Inquiry into the Aged Care Quality and Safety Commission Bill 2018

Submission to the Standing Committee on Community Affairs

September 2018

The Public Advocate

Influencing change to empower lives

Introduction

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

More specifically, the Public Advocate has the following functions:

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

The Public Advocate welcomes the opportunity to make this submission to the Inquiry into the Aged Care Quality and Safety Commission Bill 2018 and related Bill. 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 are 425,416 Australians living with dementia.[2] Without new medical discoveries and interventions, the number of Australians living with dementia is expected to increase to over 1.1 million by 2056.[3] In 2015, more than half of the people who permanently resided in residential aged care had a diagnosis of dementia.[4] This proportion is expected to increase over time as the number of people living with dementia increases as a proportion of the population.[5] In light of this, it is likely that a significant proportion of aged care recipients will have or will experience impaired decision-making capacity at some point during their engagement with the residential aged care system.

Importance of effective complaints systems

The Public Advocate welcomes the intent of the *Aged Care Quality and Safety Commission Bill 2018* (the Bill) to improve the functions and effectiveness of complaints systems for aged care services.

Given the increasing number of people in aged care with impaired decision-making capacity, the Bill should expressly acknowledge the need for support in dealing with the new Aged Care Quality and Safety Commission to achieve better outcomes and to properly make complaints when necessary. For example, under the *National Disability Insurance Scheme Act 2013* (Cth) (the NDIS Act), its general principles note that people should be supported in all their dealing and communications with its Agency and Commission so their capacity to exercise choice and control is maximised.[6] Further, the NDIS Act expressly provides that the Agency may provide support and assistance to participants in relation to achieving the purposes of the NDIS Act.[7] The Bill under

[1] *Guardianship and Administration Act 2000* (Qld) s 209.
[2] Dementia Australia, *Dementia statistics* (January 2018) Dementia Australia <https://www.dementia.org.au/statistics>.
[3] Professor Laurie Brown, Erick Hansnata and Hai Anh La, *Economic Cost of Dementia in Australia 2016-2056* (February 2017) Alzheimer's Australia, 7 <https://www.dementia.org.au/files/NATIONAL/documents/The-economic-cost-of-dementia-in-Australia-2016-to-2056.pdf>.
[4] Australian Institute of Health and Welfare, *Australia's Health 2016*, Australian Government, 109 <https://www.aihw.gov.au/getmedia/9844cefb-7745-4dd8-9ee2-f4d1c3d6a727/19787-AH16.pdf.aspx?inline=true>.
[5] Ibid 108.
[6] *National Disability Insurance Scheme Act 2013* (Cth) s 4(9).
[7] Ibid s 6.

review should make similar acknowledgements and commitments to ensure people receiving aged care services are provided with assistance.

Complaints mechanisms are integral to a comprehensive system of 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 that prevent many of these people from having their issues resolved through formal complaints mechanisms.[8] In addition to the usual reasons for not making formal complaints,[9] people with impaired decision-making capacity (including older people with dementia) are likely to experience additional barriers to making complaints for reasons that include:

- lack of knowledge and understanding of their rights;
- difficulty accessing the process or the entry points for making complaints;
- fear of not being believed or taken seriously when they do make a complaint;
- difficulty in managing and presenting evidence to support their complaint;[10] and
- fear of reprisals or withdrawal of services.[11]

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.[12] These adults frequently required additional support to use complaints systems effectively.[13] The type of support that people may require varies, from assistance to identify the need to make a complaint, to assistance with most or all aspects of the complaint-making process, including progressing the complaint to an external complaints agency. This support is not always offered through organisational complaints management systems. This was also observed to be the case for some organisations whose role it was to provide specialist supports to this group.

These and other issues are likely to significantly reduce the 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 of complaints management systems for people with impaired decision-making capacity and support to actively engage in the complaint-making process.

The United Nations *Convention on the Rights of Persons with Disabilities* places obligations on Australia to make reasonable adjustments to supports, systems and processes to ensure they are accessible to people with disability. The Convention recognises that disability is an evolving concept that results from the interaction between those with impairments and their environment.[14] This concept, and the Convention more broadly, has applicability in the context of aged care.

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[8] Office of the Public Advocate, *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>.

[9] 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.

[10] Office of the Public Advocate, above n 8, 8-10.

[11] 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>.

[12] Office of the Public Advocate, above n 8.

[13] Office of the Public Advocate, above n 8, 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 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>.

[14] *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*') preamble.

Strategies that could be used to strengthen the voices of older and vulnerable Australians who interact with the residential aged care system include:

- proactively identifying dissatisfaction;
- ensuring access to independent advocacy;
- adopting facilitative and inquisitorial approaches;
- guaranteeing safety and freedom from reprisal;
- recognising the value of informal complaint-making processes; and
- ensuring a responsive system.[15]

This office's complaints management systems project also highlighted how additional systemic review mechanisms may ameliorate some of the inadequacies of formal complaints management systems. For example, the frequent and on-going presence of external visitors may assist with identifying and raising issues for people with impaired decision-making capacity and progressing them to resolution (discussed further below).

Reports on complaints

The Public Advocate submits that the Bill should have more specific requirements in terms of annual reporting by the Commissioner. Currently, the Aged Care Complaints Commissioner's Annual Report contains some very useful information about the role and functions of the Commission and its handling of complaints. The Commissioner's Annual Report for 2016-17 detailed that 4,713 complaints were received in that year, a 20 percent increase on the previous year. It also provided some high-level detail about complainants, e.g. the proportion of complaints that were made by people receiving aged care services or by family members or other representatives.[16]

The Annual Report highlighted that 78 percent of all complaints were about residential aged care and that the number of these complaints was higher than the previous year.[17] However, the report provides no information about the types of complaints received.

This broad level of reporting does not enable the public, or agencies such as the Public Advocate, to determine whether there are any, or many, complaints about the use of restrictive practices or other conduct that would amount to elder abuse in residential aged care facilities, whether those complaints were substantiated, or whether they are increasing. Considering the number of complaints made about residential aged care, the unregulated use of restrictive practices, the vulnerability of many consumers and the importance of respecting their human rights, the Age Care Complaints Commissioner should be required to provide the public with greater detail about the type and nature of complaints received and the outcomes of those complaints.

This issue was noted in the Carnell-Paterson Review.[18] Publishing more detailed information about complaints will facilitate greater system transparency and accountability. The community, and more importantly, older Australians and their family members, are entitled to know more about these complaints. In particular, there is a need to ensure public scrutiny of the use of restrictive practices in residential aged care settings. Requiring these details in an annual report can be legislated,[19] and would ensure increased transparency in line with recommendations from the Carnell-Paterson Review.

Community visitor program

Community visitor programs (such as the one established in Queensland under the *Public Guardian Act 2014* (Qld)) can assist in detecting mistreatment and assisting aged care recipients in making

[15] Office of the Public Advocate, above n 8.
[16] Aged care Complaints Commissioner, *Annual Report 2016-17* (2017) Australian Government, 2 <https://www.agedcarecomplaints.gov.au/wp-content/uploads/2017/09/Annual-Report-2016-17-PDF.pdf>.
[17] Ibid.
[18] Kate Carnell, Ron Paterson, 'Review of National Aged Care Quality Regulatory processes' (2017) 148, 155.
[19] See, for example *Mental Health Act 2016* (Qld) s 307.

complaints. The Queensland community visitor program for adults with impaired decision-making capacity employs community visitors to undertake regular announced and unannounced visits to specified accommodation sites for the purpose of monitoring service delivery.[20] 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.[21] Community visitors can lodge reports with the Office of the Public Guardian,[22] which in turn provides a report to the service provider for follow-up action.[23]

Such programs have shown to be an effective mechanism in detecting and initiating appropriate actions, as identified by the Carnell-Paterson Review.[24]

Although there is a current Community Visitor Scheme with the Commonwealth Department of Health, it does not have the same powers or functions as the community visitor program in Queensland. Consideration should be given to the establishment of a new program in the aged care sector modeled on the community visitor program in Queensland. Such a program could be established under the Commission and be part of the complaints functions to assist people in identifying issues and following up on complaints.

Systemic advocacy

Currently under the Bill, it is not clear whether there is an overarching systemic advocacy function afforded to the branches of the Commission. One of the many findings of the Carnell-Paterson Review was that the Commission should have a systemic advocacy function.[25] The Bill should specify that systemic advocacy is a key function of the Commission so that it is properly acknowledged and performed by the Commission.

Systemic advocacy is an important function to identify to address broader system-wide issues that require a different approach from simply dealing with discrete issues separately. We should not need another Oakden before systemic issues are investigated and addressed.

Information sharing

Given that aged care services intersect with many services and functions provided by state and territory agencies, the Bill should implement provisions in which the sharing of information between the new Commission and relevant state and territory agencies is acknowledged and allowed. Such agencies include the various public guardians, public advocates and public trustees that may require certain information from the Commission to assist in making decisions on behalf of people with impaired capacity, conduct systemic advocacy on a state or territory level or manage a person's finances.

Currently, clause 61 of the Bill allows the Commissioner to disclose information on public interest grounds, which could allow disclosure to state and territory agencies. However, the NDIS Act goes further and acknowledges that its Quality and Safeguards Commissioner should work with relevant state and territory agencies, and now includes a provision to acknowledge such information sharing arrangements.[26] Further, the NDIS Act provides that rules can be created so these

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[20] Office of the Public Guardian, *Community Visitors*, Office of the Public Guardian <www.publicguardian.qld.gov.au/adult-guardian/adult-community-visitors>.
[21] Ibid.
[22] *Public Guardian Act 2014* (Qld) s 47(1).
[23] Ibid s 47(3).
[24] Kate Carnell, Ron Paterson, above n 18, 85.
[25] Kate Carnell, Ron Paterson, above n 18, 106.
[26] *National Disability Insurance Scheme Act 2013* (Cth) s 67E(b)(iii).

information sharing arrangements can be formalised, providing a level of certainty and consistency.[27]

The Bill should therefore have similar provisions to those contained in the NDIS Act. This will allow relevant agencies to access information to assist people in aged care when needed, and facilitate the important services these agencies provide to people with impaired capacity.

Restrictive practices in aged care

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.[28] 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 media devices)[29] are regularly employed in human service and criminal justice settings, such as disability accommodation and support services, residential aged care facilities, mental health services and prisons. 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[30] and may also constitute a breach of law and human rights.[31]

The lack of regulation of restrictive practices in aged care is concerning for a number of reasons. 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 dementia. There is a growing body of research indicating that dementia-related behaviours are often being managed by unregulated restrictive practices,[32] and that restrictive interventions are in widespread use in both formal and informal aged care settings.[33] This is particularly problematic given the number of people in residential aged care who have a diagnosis of dementia.

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[27] *National Disability Insurance Scheme Act 2013* (Cth) s 67F.
[28] Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* Report No 124 (2014) 243.
[29] 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.
[30] 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.
[31] 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.
[32] 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 Behaviors Associated with Dementia in Aged Care' (2010) 32(5) InPsych.
[33] 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 Behavioral and Psychological Symptoms of Dementia?' (2013) 25(5) *International Psychogeriatrics* 743-753.

Evidence also suggests that some residential aged care staff do not have the knowledge and/or skills to manage behaviours appropriately,[34] and that the wellbeing of the person being restrained may be negatively affected as a result.[35] 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.[36] In one case, the use of restrictive practices was found to be a breach of the care principles under the *Aged Care Act*.[37]

The use of restrictive practices in aged care was described as 'a matter of grave concern' to the Carnell-Paterson Review.[38] While some jurisdictions in Australia regulate the use of restrictive practices in the disability and/or mental health sectors,[39] the law governing these practices in residential aged care is unclear and, for the most part, non-existent.[40] At present, the *Aged Care Act 1997* (Cth) does not regulate the use of restrictive practices such as chemical, physical and mechanical restraint.

The increasing number of people with dementia and the potential harm that may occur as a result of ad hoc or poorly applied restrictive practices[41] suggest an urgent need to clarify the legality of restrictive practices in the Australian aged care system and to establish a more consistent, evidence-and rights-based approach to responding to dementia-related behaviours.

The Public Advocate acknowledges that the recent announcement of a Royal Commission into aged care quality and safety will no doubt address this issue in detail and at some length, but in the absence of any other solution, the Commission will most likely be the agency to oversee restrictive practices, once regulated. Although it may be seen as premature, the Bill could acknowledge it will be part of the Commission's functions to provide oversight for restrictive practices, clearly demonstrating the Commonwealth government's commitment to this issue and the recommendations of the Carnell-Paterson Review.

Concluding comment

The establishment of the Aged Care Quality and Safety Commission is a positive direction in protecting the rights of people in aged care. The Carnell-Paterson Review was an illuminating report in the various shortcomings of the current system and contained many practical recommendations that would improve the aged care system that an increasing number of people will be relying upon.

However, the Public Advocate would recommend that the aged care system also look towards state-based systems that oversee service delivery to vulnerable cohorts (such as disability services) that have been developed over time and which have established a range of safeguards and

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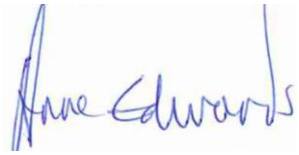
[34] See Sally Borbasi et al, above n 32.
[35] Nicholas G Castle, 'Mental Health Outcomes and Physical Restraint Use in Nursing Homes {Private}' (2006) 33(6) *Administration and Policy in Mental Health and Mental Health Services Research* 696-704; K Cubit et al, 'Behaviours of Concern in Dementia: A 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.
[36] 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>.
[37] *Saitta Pty Ltd v Secretary, Department of Health and Ageing* (2008) 105 ALD 55, at [122]. The application of restrictive practices was not the core matter being determined and the general use of restrictive practices was not explored in detail in the tribunal decision.
[38] Kate Carnell, Ron Paterson, above n 18, 114.
[39] See, for example, *Disability Services Act 2006* (Qld) pt 6; *Mental Health Act 2016* (Qld) ch 8.
[40] 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.
[41] 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*.

reporting mechanisms that continue to assist in creating more transparent, responsible systems. Such measures include community visitor programs, systemic advocacy and the regulation of restrictive practices.

Thank you for the opportunity to provide feedback to your Committee regarding the *Aged Care Quality and Safety Commission Bill 2018*. Should the opportunity arise, I would be pleased to be part of further discussions in relation to these matters or any other issues raised in my submission.

Yours sincerely



Anne Edwards

A/Public Advocate (Queensland)