MACQUARIE University SYDNEY·AUSTRALIA

LIFESPAN HEALTH AND WELLBEING RESEARCH CENTRE

29th February 2024

Exposure Draft Consultation

Submission of

The Macquarie University Lifespan Health and Wellbeing Research Centre

The Macquarie University Lifespan Health and Wellbeing Research Centre is a large multidisciplinary research centre (>100 academic members) that develops evidence-based approaches to understanding and maximising psychological, social and cognitive health and wellbeing from infancy to older adulthood. The Centre provides research, legal perspectives, policy and strategic advice on the prevention and management of emotional, cognitive and social health challenges across the lifespan. The Lifespan Health and Wellbeing Research Centre is one of Macquarie University's top 5 flagship research centres.

In consultation with Centre experts in law, aged care workforce, health economics, clinical neuropsychology and capacity decisions and clinical psychologists involved in the care of the older person we make the following comments.

We write to address aspects of the proposed *Aged Care Bill 2023*, which represents a significant step towards implementing recommendations outlined in the 2021 Royal Commission into Aged Care Quality and Safety final report. This submission aims to provide insights and recommendations regarding several key provisions within the bill.

Of particular importance is the inclusion of an expansive "statement of rights" as recommended by the royal commission, emphasizing the rights of aged care recipients to exercise choice, make decisions affecting their lives, and be free from all forms of violence. However, it is noteworthy that these rights are not enforceable through legal proceedings, as clarified in the bill. Some aspects of the rights may nonetheless be covered by existing actions, though these may differ between States, and depend on whether the provider is private or not.

While there are commendable aspects of the legislation, we wish to highlight concerns regarding provisions enabling third-party decision-making for aged care recipients and the limited attention for the link with restrictive practices.

We also consider that s 17(1)(a) could be strengthened by the addition (whether in the section or in a footnote) of a sentence to the effect that the need for restrictive practices cannot arise out of a lack of resources. We suggest adding “For the avoidance of doubt, a lack of resources cannot be a basis for the imposition of restrictive practices”, or similar wording.

A decade ago, the Australian Law Reform Commission recommended the adoption of "National Decision-Making Principles" in aged care legislation, emphasizing the importance of supporting individuals in making their own decisions and prioritizing their will and preferences in substitute decision-making processes.

The Aged Care Bill 2023 reflects this recommendation by introducing roles for "supporters" and "representatives" appointed by the System Governor to assist individuals accessing aged care services. However, given the current state of inconsistent state and territory guardianship laws, the draft bill could lead to further confusion. For instance, in NSW, guardianship laws follow outmoded “best interest” principles, rather than the “will and preference” model of the Exposure Draft.

Academics from the Lifespan Health and Wellbeing Research Centre have noted the difficulty of decision-making in relation to moving to aged care, as well as decision-making within aged care.[1] Any confusion about the appointment and principles for substitute decision-making would only exacerbate situations where family or carers are at odds, either between themselves, or with the older person, in relation to any decisions that need to be made. This may also lead to increased litigation taking up limited resources available to courts and tribunals.

Consultation paper number 2 asks “What support will providers need to transition to these new arrangements?” Given the inconsistent guidelines about how to assess decision-making ability across Australia, harmonisation of substitute decision-making laws needs to be prioritised. In tandem with developments in the law, consistent training and guidance documents will need to be developed. A priority of that training should be

[1] See for instance: Anam Bilgrami, Henry Cutler, Yuanyuan Gu, Mona Aghdaee, Megan Gu, “Complexity and Competing Interests: What Factors Bear on Payment Choices and financial decisions made for older people entering nursing homes?” (forthcoming) *Applied Economics;* Lise Barry, “He Was Wearing Street Clothes Not Pyjamas: Common Mistakes in Lawyers’ Assessment of Legal Capacity for Vulnerable Older Clients”, *Legal Ethics*, 21, 1, p. 3-22 20 p. Erlings, Esther. (2019). “False imprisonment in locked wards: the public advocate v C,B.”, *Flinders Law Journal*, 21(1), 109-120.

clear information about the pre-eminence of the will and preference of the person who is being supported to make a decision.

Research has demonstrated that care providers will benefit from training and resources to improve the decision-making abilities and participation of people with cognitive and physical impairments.[2] This may include for instance the assistance of speech-language pathologists, neuropsychologists and audiologists, or access to Augmentative and Alternative Communication (AAC). Supported decision-making guidelines, especially those based on legal decision-making, may be difficult to implement in time and resource poor aged care settings, especially when decisions need to be made urgently.

As former High Court Justice Michael Kirby noted in relation to the importance of clear guidelines for capacity assessment, "there is a clear awareness of the puzzling dilemmas and the inescapable significance of the individual attitudes and predilections of decision makers. Hence the admirable endeavour to discipline such decisions by imposing on them a systemic and rigorous approach."[3] Unfortunately, the reality of capacity assessment guidelines is somewhat different.

Further, we are concerned that the criteria for appointing representatives outlined in the draft Bill is unclear. This can lead to further conflict among families and carers. Moreover, there is no clear guidance on the possibility for institutional guardians (Public Advocate, Public Trustee) to be appointed as representatives. Given that a representative needs to have a close relationship with the aged care recipient to be able to support them and be aware of their will and preferences, it may not be feasible for institutional guardians to take on the role of representative without the commitment of significant extra resources.

The Lifespan Health and Wellbeing Research Centre endorses the recent commentary of Dr John Chesterman, Queensland Public Advocate who has suggested:

"An improvement to the bill would be for it to require that a person who does not already hold relevant decision-making power under a state or territory law can only be appointed as a representative if several conditions are met, including that:

- the appointment is consistent with the "will and preferences" of the person concerned; and

[2] Alexandra Stipinovich, Kerstin Tönsing, Shakila Dada, "Communication Strategies to Support Decision-making by Persons with Aphasia: A Scoping Review", *International Journal of Language and Communication Disorders* 58 (6) (2023), 1955.
[3] Michael Kirby, cited in Peter Darzins, William Molloy and David Strang, Who Can Decide? The Six Step Capacity Assessment Process (Memory Australia Press, 2000) 1.

- the proposed representative has “a close and continuing relationship with the person” (borrowing a phrase that exists in Victorian medical decision-making legislation); and
- there is no significant contention about the appointment among people with a genuine interest in the wellbeing of the person.”

Section 30 (e)(ii) of the Bill states that a person’s will and preference may be overridden if necessary to prevent “serious risk to the individual’s personal, cultural and social wellbeing”. A risk assessment approach to respecting decision making rights may lead to an overly paternalistic approach. Preferences over risky outcomes differ between individuals, and can differ systematically between service providers and service recipients. Consideration should be given to replacing the word “risk”, with the word “harm”. This may better protect the older person’s rights to take risks, outlined in s20(1)(c).

Furthermore, the bill's approach to informed consent for restrictive practices raises concerns. The requirement for informed consent, either from the individual or a designated representative, overlooks the complexities of decision-making in the context of restrictive practices. The definition of restrictive practices is extremely broad, encompassing everything from locked gates to chemical restraint.

Our view on the requirement for consent to restrictive practices departs somewhat from Chesterman’s (who notes that consent is antithetical to restrictive practices), in that we can imagine situations where a person would be able to agree in advance to use of a restriction in a particular situation that they themselves have identified or express a preference for a kind of restriction. However, a consent model is incapable of providing adequate protection to care recipients. Consideration should be given to explicitly including Advance Care Directives in any decision-making.

The Bill should promote best practice regarding the authorization of restrictive practices, focusing on strengthening existing authorization processes. We do agree with Chesterman’s recommendation that a senior practitioner authorization model is a more effective alternative to consent-based models, aligning with recommendations from the disability royal commission.

It would be preferable if the Bill were more specific about the extent of monitoring and review required for restrictive practices.

In relation to worker screening, we note that the Department has outlined the need for ongoing work to align the screening requirements in Aged Care with those for the NDIS and that the personal information and record keeping requirements will be refined in future consultation. We look forward to the opportunity to have further input at that stage.

In conclusion, while the Aged Care Bill 2023 represents progress towards addressing issues highlighted by the royal commission, there remain areas requiring refinement and closer alignment with existing legal frameworks and human rights principles. We urge consideration of these recommendations to ensure the effective and ethical delivery of aged care services to all Australians.

Contact for this submission:

Professor Lise Barry
Macquarie Law School

Yours sincerely,

Professor Lise Barry
On behalf of the Lifespan Health and Wellbeing Research Centre