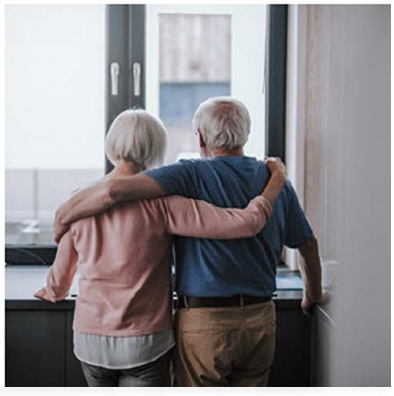
AGED CARE ACT EXPOSURE DRAFT POSITION STATEMENT

INTERNATIONAL LONGEVITY CENTRE GLOBAL ALLIANCE – AUSTRALIA (ILC-AUS)



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Position Statement: Aged Care Act Exposure Draft

International Longevity Centre Global Alliance - Australia (ILC-Aus)

The International Longevity Centre Global Alliance - Australia (ILC-Aus) is an organisation that stimulates research and advocates for improved policy and practices in aged care. As an organisation with strong alliances internationally through the International Longevity Centre Global Alliance, our members, drawn from research institutes, universities, aged care providers, and advocacy groups, have collectively reviewed the exposure draft of the Aged Care Act. We recognise the pivotal role the Act will play in shaping equitable and high-quality aged care for the future.

The proposed new Aged Care Act is positioned as a transformative instrument to address systemic failures identified by the Royal Commission. We acknowledge and support its aims to shift the focus from a provider-centric approach to one centred on the unique needs, preferences, and rights of older people. ILC-Aus also acknowledges the overdue need for aged care reform and supports the Act's goal of empowering individuals, safeguarding their rights, and fostering a culture of person-centred care.

ILC-Aus welcomes the opportunity to contribute to the consultation process, appreciating the dedication of the Federal Government in initiating these much-needed reforms in aged care. We hope that our insights can guide the refinement of the exposure draft to better meet the evolving care needs of Australians in their later years. We welcome any opportunity to work with the Department of Health and Aged Care to aid in the continued development and implementation of the Aged Care Act.

The views expressed by ILC-Aus members are their own and not a reflection of the position of their institutions or funding partners.

Executive Summary of Key Recommendations

International Longevity Centre Global Alliance - Australia

The International Longevity Centre Global Alliance – Australia (ILC-Aus) conducted a thorough review of the Exposure Draft of the Aged Care Act, key findings include:

- The Act upholds individual rights under the Statement of Rights but lacks enforceability, requiring a balance between enforceable rights and corresponding responsibilities.
- Eligibility processes need simplification, with concerns raised about overreach in determining eligibility criteria and the need for clarity in language.
- Assessment processes should prioritise understanding individual needs and goals rather than merely determining eligibility, with provisions for ongoing reassessment to accommodate changing needs over time.
- The Act fails to recognise ageing as a dynamic process, necessitating a more holistic approach to care provision.
- Support for healthy ageing and preventive measures is lacking within the Act.
- Critical processes such as reablement or rehabilitation are not adequately addressed.
- The Act lacks clear definitions and indicators for quality of life and wellbeing.
- Further mechanisms are needed to safeguard and promote dignity throughout the aged care journey.
- There is a lack of recognition of the need for empowering older individuals in decision-making processes related to their care.
- Discrepancies exist between the stated intentions of aged care reforms and the content of the draft Act.
- Roles and responsibilities regarding supporters, representatives, and guardians are unclear.
- The concept of person-centred care requires further elaboration and integration throughout the Act.
- Integration between aged care and other services should be facilitated not discouraged.
- Provisions should be included to safeguard against potential biases in AI-driven decision-making processes.
- The Act should incorporate robust quality improvement mechanisms beyond complaints-based systems.

While it is necessary to outline these imperfections, it's paramount to recognise the significance of this reform in addressing the evolving needs of older Australians. ILC-Aus stands in support of the Department's efforts to enhance the aged care system and acknowledges the complexity and challenges involved in undertaking such transformative endeavours.

RIGHTS-BASED BUT LACKS CONCRETE RIGHTS

Although the Act upholds individual rights under the Statement of Rights, ILC-Aus notes a lack of enforceability (section 21 clause 3, pg. 32). The ILC-Aus supports the inclusion of the Statement of Rights of older people that is enforceable, but this also needs to be balanced with a statement of the individual's responsibilities. There cannot be rights without responsibilities. Responsibilities are as important as rights, as they contribute to a sense of citizenship and give older people a tangible sense of contributing to community.

ELIGIBILITY OVER-REACH

There are multiple pages and repetitive clauses devoted to the determination of eligibility, when in fact this should be a given. The ILC-Aus fears this is due to the Act trying to cover younger adults with chronic conditions and illnesses that might overwise fall through the cracks in the healthcare system. While this is honourable, this Act is for older Australians who have specific and unique needs. The Act needs to stay focused on older people and not try to be a catch-all and over-reach into other populations.

ASSESSMENT SHOULD BE INFORMATIVE AND ITERATIVE

Assessment should be the first step in providing care, by helping the person to identify their needs and define their care goals. Assessment is not a test to be passed to see if the person qualifies for care, but an understanding of their situation and a prediction of the trajectory of need to assist in deciding what care will help them most.
Also, the ongoing monitoring and assessment of need should be seen as the foundation of quality, timely and responsive aged care.

REABLEMENT AND REHABILITATION

These processes are not written into the Act. There is mention of habilitation or rehabilitation services in section 49b(v) only.

HEALTHY AGEING

Healthy Ageing is not supported by the Act. Healthy Ageing (WHO 2015) represents a dynamic interaction between a person's intrinsic capacity (a person's internal strengths) and the support provided by their extrinsic social and physical environment. The balance between these factors will change over time and with age, with different trajectories of physical capacity arising depending on the balance between adversity, resistance, reserves and other resources. The overall goal of Healthy Ageing is the maintenance of an individual's abilities to do the things they choose to do and have reason to value. Aged care is critical for Healthy Ageing, assisting in balancing age-related losses and actualisation of an individual's remaining strengths across the later life course.

Important abilities to be considered in later life include to:
- move around,
- meet one's basic needs,
- learn, grow and make decisions,
- build and maintain relationships,
- contribute.

By enabling these abilities Healthy Ageing is a "freedom" that enables older people to be productive and valuable members of their communities, and not simply a burden. ILC-Aus wishes to emphasise the importance of aged care in preventing loss of abilities and maintaining overall well-being.

FAILURE TO TAKE A LIFE COURSE APPROACH

The Act does not recognise that ageing occurs within the context of a whole life, determined by previous circumstances, ongoing change, and eventual death. There needs to be more recognition of the need for transition or integration from previous services that may have been used.
Section 48, clause 49 (p57) "individual has long-term physical, mental, sensory or intellectual impairment … "
This description does not necessarily fully capture the circumstances of those needing aged care and positions the process of ageing as a collection of disabilities. For example, it underestimates the multifactorial nature of the needs of older persons, and the likely trajectory of their needs.

PREVENTION

There is no underlying concept of prevention within the Act. Aged care can and should have a strong role in preventing loss of abilities and erosion of well-being among older individuals. These roles include: maintenance of physical and social activities; prevention of depression and social isolation; provision of nutrition, hydration, and continence management; attention to skin integrity and prevention of pressure ulcers; and prevention of delirium. Aged care should be focussed on helping individuals to continue to do what they need and want to do, and maintaining their well-being, not just assisting with activities they can no longer do.

QUALITY OF LIFE AND WELLBEING

The safety, health, well-being and quality of life of individuals are the primary considerations in the delivery of funded aged care services (section 22,1 – p33). This priority is also defined within the "meaning of high-quality care" (section 19, c(i) – p27). However, there is little in the way of defining these states or their indicators.

DIGNITY

Dignity is a fundamental aspect of quality aged care, essential for upholding the rights and preserving the humanity of older individuals. While the Act acknowledges dignity twice concerning aged care rights, the further underpinning of this right is essential to ensure its comprehensive integration into all facets of aged care provision. Beyond mere mention, the Act should explicitly outline mechanisms and practices aimed at safeguarding and promoting dignity throughout the aged care journey. This may encompass the inclusion of the importance of respectful communication and interactions, provision for culturally sensitive care practices, frameworks for maintaining privacy and autonomy, and protocols for addressing instances of abuse or neglect that undermine an individual's dignity.

CONSENT

Consent is mentioned in relation to restrictive practice, recordings and privacy, and entry to the premises. The concept of consent to receive care is not defined or enshrined.

DECISION-MAKING

There is no recognition that decisions need to be made by older people who are usually disadvantageously equipped to make these decisions. The lack of understanding of how care fits into the life course is disempowering for older people who do not know what their options are or the benefits of different services. The lack of consumer skills also renders the aged care system less effective because it is impossible to deliver quality service to someone who does not understand the benefits of care and how it fits into their later lives. Age care should be a partnership between the older person and their care provider.

RELATION-BASED CARE

There is no recognition that aged care is about relationships between individuals who need care, those who care for them, and aged care providers.

PERSON-CENTRED CARE

The Statement of Principles mentions "person-centred care" (Section 22 – page 33). Person-centred communication is mentioned (section 20,6 – page 30).
There is no other mention of person-centred care, or of what this means in relation to the Act or aged care provision.

INCONSISTENCIES IN INTENTION AND INSTRUMENT

The ILC-Aus wishes to highlight inconsistencies between the stated intentions of the aged care reforms and the content of the draft Aged Care Act. This misalignment can lead to confusion and misinterpretation and hinder the effective execution of the Act's objectives.

We understand that the intention behind the reforms, and the Act, is to enshrine care that is rights-based, equitable, person-centred, safe and of a high standard. However, the individual, their rights and their care needs are missing from most of the instrument. The Act is not written from a person-centred position, it speaks more on eligibility than rights and focuses more on providers and supporters/representatives than on the individual needing care.

For Instance, the Key Concepts (Ch1, Division 2) begins with the concept of services. The concept of care does not appear until Section 19 (page 27).

"The delivery of a funded aged care service by a registered provider to an individual high-quality care if the service is delivered in a manner that:
a) puts the individual first
b) upholds the rights of the individual …."

If the Act is to achieve its intention, the Act needs to also put the individual, their care needs, and their rights at the start of the Instrument. Everything else is to service those rights and needs.

SUPPORTER, REPRESENTATIVE AND GUARDIANS

These various roles are not clearly delineated (eg. "A supporter is a person appointed as a Supporter", Definitions, pg 14). It seems the supporters and representatives are appointed by the Systems Governor and acting with the consent of the individual in the first instance, and in the interest of the individual in the second instance. It does not acknowledge that these pivotal roles should be nominated by the individual and recognised by the Systems Governor. The power seems to be flowing in the wrong direction. Moreover, the way this section is currently written, state/territory guardianship arrangements are not recognised unless appointed by the Systems Governor.

CARE INTEGRATION

There is recognition that aged care should include access to integrated services including strong linkages with health, mental health, veterans, disability and community services sector (Section 22,5 – page 34). ILC-Aus supports this inclusion but would like to see this integration strengthened throughout the Act.
In addition to addressing the social and functional aspects of care, it is imperative that the Act explicitly incorporates provisions for addressing clinical care needs within the aged care framework. Clinical care, including medical treatments, nursing interventions, and allied health services, plays a crucial role in maintaining the health and well-being of older individuals. By explicitly including clinical care within the Act, there is an opportunity to ensure that older persons receive comprehensive and coordinated care that addresses both their medical and non-medical needs. This may involve outlining standards for clinical assessments, establishing mechanisms for coordinating medical and aged care services, and clarifying responsibilities for healthcare professionals involved in the care of older individuals.

PALLIATIVE CARE

Palliative care is mentioned three times in relation to services provided, and once in relation to the needs of the individual. Interestingly, the mention of palliative care is in the same clause as assessment rather than being included with the clause on care services. Is palliative care seen to be separate from aged care? It should be integral as part of a life course approach.

EXCLUSION OF OLDER PEOPLE IN ONGOING STRATEGIC PLANNING

It is stated that the "aged care system is undertaken in collaboration of older people" (section 23,13(f) – page 36), but this intent is not elsewhere evident within the Act.
ILC-Aus advocates for the inclusion of older people in the ongoing strategic planning processes related to aged care. Excluding them from decision-making results in policies that do not adequately address the diverse and evolving needs of the ageing population.

INADEQUATE APPROACH TO IMPROVEMENT

ILC-Aus expresses concerns about the absence of a robust and continuous quality improvement mechanism across the Aged Care Act. While we acknowledge the huge positive steps the Department have taken with the inclusion of two commissions to oversee delivery, the only mechanism for improvement of the aged care system seems to be through complaints and critical incidents. Relying solely on a complaints-based system will not provide a comprehensive understanding of the effectiveness of the policies and may hinder timely adjustments to address emerging issues. This is not an effective system for driving best practices. There is Also no mention of quality indicators for either residential or home/community care.

TIMELINESS AND WAIT TIMES

It is stated that the annual report on the Act will include waiting periods. How will these be assessed and will they include periods spent waiting for the Systems Governor to determine eligibility? Wait times can always be shortened by delaying approvals for eligibility (a queue for a queue).

PRIORITY RANKING

What are the criteria for setting priorities for access to care? It is stated that a decision about the individual's priority for a service group is made by the Systems Governor (Section 36). It is impossible to provide advice on a system that is referred to in the Act but is not included in the provided draft.

UNMET NEED AND UNMET DEMAND

Annual reporting must include "the extent of unmet demand for funded aged care services" (Chapter 8, part 10, pg 322). How will this gap be defined? Will there be any attempt also to assess unmet need, inequities and inadequacies in the care system? Unmet need should include people who could benefit from support but who may not have been assessed (base need), or who are between assessments (increased need).

LACK OF PROTECTION AGAINST AI DECISION-MAKING

ILC-Aus expresses reservations about the absence of provisions to safeguard against potential negative impacts of artificial intelligence (AI) in decision-making processes related to eligibility, service provision, needs categorisation, and prioritisation. The use of automated or AI-driven decisions may lead to concerns about fairness, accountability, and potential biases unless the Rights of the Individual include the right to have one's case reviewed, and decision made, by a human.

SERVICE GAPS

While aged care cannot be seen as a funding source for other sectors (section 22,11 – p36) there must be provision for some overlap between aged care and other services, including health care. This overlap allows for integration of services to meet the needs of the individual (person-centred). It is also nonsense to consider that a person may get care for a disability when that disability could be improved through clinical intervention (and vice versa).

COLLECTION AND USE OF DATA

ILC-Aus emphasises the critical importance of collecting and utilising data within the framework of the Act to drive innovation and enhance service provision. The Act currently presents a missed opportunity by not incorporating provisions for the systematic collection of essential data, which could be instrumental in informing service improvement, planning, and projection. By capturing data on various aspects such as service needs (both met and unmet), patterns of service use, length of stay in different service categories, and rates of increasing need, the Act can provide valuable insights into the evolving landscape of aged care. By leveraging this data effectively, policymakers, service providers, and other stakeholders can identify areas for improvement, innovate service delivery models, and allocate resources more efficiently. Therefore, ILC-Aus urges the inclusion of robust data collection mechanisms within the Act to support ongoing service enhancement and ensure the delivery of high-quality aged care services for older Australians.

COMMISSIONERS

The hierarchical relationship and intended interactions between the Aged Care Quality & Safety Commissioner and the Complaints Commissioner are obscure. How will the Commissions remain independent? More detail is needed in Chapter 5 on how the two Commissioners will work together and maintain their independence.

The ILC-Aus would also like to see the inclusion of the Age Discrimination Commissioner and the Human Rights Commission included in the Act.

TWO SYSTEMS GOVERNORS – A PERSON AND A PROGRAM

Most of the decisions for an individual (including eligibility, category, priority, and wait) are said to be determined by the Systems Governor. It is of course impractical that these determinations will be made by one person for every individual over 65 years who seeks care. Later in the Act (section 398, pg 314), it is said that the Systems Governor may use a computer program to make these decisions. This use of computer algorithms should be stated up-front. Considerable checks and balances are needed in this system. No provision has been made for assisting or guiding older people to access such a system.

INTEGRATION WITH OTHER SERVICES

The Act appears agnostic on other aspects of health and welfare for older people.
The Act fails to leverage many other opportunities for integrating access to aged care into older people's lives. These include:

- Interactions with Centrelink – with many older people receiving some form of benefit, pension, or means test. This system could fast-track some aspects of the eligibility checks/assessments and may provide some referrals to services ahead of the need for funded aged care, such as exercise programs, social groups, transport, and domestic assistance.
- Health Assessments – many older people undergo annual Medicare-funded assessments undertaken by a GP or practice nurse. These assessments could articulate with the aged care system, providing minimum data and triggering when aged care assessment or reassessment may be required.
- Pharmaceutical benefits – flagging when older people have hyperpolypharmacy, or escalation of medications – triggering the potential need for comprehensive assessment.
- Hospital admission – assessment by the aged care team and indicators of care needs.

WORKER SCREENING

The current reading of this section (chapter 5, pg. 154-164) is repetitive and obtuse. It is also imprecise to list items of information that "may" be collected, but not information that must be collected. An approach that could be taken is to lay out what is needed in the database with the worker as the data unit.
ILC-Aus is happy to see that the aged care workforce database will be cross-referenced with NDIS.

Provision for expedited screening could also be considered. This will accommodate times of increased workforce need.

MISSING INFORMATION

Large sections of the Act are missing, preventing a thorough review (e.g. All of Chapter 4 Fees, payments and subsidies). We noted over 171 instances of missing or excluded information.

SUPPORT FOR THE SENTIMENT BEHIND THE DRAFT

There has been strong recognition by the Department for the need for transformative change within the aged care sector. The draft Act acknowledges the imperative to shift towards a more person-centred approach, prioritising the individual needs, preferences, and rights of older citizens. This recognition reflects a commitment to addressing systemic failures within the existing aged care system and signifies a step in the right direction towards fostering a culture of quality care and empowerment for older Australians.

Implementation

The Act is critical for the delivery of equitable, quality, effective and sustainable aged care. However, even with a perfect Act, nothing will be achieved without:

- Well-managed aged care providers.
- Adequate, trained compassionate staff.
- Older people who are empowered to make the most of their later lives, and who can make the best decisions for themselves or those they support.

International Longevity Centre - Australia (ILC-Aus) recognises the need for the Act to proceed with the enactment as scheduled. However, we ask that the Department consider an extension to the implementation timeline, accompanied by additional checkpoints to ensure emerging issues are identified and addressed.

Extending the timeline would provide a valuable opportunity to conduct thorough reviews and address any operational challenges that may arise during the initial phases of implementation. This approach would allow for a more measured and adaptable rollout, ensuring that the act's objectives are met with the highest standards of efficacy and responsiveness.

Furthermore, the ILC-Aus wishes to affirm its readiness to actively engage in consultations and collaborative endeavours throughout the subsequent stages of the Act's development. By leveraging our collective expertise and insights, we can contribute to refining and optimising the aged care system to better serve the needs of older Australians.

In essence, while recognising the urgency of enacting the Aged Care Act, the ILC-Aus advocates for a thoughtful and inclusive approach that prioritises the effective implementation of reforms while remaining open to ongoing consultation and refinement.