ADA Australia's Response to the Queensland Government Inquiry into Earle Haven Aged Care Facility – Nerang

Aged and Disability Advocacy Australia (ADA Australia) welcomes the opportunity to provide a written response to the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee following announcement of a *"Parliamentary Inquiry to investigate understaffing and the drugging of elderly Earle Haven residents."* ADA Australia for reasons outlined below brings a unique perspective and information to the Inquiry.

About ADA Australia

Aged & Disability Advocacy Australia (ADA Australia) is a not for profit, independent, community-based advocacy and education service with more than 25 years' experience in supporting and improving the wellbeing of older people and people with a disability.

ADA Australia provides individual advocacy support to users and potential users of Commonwealth funded aged care services and is a member of the Older Persons Advocacy Network (OPAN) delivering the National Aged Care Advocacy Program (NACAP) in Queensland.

ADA Australia also operates a Human Rights advocacy service in South-East Queensland supporting people with impaired capacity, including support as they engage with the Queensland Civil and Administrative Tribunal (QCAT).

ADA Australia has recently provided feedback to the Australian Government's Parliamentary Joint Committee on Human Rights expressing concern about the way the Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019 '**Principles'**, breach the United Nations Convention of the Rights of People with a Disability (UNCRPD).

ADA Australia supports the sentiments expressed by Human Rights Watch (HRW), dated 23 May 2019, the Office of the Public Advocate Victoria (OPA), dated 11 July 2019, and the draft report of the Queensland Office of the Public Guardian (OPG) in relation to the Principles. ADA Australia's submission to the Joint Committee effectively provided a "consumer voice" and highlighted the extent to which the Principles have effectively further undermined consumer rights and for this reason require urgent re-consideration.

The inappropriate use of chemical restraint in aged care has been a matter of increasing concern raised by both aged care residents and family members across Queensland supported by ADA Australia in recent years. ADA Australia's observation is that the use of restraints in the aged care sector have been unregulated for a long time, and thus welcome the Parliamentary Committee's Inquiry through what ADA Australia hopes will be the lens of Australia's Human Rights obligations.

To ensure ADA Australia's responses in this submission are informed by factual information pertaining to those residents and their representatives from Earle Haven (EH) whom the organisation has supported over recent years, the author undertook review, drawing upon confidential information captured in advocate case notes, with a start date of 1 January 2016 up to the present. The rationale is that rather than present just a very recent snapshot of resident concerns, this longer-term view provides useful insight into the nature of the

concerns being raised by EH residents and their representatives prior to the appointment of an Adviser in June 2016, the subsequent imposition of sanctions in May 2017, and this most recent closure episode in July 2019.

Older people who have resided at EH, along with their concerned representatives and other family members, are well placed to inform the Inquiry as their concerns represent the lived experience.

Stakeholders whom ADA Australia have supported made frequent reference to the incongruence between their experience of the standard of care delivered day to day, and the outcome of EH's accreditation in 2017 where the facility scored 44 out of a possible 44, apparently meeting every benchmark. The result was a further source of harm as it totally negated the very real concerns which many residents and representatives made known to the auditors during the 2017 process.

Later in 2017 when the Commonwealth Department of Health placed EH under sanction, stakeholders hoped this would bring about the improvements in care that they had been agitating for, for many years. Disappointingly, those improvements did not come about, and many residents continued to experience a sub-standard level of care and human rights abuses including the unregulated use of chemical and physical restraints.

While the specifics around the matters EH residents or their representatives sought advocacy support with may differ, the review of case files highlighted consistent themes outlined below:

Refusal to engage

- Those impacted by poor care mentioned how they'd been attempting for years to have their issues listened to and responded to appropriately. Those affected by the poor care spoke of the impact of their on-going efforts to have their needs met and how exhausting it was to keep fighting to be heard.

- In testimonies the owner/manager was singled out for their unapproachability and dismissive attitude in respect to concerns, allegedly avoiding contact with residents wherever possible. On the rare occasions concerned stakeholders were able to raise their concern with him, he was reported as being dismissive, rebuffing the issues as not a legitimate concern, or shifting responsibility for the issue onto some other party. While some reported Mr Miller as 'rude and pompous' and unapproachable, most residents reported they were afraid of him, based on his reputation as a bully. Residents would confide in each other, but very few felt empowered to speak their truth to the person ultimately responsible for the quality of their care.

High staff turnover

- The unusually high turnover of staff, from the most senior managerial and clinical staff to the personal care workers who delivered the hands-on care, was a recurring comment made by care recipients. One resident lived through 6 different managers over her 13-year residency. Residents reported the transient workforce impacted in respect to continuity of care, quality of the care, and relationships, from a social and clinical perspective. For some residents whom have no family nearby, their engagement with care staff may be their only interactions, creating an additional level of vulnerability.

- Concerned family members would speak to the family of other residents and share their concerns and this stakeholder group agitated endlessly for improvements in the standard of care but were unsuccessful for the most part in bringing about long-term improvements in the standard of care. It's reported that if families agitated with

enough persistence, small improvements might occur however things would slide back to unacceptable levels shortly afterwards and they would feel compelled to advocate strongly for their loved one once more.

Unreasonable conduct by management

- *ADA Australia's most recent case involved a former care worker of EH 'Anne'. Anne resigned 3 years ago but has maintained an enduring friendship with three residents, visiting each once a week for 1:1 outing. Effectively her role changed from paid worker to friend. Each week each of the three residents were strategically taken to the same destination so that post outing, they would have something new, fresh and shared-in-common to talk about, eg, this week each goes to the beach, next week the museum.*

- *On one occasion as Anne was returning the third of the residents back to EH after their turn at the beach, Anne was accosted by someone unknown to her, who later identified herself as the new clinical manager. This manager accused Anne of kidnapping the resident and had called the police to report the absence. Despite Anne's attempts to explain the routine, she was advised by the clinical manager that her employment with EH was terminated, effective immediately, and that she was banned from visiting the facility in future.*

- *Anne's efforts to correct the misunderstanding resulted in her behaviour being labelled as aggressive and abusive by the clinical manager. Anne was later contacted by EH and advised that she was once again free to visit EH in the capacity of a 'volunteer' and was welcome to once again take residents on outings, however the facility would decide which resident was to be the beneficiary of the outing.*

- *The small window of normality for these three residents had been halted. The right of every resident to maintain friendships with whomever they choose, and their right to continue the routines that were a feature of their lives prior to entering care, were extinguished by the actions of the most senior clinician.*

Staff disharmony and lack of communication

- The case review highlighted multiple mentions of the lack of communication between management and staff and between the hierarchy of workers providing day to day care. Residents whose lives depend on the skills and commitment of EH's workforce reported dysfunctional relationships.

- Residents often commented on the quality of EH's workforce and case notes made by ADA Australia's advocates reflect on-going concerns. Residents would comment about how wonderful the grounds staff and cleaners were and how responsive these staff were when asked to respond to an issue. In respect to the care staff, resident praise was much more circumspect.

- While some individual care staff were excellent and offered the very best care they could, notes reflect that good staff did not thrive in the culture of this facility and often left because they couldn't reconcile their obligation and duty of care in this work environment. When close relationships between these committed staff and the residents were formed, departing staff would, as a courtesy advise residents of their

decision to leave and it is reported that some confided to residents the reasons behind their decision.

Staff Skills and Sufficient Numbers

- It was reported that relatives would visit their loved one almost daily to ensure the resident was provided sufficient assistance to eat, as the only reliable assurance that they ate at all. *Over time 'Betty's' daughter 'Amanda' developed an understanding and capacity to respond to not just her mother's needs at meal time but the needs of those other residents with dementia, who also needed support with their meal. It was observed how these residents were regularly missing out on meals because there were no care staff to assist them.*

- *It was reported that unskilled, inexperienced, unsupported and unsupervised care staff, increasingly looked to her for reassurance and direction. To these staff, Amanda was readily identifiable as the otherwise only, skilled and competent individual, who was demonstrably capable of supporting several residents with their requirements at meal time. In one instance, she observed a care worker attempting to feed an older woman who didn't speak English and who didn't have any teeth, a roast dinner; and was interpreting the woman's inability to chew and swallow as a refusal to eat. Amanda intervened and had to educate this inexperienced worker about the resident's need for textured food and that her struggles weren't a refusal to cooperate.*

- *Additionally, Amanda would observe students on placement in the facility working with residents without a paid care worker in sight. She understood that students on placement must always be supervised however this frequently wasn't the case. The trainee aged care workers were operating outside their levels of competence and the facility who committed to providing the oversight and supervision was failing to provide it.*

- *The observations of Amanda are insightful as it sheds light on how it was possible for another resident with dementia 'Maria' who weighed 51kgs when she entered care in October 2015 but by June 2016 only weighed 37.9kgs. While it is acknowledged there may be multiple causes for rapid weight loss, not having adequate staff at meal time must be considered a significant concern.*

Acting without consent: Chemical / Physical Restraints and other Healthcare Decisions

- Maria's daughter 'Greta' originally contacted ADA Australia for advocacy around concerns that Maria was being subjected to unauthorised chemical and physical restraint. Given the recent disclosures at the Brisbane Hearing of the Aged Care Royal Commission, it is of concern that this complaint represents the only case in the 3.5-year period of the case review that challenged the facility over its unauthorised use of chemical and physical restraints.

- *Greta sought to understand why one day she found Maria unable to sit up and physically restrained in her chair, when only a few days earlier Maria had been alert and able to hold her head and body upright. Greta, who was Maria's enduring power of attorney (EPOA), sought answers and it was then that she learned that Maria was being prescribed anti-psychotic medication, Risperidone, without any prior*

consultation or consent. The physical restraint being used to keep her mother from falling out of the chair also occurred without consultation or consent.

- The absence of other concerned families contacting ADA Australia for support to interrogate the use of restraints, begs further interrogation. Causes for this may be: feeling too afraid to escalate their concern; whether there were intimidatory tactics used by the provider to deter escalations; a lack of understanding about resident's rights; a lack of access to information about where to seek support; the failure of agencies whose role it is to deal with clinical concerns to listen, believe and then properly investigate the complaint before the case was closed; a lack of close and continuing family relationships for the residents; and/or all of the above.

It would appear that sustained human rights abuses occurring in this care environment, for the most part, went unchallenged.

- *Greta also detailed how, despite it being well known she was her mother's EPOA, a regular visitor, and obviously actively engaged in Maria's care, the facility failed to inform her of the decision to implement palliative care.*

- *She reported a visiting Speech Pathologist ordered NIL by Mouth for her mother, without consultation. Sometime after this decision had been made, she visited Maria, oblivious, made mum a cup of tea as she always did and watched in surprise as her mother guzzled down this cup of tea, as Maria hadn't been given anything to eat or drink for some time.*
- *It was sometime later she learned of the order to withhold all food and fluid. When she pursued this with the Speech Pathologist, she was advised the order was made at the behest of the visiting GP, on the basis that the resident was no longer able to swallow. When Greta contacted the GP to clarify this, the GP denied issuing the directive.*

Record Keeping

- *'Chen' was concerned about the quality of care of her mother and was frustrated by her ineffective attempts to bring about improved care and requested to see her mother's care plan. Chen was advised by care staff that care plans didn't exist in this facility. Chen was a regular visitor to the facility, and sometime later saw students put to work creating care plans for each resident. She was aware that the scheduled accreditation was not far away, and that this task created the illusion that care plans had existed all along. Chen noted that nothing got written down and that at handover, there was no exchange of written information, just verbal exchanges.*

Accreditation and Reporting Concerns

- *Chen was one of a number who spoke up about their concerns pertaining to the standard of care in Orchid House, as part of the accreditation - stakeholder feedback process in 2017. These stakeholders reported fully briefing the auditor about their individual experiences of poor care for their family member and their long-held concerns about the standard of clinical care across the facility. Chen reported that those who were courageous enough to speak the truth, notwithstanding the risks entailed in providing their honest feedback, were stunned when EH was deemed to have scored 44/44.*

- This accreditation episode was totally demoralising for those who spoke up, because not only was it their opinion that the care provider was failing their loved one, the independent objective process designed to identify issues of concern had just validated and endorsed the agency for its poor care, almost guaranteeing the continuance of same.

- By the time Chen contacted ADA Australia, she had already referred her clinical concerns to the Aged Care Complaints Commission (ACCC) and the Quality Agency. According to Chen the ACCC complaints officer humiliated and belittled her by speaking down to her, and she told how at some later point, the complaints officer phoned and apologised to her for their behaviour. This poor behaviour aside, there was no outcome for this carer from the referral to the ACCC. It was her view that systems 'safeguards' had fundamentally failed this resident and her family.

- The experience of Chen is important to consider because she typifies the lengths concerned family went to bring about improved care for their loved ones. Anecdotal information provided by concerned families is that it did not matter whether they were patient, diplomatic, tenacious, persistent and determined in the efforts to ensure good care for their family member. The facility had a way of negating, dismissing, minimising and ignoring. Families report being labelled as 'troublemakers' or 'serial complainers' and having staff 'ducking for cover' as they entered the facility because their reputations as 'whingers' was well known throughout the facility.

- In some instances, persistence and tenacity on the part of family was branded as harassment and inappropriate behaviour by care staff, and some were banned from EH. They witnessed their loved ones suffering in EH and felt compelled to do whatever was necessary to see improved care.

Closing Remarks

The current aged care system is complex and does not operate under a human rights framework. The rights and views of aged care recipients are often ignored, as appears to be the situation in the lead up to the closure of Earle Haven.

Despite a long history of concerns from care recipients and their families, the service delivery model of Earle Haven did not appear to respond to these concerns. A reluctance to speak coupled with a fear of reprisal has allowed a toxic culture to continue unchallenged.

ADA Australia, as a member of the Older Persons Advocacy Network (OPAN) has argued to the Royal Commission into Aged Care Quality and Safety via its direct representations and written submissions, that weaknesses in the current aged care system include aspects of the way advocacy services are currently configured. OPAN argues that advocates are working directly with the complainant and therefore can assess the complainants care concerns first hand. OPAN believes that advocates are well placed to assess whether care recipient rights have been infringed by the actions of the care provider.

Under the current system, if the provider doesn't respond willingly to suggestions from the advocate about how the care could be tailored to better suit the complainant, then advocates have no authority to direct the provider to do things any differently, so advocates find this is where their capacity to influence change often ends. While some care providers are open to the advocate's input, others aren't and it's mostly these providers who are regarded as giving cause for concern.

ADA Australia believes that as part of the reform of the aged care system, advocates should be provided a stronger framework whereby, following their assessment of a complainants circumstances, including meeting with the care provider, if an advocate makes a set of recommendations, based on legislation, program guidelines and individual care agreements, then the care provider must either accept these recommendations or detail on what grounds they believe that to do so is outside the spirit of the legislation and/or general service delivery operating framework. Rejecting and/or ignoring an advocate's suggestions without reasons should not be an option.

ADA Australia is not suggesting advocates be given unlimited powers to direct care providers as this could potentially result in this power being abused. It argues that advocates who are close to a situation are better placed to make an accurate assessment of a situation involving a care recipient and a care provider that perhaps are staff from the Aged Care Quality & Safety Commission (ACQSC). The ACQSC relies heavily on information provided to them via telephone and lacks the same capacity to visit the complainant and make a direct assessment of the merits or otherwise of a complaint.

Advocates are frustrated that situations that they assess as clear instances of providers demonstrably failing to operate in accord with legislation, Departmental program guidelines or policy directives in respect to care, find if the complainant escalates their complaint to the ACQSC, the investigation which ensues often determines a lack of evidence to support the complainant's claim and the case is closed.

ADA Australia believes that stronger mechanisms must be developed whereby an advocate's 'on the ground' assessment of a situation is factored into the deliberations of the ACQSC, with ADA Australia being a legitimate partner in this process. Until such time as this occurs, ADA Australia argues that care recipients are not afforded the protections they need and providers such as Earle Haven continue to deliver poor care.

In closing, ADA Australia would encourage the Queensland Government to take a greater interest in the monitoring of restrictive practices within aged care services in Queensland, in much the same way that it took leadership of this issue in the disability sector more than 10 years ago. With reports to the Royal Commission that 71% of Earle Haven residents were subject to chemical restraint, and 50% being subject to physical restraint, this demonstrates a gross violation of the resident's human rights and demonstrates a practice of restraint as a first resort rather than a last resort.

The legislative model of managing restrictive practices in the Queensland disability sector is world leading. We should expect nothing less for the most vulnerable older members of our community.

ADA Australia thanks the Parliamentary Committee for this opportunity to provide written feedback and takes this opportunity to remind that ADA Australia's CEO – Geoff Rowe would welcome the opportunity to make direct representation to the Parliamentary Inquiry in respect to Earle Haven.

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