SUBMISSION TO
A NEW AGED CARE ACT: EXPOSURE DRAFT

Contents

AAG acknowledges Traditional Owners of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respect to Aboriginal and Torres Strait Islander cultures, and to Elders past and present, and to all Aboriginal and Torres Strait Islander peoples including members of the Stolen Generations.

1. Executive summary

With and on behalf of its members, the Australian Association of Gerontology (AAG) welcomes the efforts of the Department of Health and Aged Care in pursuing the recommendations of the Royal Commission into Aged Care Quality and Safety ('Royal Commission'), and its commitment to strengthening protections for older adults.

AAG has conducted a thorough review of the *Exposure draft – Aged Care Bill 2023*. From this review, we submit this feedback for consideration. We begin with general description of AAG and our member consultation and engagement strategies. More specifically, we:

- Commend the provision of plain language support materials and extended consultation period, but advocate that a co-design approach to the new Act be followed going forward;
- Advocate for a bespoke Aboriginal and Torres Strait Islander-specific aged care pathway;
- Reiterate the risks of framing human rights as 'consumer rights', noting the clear evidence against this approach;
- Raise the need for better support to enable people with dementia to live at home;
- Highlight that this draft focuses on the delivery of government-funded care, particularly residential care, whereas most aged care is provided in the community setting;
- Caution against fragmenting care services, noting a lack of integration between aged, health and social services;
- Point out the importance of a clear and measurable definition of high-quality care; and
- Call for greater consideration to be given to supporters and representatives.

2. Description of the Submitting Organisation

Since 1964, AAG has been Australia's peak national body working to improve the experience of ageing through connecting research, policy, and practice. AAG has a broad reach across an established network of collaborators and experts, representing all sectors and disciplines in ageing including research, policy, education, aged care, health and allied health, and consumer advocacy.

A key part of our work is to convene special interest groups to represent those with particular needs, or at higher risk of marginalisation or disadvantage as they age. This includes facilitating the Aboriginal and Torres Strait Islander Ageing Advisory Group (ATSIAAG), whose members inform the policy and practice arena of older First Nations Peoples of Australia, and Friends of ATSIAAG (for non-Indigenous members). AAG also represents Australia's gerontology community internationally by administering the executive office of the International Association of Gerontology and Geriatrics Asia/Oceania Region (IAGG AOR) and the International Longevity Centre (ILC) Australia, which is a member of the ILC Global Alliance.

AAG's approach to evidence-based policy and practice incorporates all types of evidence, namely: research evidence, professional knowledge and expertise, the full diversity of older people's needs and wishes, and the policy environment. We previously received funding by a grant from the Dementia and Aged Care Services (DACS) fund, and continue to receive peak body funding from the Department of Health and Aged Care. The aim is to support Australian governments, professionals, researchers and providers to deliver evidence-based policy and services to meet the needs of all older Australians.

3. Introductory comments

AAG welcomes the work of the Department of Health and Aged Care in pursuing the recommendations of the Royal Commission in introducing a new Aged Care Act (the new Act) that focuses on the needs and rights of older people. We are also pleased to see the introduction of stronger protections for older people and the importance of accessing timely aged care assessments.

In developing this submission, we have consulted with AAG members, in individual and group sessions, and drawn on wider engagement strategies across our membership. Our membership includes experts from academia and research, clinical and

medical roles, aged care providers and advocacy services and, importantly, older people. We have also conducted surveys, online workshops and community forums.

In reviewing the consultation paper on the new Act[1] and the Exposure Draft[2] we submit several comments for consideration. These represent insights shared with us via:

- AAG Buzz Sessions: Online forums held in November 2023, in which members shared their ideas, concerns and suggestions regarding priority areas for AAG's attention.
- AAG Pulse Check Surveys: A series of short online questionnaires distributed in 2023, used to gauge people's responses and ideas about a range of topics related to ageing and aged care.
- AAG's online community: A member-only forum in which members raise questions, share resources and hold an open dialogue about various topics in ageing and aged care, on an ongoing basis.
- Dedicated group and individual member consultations.

4. General comments on the work to date

4.1 Timing

AAG welcomes the extension to the consultation period from 16 February to 8 March 2024. AAG recognises the commitment of this Government in implementing the recommendations contained in the Final Report of the Royal Commission.[3]

The significant scale and pace of the current reforms represent a once-in-a-generation opportunity to reset and reshape Australia's aged care system. Enabling the aged care system to meet the needs of Australia's diverse and growing population of older people in a way that is achievable and sustainable depends on genuine consultation with all aged care stakeholders. We urge the Department to commit to true consultation (and co-design) with the sector. This means we need adequate time to digest the vast amounts of information we are being asked to comment on in the proposed legislation, and to fully implement the proposed changes once they are outlined.

Rather than making a large piece of (incomplete) legislation available for comment in a very short time frame, we suggest that the Department should release completed sections for comment, and include stakeholders in co-designing the incomplete sections. Work must be done to not only comprehend the reforms but to then translate them to people in a manner that is clear, concise, and accurate. While we welcome the work contained within the Exposure Draft and commend the willingness of the Department to take on this task, there are swathes of the Act that are still not publicised. Much work remains to be done for this Act to be harmonised with the various other intersecting legislative areas including health, disability, and social security. Consultation and co-design will help ensure the success of this new system-wide approach. But we note that legislation is not an accessible form of communication to most individuals who must then navigate these interlocking systems.

4.2 Access

Time and expertise are needed to maximise meaningful engagement with proposed reforms.[4] If consultation time allows only a rapid scan through (sometimes incomplete) volumes of information, the potential for real improvement is compromised. While experts may be able to quickly comprehend the reforms, it is crucial to accommodate the many stakeholders who require the content to be translated in a manner that is clear, concise and accurate.

We welcome the work involved in developing the Exposure Draft and commend the consultation efforts of the Department, but as noted above, there are important components of the Act that are still not publicly available. Little is known about the financial and governance measures and how they will affect other parts of the Act.

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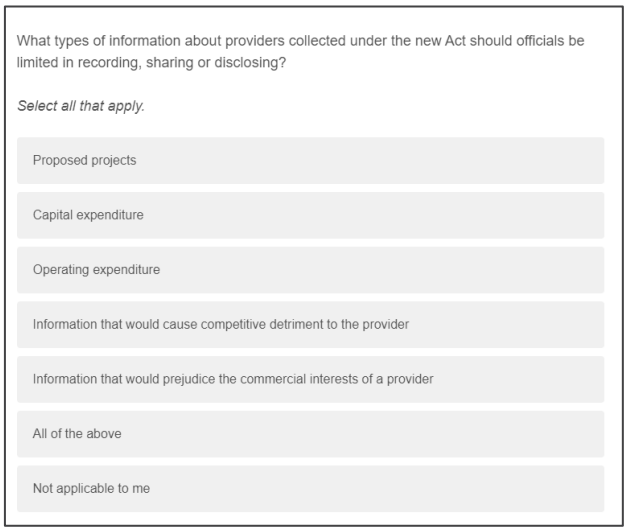
1 Department of Health and Aged Care, A New Aged Care Act: Exposure draft. Consultation paper No. 2.
2 Department of Health and Aged Care, Exposure draft – Aged Care Bill 2023.
3 Royal Commission into Aged Care Quality and Safety (2020). *Final report: Care, dignity and respect*.
4 Dizon, Wiles & Peiris-John (2020). *What is meaningful participation for older people? An analysis of aging policies*. The Gerontologist, 6(3).

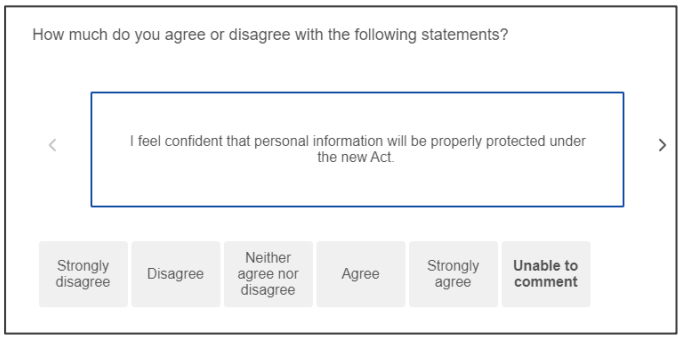
Consultation and co-design are essential to ensure the success of a new system-wide approach.[5] However, releasing draft legislation is not an accessible form of communication to most individuals and communities, who are not in a position to navigate the complexities of aged care policy and practice.

Given the technical nature of the draft Exposure Bill, the complexity of terminology, and the volume of information contained in the draft Bill, we commend the Department offering plain language materials. These are especially important for consultation with aged care service users and those outside the aged care sector. However, it is critical that these versions accurately represent the full versions of the materials. We note, for example, that the questions in the plain language version of the consultation paper do not match the survey questions. When using the plain language paper to consult with aged care residents, we had to explain the concepts referred to in the survey questions (as the detail is not contained in that paper).

Illustrative examples include:

- *Chapter 7 – Managing Information* asks about the types of information about providers, yet the information and these concepts are not included in the plain language paper.[6] While they are referred to briefly in the full consultation paper (Chapter Summary p82 and Chapter 7, Part 4 – *Data Sharing*, p86), the question refers to a section on provisions that are still under development. Meaningful input to fully develop these provisions depends on context and consideration for those answering the survey. These same issues apply to questions posed in the survey to *Chapter 6 – Regulating the Aged Care System*.





We would also like to highlight the complicated way some of the survey questions are posed.[7] For example, the following question asks about agreement/disagreement with a statement about confidence, and is open for misinterpretation. This type of question leads to concerns about the validity of the survey tool and the data collected from a broad range of stakeholder perspectives. **We strongly recommend that the Department employs evidence-based survey methodologies, to avoid the risk of misinterpretation, and the collection and use of inaccurate data.**

We call on the Department to develop appropriate plain language and accessible consultation materials for any future consultation opportunities and for future development of material relating to the new Aged Care Act. This must include engagement with aged care service users and other lived experience groups, including informal carers, and other relevant organisations, to ensure the appropriateness of the materials.[8] **We also recommend that the Department host a series of targeted consultation forums, publicised well in advance, for stakeholders to choose to attend a session that is most relevant to their expertise, experience and need.**

Through consultation with our members, we also heard that external consultants commissioned to run sessions did not have adequate experience in the field and often could not answer their questions about the draft Exposure Bill. This limited their

[5] Australian Association of Gerontology (2023). AAG 2022 Workshop report: *Developing resources to support participation in co-design*.
[6] Department of Health and Aged Care, New Aged Care Act resources.
[7] Department of Health and Aged Care, New Aged Care Act: exposure draft consultation survey.
[8] Zarshenas, Mosel & Chui, et al (2023). *Recommended characteristics and processes for writing lay summaries of healthcare evidence: A co-created scoping review and consultation exercise*. Research Involvement and Engagement 9 (121) (2023).

access to information and compromised the consultation process. One member participant described feeling unsafe and dissatisfied, saying '*it's not their world … they have no core lived experience*'. If the aim is to gauge the experience and priorities of older people, especially older people from historically marginalised and underrepresented communities, a different approach must be designed based on the pre-existing ways these stakeholders make their voices heard, for example through existing advocacy organisations, community events and outreach organisations.[9] Otherwise, the true spirit, purpose and outcomes of consultation are lost.

5. Specific comments on the exposure draft

5.1 Aboriginal and Torres Strait Islander aged care

Australia has a long history of discriminatory segregation, which many older Aboriginal and Torres Strait Islander people experienced first-hand. As demonstrated by the debate surrounding, and result of, the Voice to Parliament Referendum, Aboriginal and Torres Strait Islander peoples are still subject to racism and wilful ignorance in the broader public sphere. It is essential to protect in legislation a distinct aged care pathway into Aboriginal and Torres Strait Islander community-controlled aged care providers.

In consultation with Aboriginal and Torres Strait Islander aged care providers, recipients and stakeholders, AAG advocates for a bespoke Aboriginal and Torres Strait Islander-specific aged care pathway.[10,11] Recommendation 47 of the Royal Commission states that 'the new aged care system makes specific and adequate provision for the diverse and changing needs of Aboriginal and Torres Strait Islander people and that … priority is given to existing and new Aboriginal and Torres Strait Islander organisations, including health, disability and social service providers, to cooperate and become providers of integrated aged care services.'[12] Recommendation 53 calls for the Australian Government to 'assist Aboriginal and Torres Strait Islander organisations to expand aged care service delivery' and that 'existing Aboriginal and Torres Strait providers are not disadvantaged.'[13] **The need for specific Aboriginal and Torres Strait Islander aged care pathways into the new aged care system is clearly consistent with these recommendations. These pathways are the best way to ensure that existing Aboriginal and Torres Strait Islander providers are not disadvantaged in an environment where established and competitive services may work to gain clients, to the detriment of Aboriginal and Torres Strait Islander community-controlled organisations**. We see the distinct pathway and prioritisation of these services as the best option for ensuring that Elders and older Aboriginal and Torres Strait Islander peoples are cared for in a way that is culturally safe (Recommendation 48) and responsive to their unique, diverse and dynamic needs.[14]

We acknowledge that not all older Aboriginal and Torres Strait Islander people and Elders prefer their care services to be delivered by Aboriginal and Torres Strait Islander community-controlled organisations. In this case, we support their right to self-determination. At a minimum, we advocate for the legislation to include the Aged Care Diversity Framework and accompanying Action Plans to be brought into the realm of mainstream aged care accreditation, as they are beyond the scope of the new Act as it has been drafted.[15] **We see the actions outlined in the Diversity Framework as a clear path to producing an aged care system in which equity, safety and respect are not considered personal preferences, but the foundation of a system of characterised by high quality care. It is crucial for diversity criteria to be included in the new Act.**

Further, the human rights-based framing of the new Act should include the United Nations Declaration on the Rights of Indigenous Peoples,[16] which was recognised by Australia in 2009. This document highlights that there is a need to provide for and support the unique cultural and political place of Aboriginal and Torres Strait Islander Peoples in Australia. It is not enough to merely reduce the age of eligibility and/or age limits for specific services and program eligibility.

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[9] Polacsek & Porter (2023). *A service provider approach to rights-based research*. Routledge International Handbook of Participatory Approaches in Ageing Research.
[10] Australian Association of Gerontology (2022). AAG report: Addressing aged care workforce issues in rural and remote Australia.
[11] Australian Association of Gerontology (2023). AAG discussion paper: Recognising cultural and local knowledges in aged care.
[12] Royal Commission into Aged Care Quality and Safety (2020). *Final report: Care, dignity and respect*.
[13] Royal Commission into Aged Care Quality and Safety (2020). *Final report: Care, dignity and respect*.
[14] Bell, Lindeman & Reid (2015). The (mis) matching of resources and assessed need in remote Aboriginal community aged care. *Australasian Journal on Ageing*, *34*(3).
[15] Australian Association of Gerontology (2023). AAG background paper: The capability of the Aged Care Quality and Safety Commission to assess Aboriginal and Torres Strait Islander providers.
[16] UN Declaration on the Rights of Indigenous Peoples (2007).

5.2 A human rights-focussed Aged Care Act

As noted in our response to Consultation Paper 1, the Act is drafted from a consumer rights perspective, rather than that of fundamental human rights. A consumer rights approach prioritises the right to be *assessed* for eligibility to access funded aged care services; however, the essential right to *access* services is absent. Thus, the premise that 'consumer choice' will drive sector development is naïve and ideologically driven, rather than evidence based.

In addition, the evidence does *not* support the assumption that older people both want and are able to participate in service 'shopping'.[17,18] Indeed, the experience of older people enrolled in the NDIS overwhelmingly (80%) indicates a preference for recipients to partner with a trusted provider to coordinate and access the range of formal and informal care and support services that might be needed.[19]

Although the Exposure Draft articulates the right to access high quality care (defined as care that upholds the individuals' rights as outlined in the Statement of Rights), the consumer rights approach detailed in the Act does not compel the delivery of best practice care that is based on sound evidence, nor does it ensure equitable access to necessary and desired supports for all older adults. Instead, it offers access to the funded services which are to be outlined in the aged care services list and covered under the Rules (and are as yet unspecified). Ultimately it will be the Minister who determines the Rules, but we do not see any mechanism by which they will be informed by an evidence-based approach.

Our concern is that current scenarios will remain, as raised during AAG member consultations. For example, a person diagnosed with dementia at 65 years will receive a maximum of 20 hours of home support, making it almost impossible for the person to remain living at home and, consequently, facing a reluctant transition to residential care. If they were diagnosed at 64 years of age or younger, they would be eligible for greater support under the National Disability Insurance Scheme (NDIS), enabling them to remain at home. This illustrates that the new Act does not provide for the right to access care that serves ones needs, but rather the right to be assessed for a set of services that maybe inadequate or deliver undesired outcomes.

Aged care is a complex social and health care system that needs a clear values-based public policy framework, not a market-based model that silos aged care services from mainstream health and community services. In addition, consumer law does not address the fundamental quality of a provided good or service. It is of particular concern that the proposed delineation of rights applies only to eligible funded services and divorces these rights from regulations and quality frameworks. As such, we are concerned at the apparent absence of detail on how a consumer rights framework will be regulated, monitored and evaluated.

Human rights-based legislation should empower people. It is essential to legislate how the cited conventions – including the UN Convention on the Rights of People with Disabilities[20] (CRPD) – will be interpreted, monitored and enforced. As it stands, the inclusion of these conventions appears disingenuous and falls well short of the recommendations of the Royal Commission.[21]

For example, there appears to be a lack accountability and recourse, poor accessibility and neglect of the extent of disability in older people. This is a significant gap, given that half of all Australians aged 65 and over live with disability,[22] but cannot access the same disability support and services through the My Aged Care gateway as those who are younger and are eligible for support through the NDIS.[23]

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[17] McGrath, Clancy & Kenny (2016). An exploration of strategies used by older people to obtain information about health-and social care services in the community. *Health Expectations*, *19*(5).
[18] Van Gaans & Dent (2018). Issues of accessibility to health services by older Australians: A review. *Public Health Review,* **39(**20)
[19] Blaxland, Purcal, Robinson et al. (2020). National Disability Insurance Scheme: People who self manage their NDIS plan. Social Policy Research Centre, UNSW Sydney.
[20] United Nations Convention on the Rights of Persons with Disabilities (2006).
[21] Royal Commission into Aged Care Quality and Safety (2020). *Final report: Care, dignity and respect*.
[22] Australian Institute of Health and Welfare (2022). People with disability in Australia.
[23] Layton & Brusco (2022). The Australian assistive technology equity studies: Improving access to assistive technology for people with disability who are not eligible for the NDIS. Monash University; COTA Victoria.

5.3 Fragmentation of care services

In 2017, the World Health Organization proposed an Integrated Care for Older People approach to guide health systems and services in better supporting functional ability of older people.[24,25]

In our response to Consultation Paper 1, and as stated above where we argue for a human rights-focussed Aged Care Act, we reiterate the imperative to recognise **'aged care' as a complex social and health care system with a clear values-based public policy framework, not a market-based model that separates aged care services from mainstream health and community services**. Sustainability will only occur when aged care services are conceptualised as being part of a broader health and care ecosystem that enables people to remain living in their community, accessing local health, community and social services.

Thus, it is disappointing for us to see a lack of integration between aged care and other sectors, notably health and social services.[26] Not only was this a concern of the Royal Commission, but the recent Capability Review of the Department conducted by the Australian Public Service Commissioner noted that this was the number one priority area for 'capability improvement' within the Department.[27] There is nothing in the draft Exposure Bill that supports (or compels) the Department to engage with jurisdictions to improve the interface between health and aged care services, and to ultimately improve the care of older people.

5.4 Quality of care

The urgent need to improve the overall quality of aged care is a clear outcome of the Royal Commission. We reiterate our statement from our response to Consultation Paper 1 that a fit-for-purpose system must meet key public policy objectives:

- Equity and fairness: it should ensure the needs of older people, including the most vulnerable, are addressed.
- Quality and safety: older people should not be at risk of abuse or neglect.
- Accessible and responsive: Be capable of accommodating the needs of individuals and their communities, including those with special needs.
- Efficiency: the system must be affordable for those who pay for it, including taxpayers and care recipients.
- Sustainable and predictable: to enable certainty and transparency for governments, providers and older people.

The desire to centre quality care as an expectation represents a fundamental shift in the sector in framing what aged care should be. When read from a human rights perspective, the current definition of high-quality care contained in the Exposure Draft constitutes the minimum elements of quality care.

We also question whether high-quality care can be generated by regulation and a focus on prescriptive and punitive approaches at the level of the provider. Rather, **high-quality care must be driven by evidence-based innovation and led by service users and providers and will require some flexibility to generate collaboration.** That said, there is a clear role for government to continue to monitor the progress of innovative service models developed and ensure they are consistent with the objectives described above, including through requiring independent evaluations of models and transparency in reporting.

5.5 Supporters and representatives

Feedback from our members suggested a need for greater consideration and alignment with existing State/Territory jurisdictions when it comes to designated supporters and representatives of older people**. Both supporters and representatives are needed, but the roles should be consistent with across jurisdictions and regulatory arrangements (such as enduring powers of attorney)**.[28] The current supported decision-making provisions offer a binary model which does not

[24] Briggs, Valentijn, Thiyagarajan & de Carvalho (2018). Elements of integrated care approaches for older people: A review of reviews. *BMJ open*, *8*(4).
[25] World Health Organization (2017). Integrated care for older people: Guidelines on community-level interventions to manage declines in intrinsic capacity.
[26] Stewart, Georgiou & Westbrook (2013). Successfully integrating aged care services: A review of the evidence and tools emerging from a long-term care program. International Journal of Integrated Care (13).
[27] Australian Public Service Commission (2023). Capability Review Department of Health and Aged Care.
[28] We note the efforts of the Attorney General's Department (2023) towards Achieving Greater Consistency in Laws for Financial Enduring Powers of Attorney.

reflect people's fluctuating capacity, and stands to unfairly disadvantage the older person, while discouraging people from taking on the roles.

The term 'approved by the System Governor' should be replaced with 'notify the System Governor', to reflect the capacity of the older person more accurately (and respectfully) as the decision maker, not the System Governor who is documenting the process.

6. Contact

For further information or to discuss this submission, please contact:

Dr Amber Mills
Policy and Research Manager
Australian Association of Gerontology
[redacted]
[redacted]