.
- The evidence indicates that restraint does not prevent falls or fall-related injuries and is likely to exacerbate behaviours.
- A restraint free environment is the recommended standard of care.

A concerning aspect of the Quality Indicator Program Resource Manual regarding its handling of the use of physical restraint is that it requires providers to assess **every** resident for physical restraint on a quarterly basis. It is appalling that there is an assumption that all aged care residents may be subject to this treatment at some point during their care rather than the use of restraint being considered the exception and a last resort approach to managing challenging behaviours. Such an approach is inconsistent with a least restrictive approach to the care of residents and is symptomatic of a lack of respect for the legal and human rights of consumers within the residential

[41] MyAgedCare (Cth*), National Aged Care Quality Indicator Program – Resource Manual for residential aged care facilities*, September 2016 edition, viewed on myagedcare website 10 April 2019 <myagedcare.gov.au>. Accessed online February 2019.

aged care sector. Again, it is difficult to understand why the manual would require that every resident be assessed for physical restraint while acknowledging that it is an infringement of their right to freedom, dignity and autonomy, that the evidence indicates it does not prevent falls or fall-related injuries and is likely to exacerbate behaviours.

An equally concerning aspect of the relevant chapter of the resources manual dealing with the use of physical restraint is that it contains no guidance for aged care staff or clinicians about the relevant considerations when making a decision about the use of physical restraint on a resident. This is a significant and dangerous oversight. It is unacceptable that a resource manual held out as a 'Handbook for residential aged care facilities' providing them with 'a set of meaningful and measureable QIs [quality indicators] to assist in monitoring and improving important aspects related to quality of care' provides no specific guidance or quality indicators relating to the decision-making of care providers using physical restraint on their residents. The relevant chapter of the resource manual also makes no mention of the *Decision-making tool: supporting a restraint free environment in residential aged care* referred to by the Minister in his media release of 17 January 2019 which was held out by the Minister as a significant aspect of the government's response to public concerns about the use of restrictive practices.

The physical restraint chapter of the manual is supplemented by further material contained in 'Appendix 5 – Quality Indicator 2: Use of physical restraint'. The appendix informs the reader that 'the reasons for the decision to restrain and the process by which the decision was reached should be documented, as those making the decision are legally accountable for the decisions and their consequences'.[42] This effectively amounts to an admission that the use of restraint is not lawful (without proper informed consent) and will potentially expose staff at residential aged care facilities to legal risks.

Overall, the new provisions announced by the Australian Government in recent months do little to improve or create an appropriate legislative or operational framework for the use of restrictive practices in residential aged care facilities. The new measures do not establish the legal framework required to lawfully permit and regulate the use of restrictive practise in residential aged care facilities, nor do they demonstrate any leadership in improving the culture of human rights in the aged care sector.

Simply put, the Aged Care Minister's proposed response is wholly inadequate to address this key human rights and legal issue in residential aged care provision. It completely fails to recognise the legal implications of these actions by aged care providers and their staff and attempts to characterise the use of restrictive practices as a clinical decision. It is unlawful to actively limit a person's movement or to administer stupefying substances to them outside of a proper legal framework that permits such actions within prescribed limits.

Without appropriate action, Australia will remain out-of-step, in terms of regulation of restrictive practices in residential aged care and the protection of the rights of older Australians, compared with other Western, democratic countries. This is not a difficult issue to address. The use of restrictive practices has been properly regulated in the disability sector in Queensland and in some other Australian jurisdictions, for some time. All that is required is the commitment to legislate to introduce an appropriate regulatory framework to protect the rights of older members of our community who require care.

Best practice – Legislation and operations

Legislation

As noted above, despite the recent changes to quality standards announced by the Minister for Aged Care, there is no clear, enforceable legal framework regulating the use of restrictive practices in aged care settings across Australia.

[42] Australian Government, *National Aged Care Quality Indicator Program: Resource manual for residential aged care facilities*, myagedcare, September 2016 edition, p 78.

As already noted, some Australian jurisdictions regulate the use of restrictive practices in the disability and/or mental health sectors and, could be considered as potential models for the regulation of restrictive practices in residential aged care.

Queensland has a comprehensive regulatory framework for the use of restrictive practices by State Government-funded disability service providers, under the *Disability Services Act 2006* (Qld). The model is considered best practice, providing that restrictive practices can only be used in conjunction with a model of positive behaviour support. Positive behaviour support requires multi-disciplinary assessments of the person who may be subject to a restrictive practice and their care and support needs, along with the development of a positive behaviour support plan that identifies the person's challenging behaviours and contains less restrictive strategies for responding positively to those behaviours. The object of the approach is that the use of a restrictive practice is to be the least restrictive option and applied for the shortest period necessary, with a view to reducing the use of restrictive practices over time. Ultimately, the restrictive practice must be formally approved before it can be used.[43]

More specifically, the regulatory process for the use of restrictive practices in Queensland includes:

- Assessment by one or more qualified professionals.
- The development of a behaviour support plan, which must reflect the principles of the *Disability Services Act* in relation to restrictive practices. This requires that it be informed by a best practice evidence base, be designed to achieve behavioural change focused on skills development and environmental design, recognise that restrictive practices should only be used when necessary to prevent harm and that their use is the least restrictive way of ensuring the safety of the subject person and others.
- The plan must aim, overall, to reduce the intensity, frequency and duration of the person's behaviour and reduce or eliminate the need to use restrictive practices.
- Approval for the use of restrictive practices must be obtained from the Queensland Civil and Administrative Tribunal (QCAT).
- Approval for the use of certain restrictive practices is valid for a period of up to 12 months, after which time the approval is reviewed and reconfirmed or revoked.
- The Public Guardian can also give short-term approval for restrictive practices when there is an immediate and serious risk.[44]

This model is one that could be adapted for use in Australia's aged care sector. The adoption of a properly regulated regime has resulted in greater transparency around the use of restrictive practices in Queensland's disability sector and increased consistency, professionalism and oversight of these practices.

The paper released by my office referred to previously, *Legal frameworks for the use of restrictive practices in residential aged care: An analysis of Australian and international jurisdictions*[45], provides a summary of the other restrictive practice regimes in Australia and some overseas jurisdictions.

Innovative initiatives

While the development and implementation of a legislative framework for the use of restrictive practices is essential, the implementation of long term strategies to respond to challenging behaviours in these settings without having to resort to the use of restrictive practices should be the overall strategic goal.

The Royal Commission presents an opportunity for the Australian Government to demonstrate leadership and transform the sector through initiatives that engender respect for older people,

[43] *Disability Services Act 2006* (Qld) pt 6 – provisions relating to positive behaviour support and restrictive practices. *Guardianship and Administration Act 2000* (Qld) ch 5B – provisions relating to restrictive practices.
[44] Ibid.
[45] Office of the Public Advocate (Queensland), *Legal frameworks for the use of restrictive practices in residential aged care: An analysis of Australian and international jurisdictions* (June 2017). <http://www.justice.qld.gov.au/__data/assets/pdf_file/0005/524426/restrictive-practices-in-aged-care-final.pdf>. Accessed online December 2018.

recognise and protect their human rights and appropriately regulate the sector's approach to the use of restrictive practices. A number of best practice initiatives in this area are described below.

Numerous aged care providers in Australia and internationally now create specific environments for people with dementia, incorporating design features, programs and activities to improve quality of life and increase staff satisfaction levels. Such initiatives are a clear demonstration of truly consumer-centric service models that provide genuine 'care' for residents and uphold their human rights.

IRT, a national community owned provider of aged care facilities and services in New South Wales, the Australian Capital Territory and Queensland, have recently commenced a 'Journey of Care' project, which personalises the care for every resident and incorporates the environmental re-design of its aged care facilities to respond to the needs of people with dementia. The program assists with resident way-finding, minimises confusion, and increases independence for residents as well as improving the work environment for staff. Using an environmental design expert and the resources of Dementia Training Australia, the renovated facilities include:

- Installation of life-like garden murals to hide walls, fences and secure doors;
- Renovations to improve resident and staff sightlines between rooms and the garden;
- Introduction of natural light;
- Colour coding of walls and skirting boards to minimise falls;
- The use of intuitive visual cues to identify corridors and the dining area; and
- Personalised door decals on resident bedrooms that replicate the appearance of the front doors at former family homes so residents know which room is theirs.

As a result of the modifications, IRT's Flametree Lodge (one of the Group's specific facilities for people with dementia) has reported decreased agitation and frustration among residents and a reduction in the use of anti-depressant medication. Staff morale has also been boosted, along with an increase in the number of compliments from residents' family members visiting the facility.[46] This initiative provides a leading example of innovative ways of responding to challenging behaviours of residents with dementia using the least restrictive approach.

The Whiddon Aged Care Group, based in Grafton in New South Wales has introduced various programs and activities for residents with cognitive impairment. The *Chat, Stories and Tea group* is designed for people with memory challenges, dementia or short term memory loss, and is based on Cognitive Simulation Therapy, which was developed in the United Kingdom by Professor Marin Orrell and Dr Aimee Spector.[47] The groups have been proven to improve cognitive function and mood, and increase self-confidence and self-esteem around communication and social interaction. As a therapy, the groups are considered to be as effective as dementia medication at delaying or stabilising cognitive decline.

HenPower is another initiative of the Group[48], which is a program based around creative activities, arts, socialisation and "keeping chooks". While now undergoing a formal evaluation, the program has achieved some early positive results, particularly for residents showing early signs of dementia. The program was first developed by a British organisation, Equal Arts, and has been successfully running in the United Kingdom for a number of years, displaying significant health and wellbeing benefits, including a reduction in depression, loneliness and the empowerment of older people to build positive relationships.

The Whiddon Group examples are a demonstration of the organisation's commitment to a model of care known as 'Mylife', which was developed, trialled and evaluated using evidence-based methods. The model is relationship-based and places high importance on strong relationships between residents, clients and the employees who care for them. Staff are encouraged to get to know and understand residents and clients on a much deeper level – who they are, what they

[46] IRT, 'Environmental Design in Dementia Care' (8 November 2018), *The Good Life e-newsletter*, <http:www.irt.org.au/the-good-life/environmental-design-in-dementia-care/>. Accessed online November 2018.
[47] Orrell et al, *Cognitive Stimulation Therapy for Dementia : History, Evolution and Internationalism,* Taylor and Francis, London (2017)
[48] Ford, Kate – Whiddon Aged Care Group, Whiddon Henpower report relevels program's strength, accessed online <www.whiddon.com.au/yourlife/henpower-research-report> April 2019.

love, what makes them smile, what their life experiences are and the things about which they are passionate. Staff are trained through a specific program which equips them with the skills, techniques and approaches to deliver relationship based care.

When evaluated by the University of Sydney, the Mylife program was found to significantly improve resident moods, physical function and social engagement and participation. It was also found to improve job satisfaction for staff as they were working in a stronger team environment.[49]

A 2018 Flinders University study[50] found that aged care residents living in small home-like clusters rather than standard types of aged care facilities have a better quality of life and experience fewer hospital admissions. The facilities featured independent accessible outdoor areas, allocation of care staff to specific living units, meals cooked within units involving the participation of residents, and the self-service of meals.

In addition to resident benefits associated with the home care like model (68 per cent lower rate of being admitted to hospital and 73 per cent lower chance of admission to the emergency department), the researchers estimated that the model can save approximately $14,000 per resident per year in health and residential care costs. This study has demonstrated that it can be financially beneficial to provide consumer-focussed residential aged care.

In relation to the use of chemical restraint, a new multi-disciplinary intervention program has recently been trialled (Australian New Zealand Clinical Trial ACTRN12617001257358)[51] in 150 residential aged care facilities across Australia. This program, called the Reducing Use of Sedatives (RedUSe) intervention, aims to promote the appropriate use of antipsychotics and benzodiazepines in residential aged care facilities. It incorporated a psychotropic medication audit and feedback, staff education, interdisciplinary case review, and an audit after six months of operation.

During the six month intervention, the proportion of residents prescribed antipsychotics declined by 13 per cent and the use of benzodiazepines declined by 21 per cent. Both results were achieved without any increase in the prescription of other psychotropic drugs. The intervention was also based on the total resident aged care facility population, as opposed to just residents with dementia. The implications of this research are that targeted interventions can reduce over-reliance on psychotropic medication for managing mental and psychological symptoms of aged care residents.

The examples in this submission have been provided for illustrative purposes. There are likely to be many more meritorious program and design initiatives being used in the residential aged care sector to create environments where any type of resident restraint is the option of last resort.

The Dementia Training Australia website provides resources on environmental design, programs and activities, and general day-to-day planning for aged care providers who have residents living with dementia. Most of these resources are available free-of-charge, along with various training courses in areas such as the use of antipsychotic medication in people with dementia, caring for people with dementia at night, and caring for lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI+) residents with dementia.

Additional, proactive measures could also be considered in the recommendations of the Commission, potentially including the development of additional accreditation standards associated with; the design of care facilities, specific programs and the development, implementation and review of positive behaviour support plans for residents with dementia. This could be supported by the establishment of a funding program to initiate and trial best practice and innovative projects in this area.

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[49] Whiddon Aged Care Group, material accessed online <https.//www.whiddon.com.au>, Accessed online April 2019.
[50] Dyer et al, Clustered domestic residential aged care in Australia: fewer hospitalisations and better quality of life, *The Medical Journal of Australia* 2018; 208 (10): 433-438. || doi: 10.5694/mja17.00861, published online 4 June 2018, <https://www.mja.com.au/journal/2018/208/10/clustered-domestic-residential-aged-care-australia-fewer-hospitalisations-and>. Accessed online April 2019.
[51] Westbury et al, RedUSe: reducing antipsychotic and benzodiazepine prescribing in residential aged care facilities, *Medical Journal of Australia* 2018 (9), 21 May 2018, 398.

I request the Royal Commission make the following recommendation:

Recommendation 1
The Australian Government:

- Immediately implement a comprehensive residential aged care restrictive practices regulatory framework with all of the characteristics and protections recommended by the Australian Law Reform Commission in its report *Elder Abuse – A National Legal Response*[1] in Recommendations 4-10 and 4-11.
- Introduce additional accreditation standards relating to: the design of aged care facilities; the development or adoption of specific programs to support residents with dementia; and the development and implementation of positive behaviour support processes.
- Establish a funding program to support the initiation and trial of best practice and innovative projects to improve the quality of aged care and its responsiveness to the needs of consumers.

Effective complaint and investigation mechanisms

Effective complaints mechanisms are integral to a comprehensive system of rights and safeguards for older people.

A project undertaken by this office about complaints management systems for adults with impaired decision-making capacity identified a range of barriers preventing many of them from having their issues resolved through formal complaints mechanisms.[52] In addition to the usual reasons for not making formal complaints,[53] people with impaired decision-making capacity (including older people with dementia) may experience greater barriers to making complaints including:

- they do not understand their rights;
- the process or the entry points for making complaints are less accessible;
- not being believed or taken seriously when they do make a complaint;
- not being able to manage and present evidence to support their complaint;[54] and
- those individuals who receive services from others are often reluctant to make complaints for fear of reprisals or withdrawal of services.[55]

The project also identified that complaints systems were not always sufficiently responsive to individuals with impaired decision-making capacity who may be unable to take the action necessary to initiate and progress a complaint through to resolution.[56] These adults can require additional support to use complaints systems effectively,[57] particularly those who do not have

[52] Office of the Public Advocate (Queensland), *Strengthening Voice: A Scoping Paper About Complaints Management Systems for Adults with Impaired Capacity* (February 2015) 8-15. <http://www.justice.qld.gov.au/__data/assets/pdf_file/0020/362342/strengthening-voice-scoping.PDF>. Accessed online April 2019.
[53] Sarah Cook, *Complaint Management Excellence: Creating Customer Loyalty Through Service Recovery* (electronic version, Kogan Page, 2012); Clay M Voorhees, Michael K Brady and David M Horowitz, 'A Voice from the Silent Masses: An Exploratory and Comparative Analysis of Noncomplainers' (2006) 34(4) *Journal of the Academy of Marketing Science* 514-527.
[54] Office of the Public Advocate (Queensland), *Strengthening Voice: A Scoping Paper About Complaints Management Systems for Adults with Impaired Capacity* (February 2015) 8-10.
[55] See, for example, Alisoun Milne, 'Commentary on Protecting My Mother' (2011) 13(1) *The Journal of Adult Protection* 53-56; Queensland Parents for People with a Disability (QPPD), *Papering Over the Cracks: The Veneer of Prevention* (2005) 39 <http://www.qppd.org/images/docs/ci_report_2005.pdf>. Accessed online December 2018.
[56] Office of the Public Advocate (Queensland), *Strengthening Voice: A Scoping Paper About Complaints Management Systems for Adults with Impaired Capacity* (February 2015).
[57] Office of the Public Advocate (Queensland), *Strengthening Voice: A Scoping Paper About Complaints Management Systems for Adults with Impaired Capacity* (February 2015), 28; International sources also identify the importance of support during complaint making, see Healthwatch England, 'Suffering in Silence: Listening to Consumer Experiences of the Health

family, friends or other people available to provide them with support. This support is not always offered through organisational complaints management systems.

These and other issues are likely to significantly reduce the use and effectiveness of complaints systems for older people who are diagnosed with dementia or other capacity-affecting conditions. Complaints schemes for this group should therefore incorporate mechanisms that maximise accessibility and support people to actively engage in the complaint-making process.

The *Convention on the Rights of Persons with Disabilities* (CRPD) places responsibility on Australia to take appropriate measures to ensure the accessibility of services and systems to all people (including those with aged-related impairments) and provide appropriate assistance and support.[58] Further, the CRPD requires that States ensure that people receive the support they need to exercise their legal capacity and make decisions for themselves.[59] This should include assisting people to enforce their rights as consumers and to exercise choice to change service providers when they are dissatisfied with their care and treatment. Accordingly, all complaints and consumer protection mechanisms in the aged care sector must uphold the principles of the CRPD and, to the greatest extent possible, support older people to exercise their autonomy and legal capacity.

Based on work undertaken by the South Australian Ombudsman[60], the essential components of an effective complaints management system include:

1. Commitment – developing a culture that welcomes complaints;
2. Facilitation – making it easy for people to make complaints;
3. Resourcing – appropriate training, empowerment and resourced staff to manage complaints;
4. Learning – analysing complaints and their outcomes to improve systems and processes; and
5. Guidance – developing policies and procedures to assist staff in the management of complaints.[61]

Until the beginning of 2019, the Aged Care Complaints Commissioner was responsible for the initial receipt and resolution of aged care complaints and made referrals, where appropriate, to a range of external agencies, including the Department of Health, the Aged Care Quality Agency, state and territory governments, Public Health Units, the police, coroners, the Australian Health Practitioner Regulation Agency and health care complaints bodies.

In 2017-18, the Aged Care Complaints Commissioner received 5,779 complaints, an increase of 23 per cent in comparison with 2016-17 and 47 per cent more than it received in 2015-16. The majority of these complaints (75 per cent) related to residential aged care and a significant proportion (1,073 cases) were referred to the Aged Care Quality Agency, an increase of more than 100 percent on 2016-17[62].

In 2017-18, the most common issues raised in complaints about residential aged care related to medication administration and management (706 complaints), personal and oral hygiene (473 complaints) and personnel numbers/ratios (452 complaints).[63]

This broad level of categorising and reporting of complaints does not enable government agencies, the public or agencies such as the Public Advocate, to determine whether there are any, or many, complaints about specific issues such as the use or misuse of restrictive practices or other conduct that would amount to elder abuse in residential aged care facilities. Aged care complaints agencies should also provide information about whether complaints are being substantiated, and whether certain types of complaints are increasing. Considering the vulnerability of many aged care consumers, it is important that the responsible complaints body is

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and Social Care Complaints System' (A Healthwatch England Report, October 2014) <http://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/complaints-summary_0.pdf>. Accessed online January 2019.

[58] *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007 [2008] ATS 12 (entered into force 3 May 2008) ('*Convention on the Rights of Persons with Disabilities*') art 9.

[59] Ibid art 12.

[60] This work draws on the Australian and New Zealand Standard Guidelines for complaint management (AS/NZS 10002:2014).

[61] South Australia Ombudsman, *Complaint Management Framework March 2016*, Crown Copyright New South Wales Ombudsman June 2015, South Australia Ombudsman's Office, Adelaide South Australia (2016).

[62] Aged Care Complaints Commissioner, *Annual Report 2017-18*, Canberra, Australian Capital Territory (2018)

[63] Ibid.

required to provide meaningful public information in greater detail about the type and nature of complaints received and the outcomes of those complaints.

Publishing more detailed information about complaints will facilitate greater system transparency and accountability. The community is entitled to this information. Most importantly, older Australians and their family members are entitled to know more about complaints that are made in relation to elder abuse in residential aged care settings and, more particularly, in the facilities that they are considering for their accommodation and care.

In January of 2019, the Aged Care Quality and Safety Commission replaced the Australian Aged Care Quality Agency and the Aged Care Complaints Commissioner, combining the functions of both into one independent agency, aimed at strengthening the focus on consumers, streamlining regulation, supporting improved engagement with consumers and providers and promoting transparency. The Commission will begin assessment and monitoring against the new Aged Care Quality Standards from 1 July 2019.

At this time, it is not clear that the Aged Care Quality and Safety Commission has any specific practices or procedures in place to facilitate complaints and support people receiving aged care supports to make complaints to the agency. It is hoped that the new Commission will adopt processes for complaints handling and reporting that address the framework and reporting issues noted above.

I request the Royal Commission make the following recommendations.

Recommendation 2
The Australian Government require the Aged Care Quality and Safety Commission to undertake more detailed categorising and reporting of complaint types and trends to assist in the identification of systemic issues and trends in complaints and quality of care issues in aged care service provision.

Other programs that can complement existing complaints mechanisms include the funding of advocacy and community visitor programs, which are discussed below.

Advocacy and community visitor programs

While formal complaints mechanisms are essential in any properly regulated aged care system, they are insufficient in themselves for protecting older people from abuse and exploitation, and must be complemented by additional safeguards. Two such safeguards are community visitor and advocacy programs.

Community visitor programs (similar to the community visitor program that operates under the *Public Guardian Act 2014* (Qld)) monitor the treatment and services provided to vulnerable people living in defined types of accommodation. They provide an on-going presence of external visitors, with a complaints and inquiry function[64], who may assist with identifying and raising issues for people with vulnerabilities and capacity issues and progressing them to resolution.

Independent advocates can perform similar functions to community visitors, although engaging their services generally requires proactive effort that may be beyond the capabilities of some aged care residents.

Anecdotal information suggests that aged care advocacy is insufficiently resourced to meet the needs of a rapidly growing cohort of older Australians requiring advocacy and support, especially those with impaired decision-making capacity.

The Commonwealth Government funds the National Aged Care Advocacy Program (NACAP) which provides free, independent and confidential advocacy support and information to older

[64] S 41 *Public Guardian Act 2014*(Qld).

people receiving, or seeking to receive, Commonwealth Government funded aged care services. It is critical that the NACAP is adequately funded to meet current and future demand for aged care advocacy services. Insufficient funding of advocacy services could become a significant barrier to aged care residents being able to seek redress for mistreatment and abuse and to access consumer protection mechanisms.

The issue of adequate resourcing of advocacy is particularly relevant to this inquiry given that data provided by the NACAP agencies indicate that elder abuse and the mistreatment of older people is an increasing concern among advocacy services across Australia.[65] Accordingly, there is a need to revisit the Productivity Commission's 2011 report[66] and the Department of Social Services' 2015 report[67] recommendations to expand the NACAP to meet anticipated demand:

> *The predicted increase in the proportion, and absolute numbers, of people aged over 65 years of age is likely to drive higher demand for advocacy services. At a minimum, funding could increase in line with these projections and inflation to maintain current service levels.*[68]

The current Commonwealth-funded aged care community visitor scheme has potential to reduce the incidence of elder abuse in residential aged care. At present, the scheme links volunteer community members with aged care residents for the purpose of companionship and friendship.[69] It is unclear whether these volunteers would have the skills or inclination to identify and address the mistreatment of residents appropriately and effectively.

In contrast, the Queensland community visitor program employs community visitors to undertake regular announced and unannounced visits to specified accommodation sites for the purpose of monitoring service delivery.[70] Queensland community visitors have legislative authority to undertake functions such as lodging and resolving complaints on behalf of residents with impaired decision-making capacity, talking with staff and residents to clarify issues and concerns, and reviewing documentation and programs relating to their support and care.[71] Community visitors can lodge reports with the Office of the Public Guardian[72] that also provides the reports to service providers for their information and follow-up action.[73]

The Public Advocate supports the establishment of a government-funded aged care community visitor scheme based on the community visitor program model provided for under the *Public Guardian Act 2014* (Qld). Such a program, along with an expanded NACAP, would form a significant part of a comprehensive complaints and oversight framework to ensure quality and safety in residential and community-based aged care services.

I request the Royal Commission make the following recommendations:

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[65] Department of Social Services, *Review of Commonwealth Aged Care Advocacy Services: Final Report* (December 2015) 44 <https://agedcare.health.gov.au/support-services/aged-care-advocacy/review-of-commonwealth-aged-care-advocacy-services-final-report>. Accessed online April 2019.
[66] Commonwealth Government Productivity Commission, *Caring for Older Australians* (Productivity Commission Inquiry Report No 53 Vol 1) (2011) lxix <http://www.pc.gov.au/inquiries/completed/aged-care/report>. Accessed online February 2019.
[67] Department of Social Services, *Review of Commonwealth Aged Care Advocacy Services: Final Report* (December 2015) 6-7 <https://agedcare.health.gov.au/support-services/aged-care-advocacy/review-of-commonwealth-aged-care-advocacy-services-final-report>. Accessed online February 2019
[68] Ibid, p 72.
[69] Commonwealth Government Department of Health, Ageing and Aged Care: *Review of the Commonwealth Aged Care Advocacy Services* (20 February 2016) <https://agedcare.health.gov.au/support-services/national-aged-care-advocacy-framework-consultation>; See also *Aged Care Act 1997* (Cth) ch 5 pt 5.6 div 82 s 82-1(1)(a)(b)(c). Accessed online February 2019.
[70] Office of the Public Guardian (Queensland), *Community Visitors*, Office of the Public Guardian <www.publicguardian.qld.gov.au/adult-guardian/adult-community-visitors>. Accessed online April 2019.
[71] Ibid.
[72] *Public Guardian Act 2014* (Qld) s 47(1).
[73] Ibid s 47(3).

Recommendation 3
The Australian Government adequately fund the National Aged Care Advocacy Program to ensure that older Australians receiving aged care services can access advocacy to assist them to make complaints and raise issues about their treatment and care.

Recommendation 4
The Australian Government introduce a fully funded aged care community visitor scheme (with paid employees, not volunteers) based on the Queensland community visitor program under the *Public Guardian Act* 2014 (Qld), as a key program supporting the complaints management framework applicable to aged care service providers.

Reportable deaths in care

The final potential oversight mechanism that should be considered for the protection of consumers of aged care services, is the investigation of aged care deaths by the Coroner when the death may be related to the quality of care provided at a residential aged care facility.

Currently there is no system or framework in Australia for reviewing deaths in residential aged care facilities unless a number of circumstances make the death reportable to the Coroner. As noted in a recent article in the *Journal of Law and Medicine* that examined the Coroner's role in the prevention of elder abuse,[74] currently residential aged care facilities are:

> … not a prescribed setting in any Australian coronial legislation. Consequently, a death in a residential aged care facility does not automatically trigger coronial investigations. A death in a residential aged care facility may trigger a report to the coroner if the death was violent, unnatural, suspicious, health-care related or where the death certificate was not issued.[75]

The article also identified that some Australian jurisdictions use age as a constraint or limitation on the reporting of deaths in aged care, including New South Wales, where the age of 72 is used to limit deaths that are reportable to the coroner. The article went on to say, based on evidence from a variety of scholars, that under-reporting of deaths in residential aged care facilities to the coroner is prevalent, particularly in cases associated with advanced bed sores.

In recent years I have been invited by Queensland Coroners to make submissions in inquests into the deaths of people with complex health needs in disability and aged care. One particular case involved the death of a younger person with disability residing in an aged care facility who died from choking on food. The Deputy State Coroner asked for submissions from the Public Advocate as a result of work undertaken by my predecessor for the report, U*pholding the right to life and health: A review of the deaths in care of people with disability in Queensland*, which identified a range of risks for people with dysphagia (difficulty swallowing) that contributed to their deaths.

The Deputy State Coroner in this case acknowledged choking to be a systemic issue in residential aged and disability care, and noted that strategies to monitor, review and report on this particular issue should be built into the National Disability Insurance Scheme (NDIS) quality assurance and reporting framework.

It is pleasing to note that the new Aged Care Standards now include specific reference to "managing the risks of choking" under *Standard 3 - Effective management of high-impact or high-prevalence risks associated with the care of each consumer.*

In the same matter also suggested the Deputy State Coroner consider recommending the introduction of an Aged Care Death Review Process (or alternatively, an Elder Abuse Death Review process) on the basis of the following:

[74] Catherine Sharp, Jennifer Sarah Schulz Moore and Mary-Louise McLaws, 'The Coroner's Role in the Prevention of Elder Abuse: A study of Australian Coroner's Court Cases Involving Pressure Ulcers in Elders', *Journal of Law and Medicine*, Vol 26, No 2, p 494, 28 October 2018, Lawbook Co. Australia
[75] Ibid p 498.

- The wide-ranging care and systemic issues that have been identified in this and other coronial matters that demonstrate the benefits of taking a broader systemic view in certain types of coronial investigations;
- The specialist knowledge and skills that can be developed from the adoption of specialist death review processes that could help to reduce unexpected and potentially avoidable deaths in the target population;
- The risk that without these specialist review processes, the limitations of the definitions in the *Coroners Act 2003* for reportable deaths or deaths warranting coronial investigations could result in missed opportunities to identify systemic issues in the residential aged care and disability care systems that are causing or contributing to potentially avoidable deaths.

It is important to note, in relation to the choking case above, that the Autopsy Report identified significant deterioration in the health of the deceased's lungs that evidenced serious ongoing difficulties with eating and swallowing. In the opinion of the forensic pathologist this deterioration was due to food aspiration, which causes severe necrotising pneumonia and over time can lead to death. Had the deceased not died from choking on food, an event which caused his death to be viewed as 'unnatural' and therefore reportable under the *Coroners Act 2003* (Qld), he may well have died from aspiration pneumonia. Had he died from aspiration pneumonia, the death would most likely have been considered 'natural', because without an autopsy it would only be identified as death by pneumonia. As a consequence, there would have been no basis to investigate the death and improve the level of care provided to patients with these types of conditions, even though it would have been a preventable death resulting from lack of appropriate care and mealtime supervision.

While it is acknowledged that Australians entering residential aged care facilities or using services provided by the aged care sector in their homes are potentially suffering from conditions that are life-limiting, **not** actively reviewing deaths in aged care has the potential to allow poor practices and quality of care to go unchecked. Our ultimate objective (and indeed the objective reinforced in the revised Aged Care Quality Standards) should be to treat our aged (and most vulnerable) with dignity and respect, and this standard should apply to their deaths as well as their lives. If we continue to not report and review deaths in aged care facilities, and conduct investigations only in very limited circumstances, the individual and systemic failures contributing to those deaths will remain unaddressed.

An epidemiological analysis of deaths in residential aged care by Professor Ibrahim et al[76] , found that a significant number of deaths in aged care are 'premature' and potentially 'preventable', challenging the misconception that all deaths of frail, older people living in residential aged care are natural. It also found that the incidence of preventable deaths of nursing home residents has increased over the past decade. The research noted that, although there are mechanisms to actively monitor residential aged care, there is no one organisation responsible for the reduction of harm by improving practice. In contrast, general health care has a leading national agency, the Australian Commission on Safety and Quality in Health Care which monitors and investigates preventable harm and provides resources, training, education and research to address problems and improve care.

The reporting of deaths of people in aged care and investigation by the Coroner is the first step towards greater scrutiny of deaths in residential aged care to improve practices, so that the prevalence of external deaths, which are by definition, preventable, can be reduced in the future.

Further, the Aged Care Quality and Safety Commission should be given responsibility for reduction of harm in aged care by improving practice, similar to the role of the Australian Commission on Safety and Quality in Health Care. Part of that work should include more detailed categorising and reporting of complaint types and trends. This will assist the community and other agencies to identify systemic issues and trends in complaints and quality of care in aged care service provision.

I request the Royal Commission make the following recommendations:

[76] Ibrahim, Joseph et al, Premature deaths of nursing home residents: an epidemiological analysis, *Medical Journal of Australia* 206 (10), 5 June 2017, Australia.

Recommendation 5
The Australian Government introduce and fund a national Deaths in Aged Care Review Process, where deaths in aged care are reported to and investigated by State and Territory Coroners.

Recommendation 6
The Australian Government give the Aged Care Quality and Safety Commission responsibility for reduction of harm in aged care by improving practice, similar to the role of the Australian Commission on Safety and Quality in Health Care.

The aged care workforce

The number and mix of appropriate skills, qualifications and experience within the aged care workforce has a direct impact on each of the issues addressed in this submission.

Calls for the development and implementation of staffing ratios within aged care facilities, similar to those used in childcare facilities, are now being made by various peak bodies, including the Australian Nursing and Midwifery Federation (ANMF), the Australian Medical Association (AMA) as well as various politicians and advocates.

As the Commission would be aware, the House of Representatives Standing Committee on Health, Aged Care and Sport released an Advisory Report in December 2018 on the Aged Care Amendment (Staffing Ratio Disclosure) Bill 2018, recommending the passing of an amendment which will require the Department of Health to publish staffing ratio data for aged care facilities in a form that allows consumers to consider resident acuity levels when comparing facilities.

The Committee also reiterated recommendations made in its report on the Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia, including that the Commonwealth Government:

- legislate to ensure that residential aged care facilities provide for a minimum of one Registered Nurse to be on site at all times; and
- specifically monitor and report on the correlation between standards of care (including complaints and findings of elder abuse) and staffing mixes to guide further decisions in relation to staffing requirements.[77]

On 10 April 2019, the Senate Community Affairs References Committee released its Final report[78] into the effectiveness of the Aged Care Quality Assessment and accreditation framework. Among other matters, the Committee recommended:

> … that the Aged Care Quality and Safety Commission work collaboratively with the Department of Health, the Australian Commission on Safety and Quality in Health Care and aged care stakeholders to develop benchmarks for staffing levels and skills mix, which includes the requirement to roster a Registered Nurse on duty at all times, to assist residential aged care providers in staff planning and aged care assessors in regulating safe and appropriate staffing. (Rec 8)

The debate surrounding the development and implementation of staffing ratios in aged care facilities does, initially, look like a simple one – if you want residents to receive a good standard of care you need to make sure that there are sufficient staff to provide that standard of care. The fewer staff you have, the lower the standard of care and vice versa.

However, if thought is given to staffing ratios in terms of resident outcomes, namely the quality of care they receive, the application of ratios may oversimplify the issues involved.

[77] House of Representatives Standing Committee on Health, Aged Care and Sport, *Advisory Report on the Aged Care Amendment (Staffing Ratio Disclosure) Bill 2018*, December 2018, Canberra.
[78] The Senate Community Affairs References Committee, *Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised,* Final report, April 2019.

The Productivity Commission considered the issue of quality care in residential aged care facilities in its report *Caring for Older Australians* released in August 2011.[79] In this report, the Commission recognised that defining and measuring the quality of care and support in aged care facilities is not straightforward. The Commission did, however, identify some common themes associated with quality care including effectiveness, safety, efficiency and the experience of care consumers.

The Commission concluded that an across-the-board simple staffing ratio is a 'relatively blunt instrument for ensuring quality care, particularly given that the care resident profile of every facility will be ever changing.'[80]

Instead, the Commission suggested that there could be a more direct link between the funding provided for the complex health needs of aged care residents and how much care providers allocate to health care funding, including wages for nurses, over a period of time. They suggested that aged care providers should be required to make available information about the staff and skill mix for the profile of aged care residents, so that consumers could make more informed choices about what services best suit their needs. Such an approach will also encourage aged care providers to aspire to higher levels and quality of care as a point of differentiation, rather than only focusing on meeting minimum standards that might be set by a minimum staff-to-resident ratio. Uniform standards for the provision of this information may need to be set to ensure the information provided is accurate and that aged care consumers and their supporters can make ready comparisons between facilities.

This position has been echoed more recently by The Council on the Ageing (COTA). In its position paper released in late 2018 – *Keep fixing Australia's aged care system … taking the next steps in tandem with the Royal Commission,*[81] COTA took the view that mandated staffing ratios are not necessarily 'the answer' to issues around quality of care in aged care facilities and that, on their own, will not reduce or resolve whatever quality or safety concerns or gaps a facility may have.

COTA, in calling for 'the right staffing levels and skill mixes' for particular facilities, supports a report commissioned by the Australian Nursing and Midwifery Federation prepared by Flinders University, which proposed a skill mix of 30 per cent registered nurses, 20 per cent enrolled nurses and 50 per cent personal care workers in aged care facilities. This skill mix approach has, however, also been questioned.

An alternative approach may lie in the development of a staffing ratio or mix that is directly and legislatively related to the care levels provided at each aged care facility, based on the Aged Care Funding Instrument (ACFI). The instrument assesses each resident of an aged care facility, focusing on the main areas that discriminate core care needs. It then assesses core care needs as a basis for allocating funding. Given that the instrument provides for high, medium and low rating scores for each resident in three main areas (activities of daily living, behaviour, and complex health care) it may be possible to link staffing ratios to actual care requirements that are already documented in a cost and time effective way. Of course, as new residents enter the facility the assessment levels will change and staffing ratios will also need to be altered, however there are examples in other areas of health service provision (e.g. operating theatres in hospitals) where rostering based on care needs is undertaken, providing evidence that such an approach to staffing may be effective.

A staffing ratio system of this nature would require further research and feasibility work, including the identification of the skill mix required for each level of care. However it would potentially provide an additional layer of protection for residents in that it is transparent and accountable to government (i.e. directly linked to the funding instrument and funding model for aged care) and would be consistent across all aged care facilities. It could also be used to set the minimum

[79] Commonwealth Government Productivity Commission, *Caring for Older Australians Inquiry Report,* August 2011.
[80] Ibid. p 370.
[81] Council of the Ageing (COTA) Australia*, Keep fixing Australia's aged care system,… taking the next steps in tandem with the Royal Commission,* September 2018 <https://www.cota.org.au/wp-content/uploads/2018/09/Policy-Paper-Five-Fixes-Aged-Care-September-2018-FINAL-SOFT-COPY.pdf>. Accessed online December 2018.

standards that need to be met, thereby encouraging aged care facilities to adopt higher staffing ratios and skill mixes than the minimum as a point of differentiation.

I request the Royal Commission make the following recommendations:

Recommendation 7
The Aged Care Quality and Safety Commission be directed by the Australian Government to undertake further research and feasibility work, to develop a staff ratio and skill/experience mix for residential aged care facilities based on the Aged Care Funding Instrument and the level of need of residents.

Recommendation 8
The Australian Government, consistent with the Productivity Commission recommendation, require residential aged care facilities to publish information about the staff and skill mix the facility provides for the profile of aged care residents, so that consumers can make more informed choices about what services best suit their needs. Uniform standards for the provision of this information may need to be set to ensure the information provided is accurate and that aged care consumers and their supporters can make ready comparisons between facilities.

End-of-life planning and care

Palliative care for people with dementia

Palliative and end-of-life care has been the subject of numerous reports and inquiries over the last 15 years in Australia, including the Senate's Community Affairs Reference Committee's inquiry into *Palliative Care in Australia*[82] completed in 2012 and the Productivity Commission's Inquiry Report, *Introducing competition and informed user choice into human services: reforms to human services,*[83] which was completed in late 2017 and included a chapter on end-of-life care in Australia.

Both of these inquiries acknowledged that end-of-life and palliative care is the core business of residential aged care but that the quality of end-of-life care provided throughout Australian aged care facilities is variable at best.

The right to palliative care has been recognised by both the United Nations and The World Health Organisation (WHO).[84] WHO has released a set of recommendations as a guide to the minimum standards expected by the international community that include all countries:

- adopting a national palliative care policy;
- ensuring the training and education of health professionals;
- raising public awareness of palliative care and its principles;
- ensuring the availability of morphine in all health care settings; and
- ensuring that minimum standards for pain relief and palliative care are progressively adopted at all levels of care.

The 2018-19 Commonwealth budget recognised the need for the provision of comprehensive palliative care in the aged care sector and, as a component of its commitment to an increase in aged care funding of $5 billion over 5 years, allocated $32.8 million to facilitate the development and implementation of new models of palliative care in aged care facilities.[85]

[82] The Senate Community Affairs Reference Committee, *Palliative Care in Australia*, Canberra (2012).
[83] Productivity Commission, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, Report No. 85, (2017) Canberra.
[84] Frank Brennan, MBBS, FRACP, FAChPM, LLB, 'Palliative Care as an International Human Right', *Journal of Pain and System Management,* Vol 33, No 5, 5 May 2007, doi:10:1016/j.jpainsymman.2007.02.022.
[85] Department of Health (Cth), *Budget 2018-19 Better Quality of Care – comprehensive palliative care in aged care*, budget fact sheet – ageing and aged care, Parliament House, Canberra, 2018.

While this budget allocation is a commendable initiative, the provision of palliative care in aged care facilities for residents with dementia remains an ongoing issue. In a joint policy statement, Palliative Care Australia and Dementia Australia highlighted that many aged care providers are 'not equipped to address the unique palliative care needs of people living with dementia due to limited resources or appropriately trained staff'.[86]

This statement is supported by statistics from the Australian Institute of Health and Welfare about the characteristics of aged care residents requiring palliative care. The figures indicate that of the very small percentage of aged care residents who receive palliative care (2 per cent), residents with a dementia diagnosis are under-represented (43 per cent compared with 52 per cent of the general residential aged care population)[87].

Personal stories also illustrate the need. An article that appeared in the Ageing Agenda in early 2017 highlighted the issues faced by families and carers of people living with dementia who are often not made aware of palliative and end-of-life care services and supports.[88] The article tells the story of Rosemary and her husband Don, who had become a resident of an aged care facility following a diagnosis of Lewy Body Dementia seven years previously. While recognising Don's condition was terminal, Rosemary said that palliative care for Don had never been raised, however it was offered immediately when her son was diagnosed with terminal cancer. In Rosemary's view:

> people with dementia, let alone their families and carers, don't seem to be considered worthy of palliative care. And yet their need can be much more protracted than others with dying relatives or family.[89]

Given that dementia is the second most common underlying cause of death in Australia and that almost a million Australians will be diagnosed with the disease by 2050,[90] recognition of the condition as terminal is essential, along with the adoption of a standard and consistent approach to palliative care in residential aged care facilities.

A number of peak bodies nationwide, including Palliative Care Australia, Alzheimer's Australia, Council of the Ageing (COTA) Australia, Aged and Community Services Australia, Leading Age Services Australia, Catholic Health Australia and the Aged Care Guild have released *Principles for Palliative and End-of-Life Care in Residential Aged Care.*[91] The principles demonstrate a commitment to recognising the diverse needs of residential aged care consumers, families, carers, aged care staff and service providers in providing palliative and end-of-life care.

These principles need to be incorporated into the appropriate residential aged care standards, and assessed as a component of the accreditation process.

Additionally, research is being undertaken under the auspices of Hammond Aged Care to improve palliative care for people with advanced dementia living in residential care.[92] The aim of this research is to develop case conferencing resources to facilitate communication between aged care staff, health professionals (including general practitioners) and substitute decision makers

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[86] Palliative Care Australia and Dementia Australia, *Policy Statement – Palliative Care and Dementia* <https:\\www.palliativecare.og.au>, originally published October 2013, updated May 2018. Accessed online December 2018.

[87] Australian Institute of Health and Welfare (Cth), *Palliative care services in Australia,* web report <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-in-residential-aged-care/characteristics-of-residential-aged-care-residents-receiving-palliative-care,> 17 October 2018. Accessed online January 2019.

[88] Megan Stoyles, People living with dementia face a lack of support on end-of-life care, *Australian Ageing Agenda,* 1 March 2017, <https:\\www.australianageingagenda.com.au/2017/03/01/people-living-with-dementia-face-a-lack-of-support-on-end-of-life-care>. Accessed online January 2019.

[89] Ibid, p 3

[90] Dementia Australia, *Dementia Prevalence Data 2018-2058*, cited in *Dementia Australia, Key Facts and Statistics* (November 2018), Dementia Australia <https://www.dementia.org.au/statistics>. Accessed online January 2019.

[91] Palliative Care Australia et al, *Principles for Palliative and End-of-Life Care in Residential Aged Care,* accessed online on 22/3/2019 < https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2017/05/PCA018_Guiding-Principles-for-PC-Aged-Care_W03-002.pdf>. Accessed online January 2019

[92] Hammond Care Australia, *Research on Dementia and Aged Care*, < https://www.hammond.com.au/research/dementia-and-aged-care-research>. Accessed online January 2019.

(family and/or guardians) to discuss the current stage of the illness and agree on a management plan utilising evidence-based best practice. The impact of case conferencing and joint planning will also be evaluated from the perspective of the resident, family satisfaction with care staff attitudes and care delivery.

This project is funded by the Commonwealth Department of Health and Ageing and is being undertaken in collaboration with investigators from the University of Technology Sydney, University of Queensland, Queensland University of Technology, and the University of Notre Dame in Perth. The research will complement work already completed in this area by Dementia Australia[93] and the results may be available for reference during the course of the Royal Commission.

I request the Royal Commission to make the following recommendation:

Recommendation 9
The Australian Government incorporate the *Principles for Palliative and End-of-Life Care in Residential Aged Care*[1] into the Quality of Care Principles for aged care, and require that compliance with these standards be a component of the assessment for accreditation of aged care providers.

Substitute decision-making in the aged care sector

There are three key issues in relation to substituted decision-making in the aged are sector that will be addressed in this submission. These are the increasing prevalence of:

- residential aged care providers requiring that a prospective resident has either a valid enduring power of attorney or a guardianship order before considering them for a waitlist or admission into the facility;
- aged care providers and staff liaising with the person appointed as the resident's enduring attorney when a decision has to be made in relation to the resident, when the resident still has decision-making capacity; and
- moving older people against their will from their homes into residential aged care without appropriate consideration of alternative options to support the person continuing to live at home.

Enduring documents, such as enduring powers of attorney and advance health directives, are useful legal devices that allow people to choose a person (or persons) to make decisions on their behalf should they lose decision-making capacity in the future. They can enable a person to maintain a degree of autonomy in their lives even after losing capacity by documenting their views and choices about their health care and/or the person they want to make decisions for them, should they lose capacity. They also can protect a person who has lost decision-making capacity from being exploited and abused by others.[94]

There is now a relatively common practice among residential aged care providers of requiring that an older person has either a valid enduring power of attorney or a guardianship order before adding them to a placement waitlist and/or accepting the person into the facility. It seems aged care providers have adopted this practice to ensure that all people seeking placement in a facility have a mechanism in place for continuity of decision-making in the event the person ceases to have decision-making capacity sometime in the future.

The failure of residential aged care providers and other organisations, such as financial institutions, to recognise informal decision-making is a long-standing issue. In 2015, the Australian Guardianship and Administration Council expressed concern about the absence of engagement with informal decision-makers in the aged care system and recognition of the obligation to support people's autonomy and agency and uphold their rights to make their own decisions. The Council observed that the:

[93] Dementia Australia, *Library resources*, <https://dementiaresources.org.au/>. Accessed online January 2019.
[94] Australian Law Reform Commission, *Elder Abuse*, Discussion Paper 83, Australian Law Reform Commission, Sydney 2016.

> concept of supported or informal decision-making appears to be completely absent from the way in which providers operationalise the aged care reforms. There are often family members who are able to assist their family member to make aged care placement decisions and/or to make decisions on their behalf, but this appears to no longer be deemed sufficient.[95]

Guardianship and administration appointments are last resort decision-making mechanisms that should only be considered when all other less restrictive alternatives are exhausted. In essence, residential aged care providers, in adopting policies requiring the appointment of an attorney or guardian, are requiring that the older person be stripped of their legal capacity as a condition of obtaining a residential aged care placement. They also are inconsistent with Australia's obligations under the *Convention on the Rights of Persons with Disability* (CRPD).

Further, the ALRC considers that appointing a representative decision maker (e.g. an attorney, guardian or administrator) should not be required as a condition of receipt of residential aged care and recommended that aged care legislation should provide that agreements cannot require that the care recipient has appointed a decision-maker for lifestyle, personal or financial matters.

In the report, *Equality, Capacity and Disability in Commonwealth Laws*,[96] the ALRC recommended a set of four decision-making principles and accompanying guidelines to guide the reform of Commonwealth laws and the review of State and Territory laws. These principles emphasise the autonomy and independence of people with disability who may require support to make decisions. The ALRC advocated that a person's will and preferences must drive decisions that they are supported in making, or that others may make on their behalf. The National Decision-Making Principles are consistent with the CRPD and provide the conceptual framework for a Commonwealth decision-making model that encourages supported decision-making. The four principles are:

> **Principle 1**: The equal right to make decisions – all adults have an equal right to make decisions that affect their lives and to have those decisions respected.
>
> **Principle 2**: Support - persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.
>
> **Principle 3**: Will, preferences and rights – the will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.
>
> **Principle 4**: Safeguards – laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

Another long-standing issue relating to substitute decision-making, is the problem of many residential aged care providers insisting on only dealing with the person appointed as the enduring attorney, even when the resident still has legal capacity and the attorney's powers have not been enlivened. These practices reflect ageist attitudes, breach the human rights of older people, are unlawful and constitute a form of elder abuse.

Also of concern is the now common practice in the Australian community of moving older people against their will from their homes into residential aged care. Substitute decision-makers often make such decisions without giving serious consideration to the possibility of the person remaining in their own home with appropriate support and services. Unfortunately, this occurs even when the older person has indicated that it is their preference to remain living in their home. While family members clearly have genuine concern for the health and safety of their aged relatives, these decisions can often be driven by a desire to do 'what's best' for their family member and to protect them from

[95] Australian Guardianship and Administration Council, Submission to the Department of Human Services, *Discussion Paper – National Aged Care Reforms*, February 2015, 1 as cited in Office of the Public Advocate (Queensland), *Decision-making support and Queensland's guardianship system* (2016) 17.
[96] Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws,* ALRC Report 124, August 2014, Sydney, Australia.

risk. However, they can also be motivated by convenience for the family, to reduce the need to check in on the older person and to minimise worry over their safety and care.

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 them, even when the person has been found to have impaired decision-making capacity, breach their human rights under the CRPD. The *Guardianship and Administration Act 2000* (Qld) contains numerous provisions supporting the rights of people with impaired capacity to make, and be supported to make, decisions. This includes their right to make decisions with which others may not agree (section 5(b)) and the General Principles that recognise the importance of empowering adults to exercise their basic human rights and make their own decisions (General Principles 2 (2) and 7(2)).

It is evident that there has been little support or guidance provided by the Australian Government to residential aged care providers in relation to appropriate policy and practice in terms of recognising and upholding the rights of older people to make their own decisions and exercise their legal capacity. The main support has been the circulation of the Supported Decision Making Policy Development Guideline, developed by the University of Sydney. While the guideline appears to be well-informed and of high quality, it alone is not enough to drive the cultural and practice change that is needed to change attitudes and address ageism in the aged care sector.

There is yet to be an official Australian Government policy or legislative response to the ALRC *Equality, Capacity and Disability in Commonwealth Laws* report[97], however the new Aged Care Quality Standards, which come into effect on 1 July 2019, appear to acknowledge to some degree, the principles of supported decision-making recommended in that report. 'Standard 1 – Consumer dignity and choice', requires residential aged care facilities to ensure that:

> (c) each consumer is supported to exercise choice and independence, including to:
> (i) make decisions about their own care and the way care and services are delivered; and
> (ii) make decisions about when family, friends, carers or others should be involved in their care; and
> (iii) communicate their decisions; and
> (iv) make connections with others and maintain relationships of choice, including intimate relationships;
> (d) each consumer is supported to take risks to enable them to live the best life they can.

The Aged Care *Quality of Care Principles 2014* need to be supported by the formal adoption of the four decision-making principles and accompanying guidelines recommended by the ALRC as well as legislation prohibiting a requirement for prospective residential aged care residents to have an enduring document or guardianship order in place to gain entry into a residential aged care facility. Further, the Australian Government should be providing greater education and guidance to the sector about decision-making support and the roles and responsibilities of attorneys, guardians and financial administrators.

I request the Royal Commission to make the following recommendations:

[97] Ibid.

Recommendation 10
The Australian Government legislate to prevent residential aged care facilities requiring prospective residential aged care residents to have an enduring power of attorney or guardianship order in place as condition of entry into a residential aged care facility.

Recommendation 11
The Australian Government formally incorporate the four decision-making principles and accompanying guidelines recommended by the Australian Law Reform Commission in its report *Equality, Capacity and Disability in Commonwealth Laws* report into the Quality of Care Principles.

Recommendation 12
The Australian Government take action to initiate education and training in the aged care sector about:
- decision-making support;
- the roles and responsibilities of attorneys, guardians and financial administrators; and
- the rights of people with impaired decision-making capacity to:
  - respect and dignity;
  - have their views and preferences considered and acted upon; and
  - be supported to exercise their autonomy and agency to the greatest extent possible.

Younger people with disability residing in aged care facilities

According to the Summer Foundation (a non-profit advocacy group for young people living in residential aged care), there are currently more than 6,200 younger people with a disability living in residential aged care across Australia. Around 50 younger people with disability enter an aged care facility every week, 59 per cent of whom are transitioning to aged care from a hospital setting.[98]

The 2014-15 Senate Committee *Review of the adequacy of residential care arrangements for younger people with disability* [99] received a range of evidence from individuals, families, peak bodies, advocacy and charity groups and service providers about the inappropriateness of aged care accommodation for younger people. The Committee found that, in relation to the care for younger people, there was a lack of:
- independent living options;
- rehabilitation options to facilitate a transition to more independent living;
- age appropriate activities and friendships;
- options for supported accommodation;
- advocacy support for young people and their families; and
- a sense of community and economic involvement.[100]

A fact sheet produced by Synapse (an organisation providing supports for people with acquired brain injury)[101] adds to these findings, noting that:
- 82% of younger people residing in aged care facilities rarely or never visit their friends;
- 13% never or hardly ever go outside;
- 56% don't have a say in when they go to bed;
- 52% will not receive a visit from a friend this year; and

[98] Summer Foundation, *The Issue*, <https://www.summerfoundation.org.au/about-us/the-issue/>, accessed online April 2019.
[99] The Senate (Cth) Community Affairs Reference Committee, *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*, Parliament House, Canberra (2015).
[100] The Senate (Cth) Community Affairs Reference Committee, *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*, Parliament House, Canberra (2015).
[101] Synapse, *Get the Facts – Young People in Nursing Homes- Fact Sheet*, < https://synapse.org.au/information-services/young-people-in-nursing-homes.aspx>, accessed 26 April 2019

- 27% are parents of school aged children.

The Senate Committee, as well as most advocacy organisations in this area, note that residential aged care is not an acceptable living arrangement for a younger person with disability. It is instead the 'last resort' for people with particularly complex needs i.e. the only facility that can provide the level of health and disability supports that they require, often on a 24/7 basis.

The introduction of the NDIS has not resolved this issue. Instead, recent commentary about the NDIS and its provision of accommodation, particularly accommodation suited to younger people currently residing in residential aged care facilities, indicates that:

- More than one in twenty young people in residential aged care facilities have been determined as ineligible for NDIS funding (118 of those assessed);
- When approved for NDIS funding, the median amount of annual plans for younger people in residential aged care is $104,563. Of this total, $77,539 is allocated to aged care costs, leaving only $31,990 for disability related supports, including making plans for alternate accommodation and transition out of residential aged care facilities. While 996 Specialist Disability Accommodation (SDA) places are currently under construction in Australia, only 22 young people with disability in residential aged care currently have SDA included in their SDA plans;
- While the overall admission rate for younger people associated with the trial of the NDIS in three regions fell by 5 per cent in the period between 2013 and 2017, in one region in particular (Barwon, Australian Capital Territory) the admission rate actually increased by 37 per cent, due to a lack of suitable accommodation being available for NDIS participants.[102]

Further, data is not publicly available about the number of young people who became NDIS participants while living in residential aged care and have since moved to another form of accommodation.

This evidence demonstrates the urgent need for specialised disability accommodation to be constructed to better address the needs of young people with disability who need high levels of care. While SDA funding can provide for this type of accommodation in individual NDIS plans, the number of NDIS participants with SDA in their plans (6,400)[103] and the rate of construction (as outlined above – 996 places currently under construction) indicates there is a significant shortfall in terms of meeting demand. To address this, there needs to be a comprehensive national review of the SDA needs of current and prospective NDIS participants on a regional basis, and potentially the commencement of a new and/or fast-tracked construction program. This review should address issues relating to the respective roles and contribution of state and territory Governments as well as service providers and investors in the SDA market. If new approaches to the construction or acquisition of accommodation are not considered, the waiting times associated with SDA (if applicants are fortunate enough to be considered eligible for the funding) will be prohibitive, leaving younger people with disability continuing to reside in unsuitable aged care facilities and the goals of the NDIS for this group unfulfilled.

There are a number of best practice examples of accommodation provision for younger people with disability requiring high level supports (such as those in residential aged care facilities), including projects undertaken by YoungCare[104] and The Summer Foundation.[105]

I request the Royal Commission make the following recommendation:

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[102] Summer Foundation, *NDIS report card June 2018*, <https://www.summerfoundation.org.au/wp-content/uploads/2018/06/ndis-report-card-june-2018.pdf>. Accessed online February 2019.
[103] Ibid.
[104] Youngcare, *Youngcare's High Care Housing*, Youngcare website, accessed online April 2019. <https://www.youngcare.com.au/what-we-do/housing/>.
[105] The Summer Foundation, *Housing Prototypes*, The Summer Foundation website, accessed online April 2019, <https://www.summerfoundation.org.au/housing/housing-prototypes/>.

Recommendation 13
The Australian Government undertake a comprehensive national review of the SDA needs of current and prospective NDIS participants on a regional basis, and consider initiating a new and/or fast-tracked construction program for SDA. This review should address issues relating to the respective roles and contribution of state and territory Governments as well as service providers and investors in the SDA market.

Australian Government Action Plan

On 25 March 2019, the Australian Government released a *Younger People in Residential Aged Care – Action Plan*, as part of its commitment to minimising the need for younger people to live in residential aged care facilities.[106] This plan outlined a series of actions to fast track younger people with disability residing in (or at risk of entering) residential aged care that are eligible for NDIS funding into appropriate accommodation and supports within the community.

However, the plan continues to rely on the implementation of the NDIS complex support needs pathway and SDA program. The NDIS complex support needs pathway has not yet been formally rolled out across all jurisdictions, but already it appears that the capacity of this program is limited. Further, as noted above, the SDA is currently stretched beyond capacity. This means that wait times will potentially stretch to years, which will increase the degree of social isolation and potential mental health conditions experienced by younger people with disability who have to enter, or remain residing in, aged care.

While the plan acknowledges that 'younger people with disability often have complex health needs and the difficulty in accessing appropriate health supports in other settings is one of the main reasons younger people go to live in aged care,'[107] the focus of the national plan is on appropriate accommodation and disability supports only, rather than health care needs. The complex health supports this cohort requires are currently not being provided in community-based accommodation.

At present, the NDIS does not support the provision of what it considers to be mainstream health supports to people with disability. What this means is that young people with disability and complex health needs who want to move from hospital or residential aged care settings into community-based accommodation, they will have to do this without specialised health and medical supports in place.

Living without these necessary health supports means that people with complex conditions, including epilepsy, respiratory and circulatory system diseases, cerebral palsy and dysphagia, combined with intellectual and physical disabilities need to rely on mainstream health services. This means relying on:

- general practitioners — if and when they get to see them, depending on whether their service providers and support workers identify (and act on) the person's health needs, organise appointments and get the person to them;
- emergency room and hospital admissions — to provide emergency responses to acute health events and conditions and monitor and manage their ongoing conditions.

The complex health conditions with which many people with disability live require proactive and timely health care monitoring and medical interventions that can only be provided by health professionals and specialists, not disability support workers.

At present, mainstream state-based health services and the NDIS have no key points of connection that provide for engagement and follow up to coordinate health and disability supports and services. This situation is exacerbated by ongoing unresolved issues between state and territory

[106] Commonwealth Government, *Younger People in Residential Aged Care – Action Plan,* <https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-younger-people-with-disability-in-residential-aged-care-initiative/younger-people-in-residential-aged-care-action-plan> (2019). Accessed online April 2019.
[107] Op. cit. 2.

Government mainstream health services and the National Disability Insurance Agency about funding for health services that are critical to the health and wellbeing of people with disability.

The very real consequences of this situation was evidenced in a report by my office, *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland*[108], which investigated the circumstances surrounding the deaths of 73 Queenslanders living in supported accommodation between 2009 and 2014. This review found that 53 per cent of the deaths reviewed were potentially avoidable, highlighting a range of systemic issues that need to be addressed as a government priority.

These included:

- The need to address risk factors and vulnerabilities for people with disability in care, including issues associated with respiratory diseases (mainly pneumonia and aspiration pneumonia), epilepsy, circulatory system diseases (including Ischaemic heart disease), choking/food asphyxia and the use of psychotropic medications to manage challenging behaviours.
- The need to improve the quality of health care and disability supports, including improving primary care and intervention practices with regular general heath and annual comprehensive health checks, identifying the signs of serious illness early, improving access to health care and support including medical specialists for complex conditions, enhancing the coordination of health care and disability services and end-of-life care and decision-making[109].

The rollout of the NDIS is likely to experience the usual problems and service gaps that arise during with the implementation of new and complex social programs. If this occurs, there is a risk that the rate and types of avoidable deaths identified in the Upholding the right to life and health report will potentially escalate. This will be a particular concern if young people residing in residential aged care facilities (and long-term in health facilities) are transitioned into accommodation within the general community without the necessary health supports to keep them safe and well.

I request the Royal Commission make the following recommendation:

Recommendation 14
The Australian Government, as a matter of urgency, seek to clarify and finally settle with state and territory Governments the funding issues associated with the provision of necessary health supports for NDIS participants with complex health and disability needs, who are wanting to transition from residential aged care facilities (and other health and disability facilities) to community-based accommodation.

Deaths of young people residing in aged care facilities

Deaths of young people with disability residing in residential aged care facilities can also potentially go unreported, as deaths in aged care are reported under a different, narrower regime (as previously explained under the heading 'Reportable deaths in care'[110]).

For example, the *Coroners Act 2003* (Qld) currently defines a death to be reportable if it was a death in care. Under section 9(1)(a), a person's death is a death in care if, when the person died, the person had a disability noted in the *Disability Services Act*, section 11 and is living in certain types of residential services (like level 3 accredited residential services) or receiving services providing accommodation funded by the department administering the *Disability Services Act*. This legislation is currently under review to reflect the changes to the NDIS disability service environment, however, it is anticipated that a similar definition will also apply in the future, i.e. a death is reportable if it is a death in care.

[108] Office of the Public Advocate (Qld), *Upholding the right to life and health: A review of deaths in care of people with disability in Queensland,* (2016) <https://www.justice.qld.gov.au/data/assets/pdf_file/0008/460088/final-systemic-advocacy-report-deaths-in-care-of-people-with-disability-in-Queensland-February-2016.pdf> Accessed online April 2019
[109] Ibid.
[110] At p 21 of this submission.

The arrangements for reporting and investigating deaths in aged care facilities are quite different from disability deaths. Residential aged care facilities are not prescribed places for reporting deaths in any Australian coronial legislation. Therefore, unless the death of a young person with disability residing in an aged care facility is considered to be 'unnatural', suspicious or health care related, it will not be reported to the coroner. Nor will it be reported by the NDIS Quality and Safeguards Commission, in the way any other death of a person receiving NDIS-funded services would be.

When a young person with disability is accommodated in a residential aged care facility, that person does not have the benefit of the oversight and other accountability mechanisms available to people with disability, such as community visitor programs. These inequities further highlight the inappropriateness of residential aged care facilities as accommodation for younger people with disability.

I request the Royal Commission make the following recommendation:

Recommendation 15
The Australian Government legislate to require the deaths of young people residing in aged care facilities, who would otherwise be eligible for the NDIS, but cannot access appropriate accommodation and health supports, be reported by the NDIS Quality and Safeguards Commission and be potentially reportable to the Coroners in States and Territories as deaths in care.

Concluding comments

I fully support the Royal Commission of Inquiry into Aged Care Quality and Safety. I am confident the Royal Commission will be a catalyst for enduring and positive policy, legislative and practice change across Australia's aged care sector.

The change required in the Australian aged care sector will need strong direction and leadership that delivers clear legislative and regulatory frameworks, and enforceable standards that clearly articulate service level expectations. These changes should also include effective safeguards to ensure that older Australians receiving aged care services, many of whom are some of the most vulnerable members of our community, receive appropriate quality care, have their human and legal rights protected, and are treated with respect and dignity.

This submission has addressed issues relating to:

- the use of restrictive practices in residential aged care;
- effective complaint management frameworks, including advocacy, community visitor programs and the reporting of deaths in care;
- the aged care workforce;
- end-of-life planning and care, including substitute decision-making; and
- younger people with disability residing in aged care.

I have proposed a series of recommendations for the Commission to consider, which are summarised below.

Finally, I thank the Royal Commissioners and the Commission staff for your work on this very important Inquiry and for the opportunity to provide this submission. I look forward to the Commission's reports and recommendations.

Yours sincerely

Mary Burgess - Public Advocate (Queensland)

Summary of recommendations

Issue	*Recommendations*
Restrictive practices	**Recommendation 1** The Australian Government: • Immediately implement a comprehensive residential aged care restrictive practices regulatory framework with all of the characteristics and protections recommended by the Australian Law Reform Commission in its report *Elder Abuse – A National Legal Response*[1] in Recommendations 4-10 and 4-11. • Introduce additional accreditation standards relating to: the design of aged care facilities; the development or adoption of specific programs to support residents with dementia; and the development and implementation of positive behaviour support processes. • Establish a funding program to support the initiation and trial of best practice and innovative projects to improve the quality of aged care and its responsiveness to the needs of consumers.
Effective complaint and investigation mechanisms	**Recommendation 2** The Australian Government require the Aged Care Quality and Safety Commission to undertake more detailed categorising and reporting of complaint types and trends to assist in the identification of systemic issues and trends in complaints and quality of care issues in aged care service provision. **Recommendation 3** The Australian Government adequately fund the National Aged Care Advocacy Program to ensure that older Australians receiving aged care services can access advocacy to assist them to make complaints and raise issues about their treatment and care. **Recommendation 4** The Australian Government introduce a fully funded aged care community visitor scheme (with paid employees, not volunteers) based on the Queensland community visitor program under the Public Guardian Act 2014 (Qld), as a key program supporting the complaints management framework applicable to aged care service providers. **Recommendation 5** The Australian Government introduce and fund a national Deaths in Aged Care Review Process, where deaths in aged care are reported to and investigated by State and Territory Coroners. **Recommendation 6** The Australian Government give the Aged Care Quality and Safety Commission responsibility for reduction of harm in aged care by improving practice, similar to the role of the Australian Commission on Safety and Quality in Health Care.
The aged care workforce	**Recommendation 7** The Aged Care Quality and Safety Commission be directed by the Australian Government to undertake further research and feasibility work, to develop a staff ratio and skill/experience mix for residential aged care facilities based on the Aged Care Funding Instrument and the level of need of residents.

Recommendation 8
The Australian Government, consistent with the Productivity Commission recommendation, require residential aged care facilities to publish information about the staff and skill mix the facility provides for the profile of aged care residents, so that consumers can make more informed choices about what services best suit their needs. Uniform standards for the provision of this information may need to be set to ensure the information provided is accurate and that aged care consumers and their supporters can make ready comparisons between facilities.

End of life planning and care

Recommendation 9
The Australian Government incorporate the *Principles for Palliative and End-of-Life Care in Residential Aged Care*[1] into the Quality of Care Principles for aged care, and require that compliance with these standards be a component of the assessment for accreditation of aged care providers.

Recommendation 10
The Australian Government legislate to prevent residential aged care facilities requiring prospective residential aged care residents to have an enduring power of attorney or guardianship order in place as condition of entry into a residential aged care facility.

Recommendation 11
The Australian Government formally incorporate the four decision-making principles and accompanying guidelines recommended by the Australian Law Reform Commission in its report *Equality, Capacity and Disability in Commonwealth Laws* report into the Quality of Care Principles.

Recommendation 12
The Australian Government take action to initiate education and training in the aged care sector about:

- decision-making support;
- the roles and responsibilities of attorneys, guardians and financial administrators; and
- the rights of people with impaired decision-making capacity to:
  - respect and dignity;
  - have their views and preferences considered and acted upon; and
  - be supported to exercise their autonomy and agency to the greatest extent possible.

Younger people with disability residing in aged care facilities

Recommendation 13
The Australian Government undertake a comprehensive national review of the SDA needs of current and prospective NDIS participants on a regional basis, and consider initiating a new and/or fast-tracked construction program for SDA. This review should address issues relating to the respective roles and contribution of state and territory Governments as well as service providers and investors in the SDA market.

Recommendation 14
The Australian Government, as a matter of urgency, seek to clarify and finally settle with state and territory Governments the funding issues associated with the provision of necessary health supports for NDIS participants with complex health and disability needs, who are wanting to transition from residential aged care facilities (and other health and disability facilities) to community-based accommodation.

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The Australian Government legislate to require the deaths of young people residing in aged care facilities, who would otherwise be eligible for the NDIS, but cannot access appropriate accommodation and health supports, be reported by the NDIS Quality and Safeguards Commission and be potentially reportable to the Coroners in States and Territories as deaths in care.