8 March 2024

Legislative Reform Team
Department of Health and Aged Care
GPO Box 9848
Canberra ACT 2601

By email: AgedCareLegislativeReform@health.gov.au

Dear Colleagues

Exposure Draft | Aged Care Act

Thank you for the opportunity to provide feedback on the exposure draft of the Aged Care Act (the **Exposure Draft**). Aged and Disability Advocacy Australia (**ADA**) appreciates being consulted on the development of this critical reform.

About ADA Australia

ADA is a not for profit, independent, community-based advocacy and education service with more than 30 years' experience in informing, supporting, representing and advocating in the interests of older people, and persons with disability in Queensland.

ADA also provides legal advocacy through ADA Law, a community legal centre and a division of ADA. ADA Law provides specialized legal advice to older people and people with disability, including those living with cognitive impairments or questioned capacity, on issues associated with human rights, elder abuse, and health and disability legal issues related to decision-making.

ADA advocates and legal practitioners work with identified First Peoples advocates through the Aboriginal and Torres Strait Islander Disability Network Queensland (**ATSIDNQ**), a network established to support mob with disability and provide individual advocacy services for Aboriginal and Torres Strait Islander people with disability.

ADA has reviewed the Exposure Draft and provides the following for the Department's consideration. In forming our response, we have consulted with older persons, clients and advocates.

ADA is the Queensland Service Delivery Organisation (**SDO**) for the Older Persons Advocacy Network (**OPAN**) and has contributed to and endorses the submission provided by OPAN.

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Key recommendations

1. As drafted, the Exposure Draft does not provide a regulatory framework or operational grounding that will effectively support, promote and aid the enforcement of human rights, as recommended by the Royal Commission into Aged Care Quality and Safety (the **Royal Commission**). The proposed legislation must be amended to ensure that the new act truly embeds a human rights-based framework.

2. Enforcement provisions in the Exposure Draft are inadequate and must be strengthened in the proposed legislation. It is essential that a right or obligation as purported to be supported by law and government, be attended by an appropriate sanction for non-compliance.

3. The Complaints Commissioner should report directly to the Minister, and not to the Aged Care Commissioner.

4. The presumption of capacity is a right. The presumption is a legal foundation that presumes that all adults are capable of making their own decisions, and requires that the presumption is applied to each fresh decision which is to be made. The concept recognises that capacity may fluctuate. The proposed legislation should be amended to ensure that the presumption of capacity is recognised, respected and supported systematically. The proposed legislation must explicitly and operationally have regard to the presumption. At a minimum, this requires that the proposed legislation be amended to:

    a. Recognise and support the autonomy of older persons, and revise drafting to ensure that a 'supporter', 'representative' or any other supported or substituted decision-maker is not imposed where one isn't necessary; and
    b. For decisions where an older person may need to rely on decision-making support, require that comprehensive consultation with the older person occurs prior to a decision being made, whether the decision is intended to be in the older person's interests or otherwise on their behalf.

5. The right to advocacy identified in the Objectives must be expressly connected to the principles of the proposed legislation. The drafting should be amended to clarify that:
    a. the right applies at every stage of administration and operation provided for by the legislation. This appears to have been the intended effect and would align with the recommendations of the Royal Commission; the current drafting should be refined to clarify this intention.
    b. This right is distinguishable (and separately available) from support that may be provided by a supporter or representative. The drafting should be clear that it relates to an independent and professional Advocacy Officer, whether that be in the form of legal or general advocacy.

Objects, rights and principles

ADA generally supports the drafting under Chapter 1, Part 1 which states that the objects of the Act are *'to give effect to obligations under the International Covenant on Economic, Social and Cultural Rights, and the Convention on the Rights of Persons with Disabilities*'.

The objectives also include providing a '*forward-looking aged care system*' and references upholding the rights of individuals under the Statement of Rights, assisting persons to live active and meaningful lives with self-determination, putting older persons first, and promoting positive community attitudes to ageing.

However as currently drafted, the objectives of the Act do not rise to the description recommended by the Royal Commission. Further, upon review of the Exposure Draft as a whole it is our position that other key provisions of the draft do not support, and in some parts will operate to limit the stated objectives.

This is clearly demonstrated by the lack of enforceability of rights for an individual. Clause 21 seeks to explicitly disallow an individual from seeking to enforce a right or duty provided for under the Statement of Rights in a court or tribunal is troubling. Inclusion of a provision to this effect conveys two messages:

- That the human rights and principles stated in the objectives of the Act and listed in the Statement of Rights are tokenistic; and
- That older persons and persons receiving aged care should not be permitted to access all avenues and forms of recourse when seeking to enforce their rights. This exclusion is discriminatory and will reinforce existing ageist attitudes and policies that permit abuses to continue.

By excluding an avenue for a person seeking to enforce their rights, the legislation cannot be compatible with the stated objectives *'to give effect to'* the obligations stated under the International Covenant on Economic, Social and Cultural Rights (the **ICESC**) and the Convention on the Rights of Persons with Disabilities (the **CRPD**).

We also note that the complete list of rights that are named under ICESC and the CRPD have not been included under the Exposure Draft's Statement of Rights. The Statement of Rights should be revised to ensure that all of the rights listed by these treaties are named. Doing so will assist in ensuring that the Act operates in accordance with the stated objective of the legislation.

Further, the objectives should be amended to refer to the International Convention on Civil and Political Rights (the **ICCPR**) and the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. This will allow for the insertion of key rights that are directly relevant to persons who receive aged care, including the right to be free from torture or cruel, inhumane or degrading treatment or punishment; the right to life; right to liberty of movement and freedom to choose their residence, amongst others.

These rights should also be listed in the Statement of Rights.

Further, the Statement of Rights should be amended as follows:

a) Amend clause 20(1) to include the right to the presumption of capacity at (b) and reorder the clause accordingly –

(1) An individual has a right to:

a. Exercise choice and make decisions that affect the individual's life, including in relation to the following:

i. The funded aged care services the individual has been approved to access;

ii. How, when and by whom those services are delivered to the individual;

iii. The individual's financial affairs and personal possessions; and

b. The presumption of capacity, which must be applied in relation to the making of each decision; and

c. At least one visitor of choice at all times, including when residing in residential aged care facilities and during periods of outbreaks or other emergency scenarios;

d. Be supported (if necessary) to make those decisions, and have those decisions respected; and
e. Take personal risks, including in pursuit of the individual's quality of life, social participation and intimate and sexual relationships.

b) insert an additional right under clause 20(7) to clarify that an individual has a right to all documents that relate to or contain information about the individual and that are associated with the application for or provision of aged care services.

c) Amend clause 20(10) to clarify that the right to advocacy includes the right to a ***professional advocate***. A definition of 'professional advocate' should be inserted to clarify that the term relates to a person employed by an identified, independent and government-funded advocacy agency or program that provides free support, information, and advocacy to individuals seeking or accessing aged care services, including with respect to their rights. The provision should also expressly include a right of entry to facilities providing aged care services for the purpose of providing advocacy services to an individual.

ADA supports the inclusion of a right to palliative care and end-of-life care at clause 20(2)(b). We suggest that an additional right be included in this section at clause 20(2)(c) setting out the ***right to access health care services and benefits*** that are available to all persons outside of the aged care system, such as inpatient and outpatient rehabilitation services, medical aids, Medicare services, specialist and consultancy assessments and treatments and so forth. This is a necessary inclusion as persons in residential aged care facilities regularly face challenges when seeking to access these services.

Statement of Principles

ADA is supportive of the listed principles set out under clause 22, and the stated intention under clause 23 that the intended effect of the principles is that *"the Minister, the System Governor, the Commissioner and any other person or body, performing functions or exercising powers under this Act, must have regard to the principles specified in section 22 when performing those functions or exercising those powers.*"

We suggest that the 'Complaints Commissioner' should also be listed in this clause.

The noted concerns about about the utility of the Statement of Rights is repeated in relation to the Statement of Principles, with the inclusion of drafting at clause 23(2) which states that the principles cannot be enforced by a court or tribunal, and that a failure of those listed persons to comply with the principles is not a ground for review of their decision (clause 23(3).

Mental Health support for persons receiving aged care

It has been identified that there is a substantial gap in older people in residential aged care accessing support for mental health conditions. Older persons residing in residential aged care facilities are more likely to have a mental health condition compared to those who remain living in the community.

The Exposure Draft mentions 'mental health' twice: at clause 19(c)(i), in the context that the definition of *'high quality care'* includes a registered provider prioritising *"kindness, compassion and respect for the life experiences, self-determination, dignity, quality of life,* ***mental health*** *and well-being of the individual'*, and at clause 22(5)(b) which states that the Commonwealth aged care system…. *"builds the capacity of registered providers and connections with individuals in the*

community to support…..access to integrated services, including strong linkages with the health, ***mental health****, veterans, disability and community services sectors."*

ADA strongly supports the inclusion of mental health as a pillar of high-quality care, and the recognition of the importance of connecting aged care with other community services, including mental health services.

However, we are disappointed that the Exposure Draft does not provide definitive requirements in relation to accessibility and provision of mental health support services for persons accessing aged care, particularly, for those persons in aged care facilities who have limited access to community services.

The draft does not address how the gap in providing mental health supports for older people receiving aged care will be received, and the 'capacity building' reference is included as a Principle only, which, as discussed above, the draft makes explicit is unenforceable.

It would appear that the Exposure Draft does not recognise the extent of mental health supports that are required for older persons seeking or receiving aged care. Most people enter residential aged care at a time of crisis, and many involuntarily. This time of crisis, if not appropriately recognised and engaged with by agencies, facilities and the community, can lead to an over-reliance on chemical restraint of older persons. Various inquiries, including the Royal Commission and the Queensland Parliamentary Inquiry into Social Isolation and Loneliness have concluded that older persons are at particular risk of suffering from the effects of social isolation and loneliness. Factors such as restriction of social activities, loss of relationships and other chronic health issues are often experienced by a person when they enter residential aged care.

We strongly recommend that amendments to the Exposure Draft are made to support the mental health of older persons in aged care beyond an unenforceable principle. This would include amendments so that the Statement of Rights and Statement of Principles can be enforced by a court or tribunal. Further, clause 8(5) of the draft should be amended as follows:

Clause 8 – Aged care service list and funded aged care services

> ***(5)*** *The Minister must ensure that for each service group for which the service types in that group are specified as delivered in a residential care home, nursing services and* ***mental health*** *services are listed services that are in at least one service type that is in that group.*

We note that community based older person's mental health services are a good starting point, though if these alone are to be relied on the Exposure Draft should be amended to ensure that older persons in residential aged care facilities are able to access these – either through facilitation and transport to the service, or by allowing the service to enter the facility. Further, significant funding and resourcing assistance would be required to increase and improve availability of specialised older persons community mental health support services.

Supporters and Representatives

ADA supports the introduction of a system that is intended to recognise the existence and importance of an informal supporter of a person seeking, applying for, or receiving aged care services.

However, there are significant concerns with the model as currently proposed. Chapter 1 Part 4 does not refer to the presumption of capacity. Rather, it implies that all older persons need another

person to assist them in making decisions about aged care, either in a supported or substitute decision-making capacity.

This is problematic. ADA is concerned that drafting to this effect will have the unintended consequence of promoting the position held by many aged care providers that an older person who applies for services cannot be approved entry (or recognised as the sole decision-maker for any other substantive decision) unless a guardian and/or administrator has been appointed, or an enduring power of attorney (**EPOA**) is in place and the attorney has approved the decision (whether the EPOA is enlivened or not). This is a routine practice of many residential aged care facilities and one that effectively dismisses the presumption of capacity and respect for individual autonomy.

The process of appointment of supporters and representatives is covered at a later section of the Exposure Draft, under Chapter 8 - Miscellaneous, at Part 4, Division 1, which sets out the process whereby a System Governor may appoint a supporter (clause 374) or a representative (clause 376). It is our view that the provisions governing the appointment of these roles should be in Chapter 1 alongside the operative provisions of these roles, and not in Chapter 8.

It is critical that Chapter 1, Part 4, Division 1 is amended to firstly, reiterate that the presumption of capacity is a right applying to all persons, regardless of age, disability, mental illness or impairment. The section could then refer to the important role of informal or appointed supporters, and their recognition should the older person wish for that person to be included or should circumstances necessitate their involvement.

Clauses 26 and 30 (Duties of Supporters and Representatives, respectively) should be amended to require any person identified as such to recognise and apply the presumption of capacity to the adult.

Clause 26 should be amended to insert a new subsection 26(1)(a) as follows:

> ***26 (1) A supporter of an individual has:***
>
> *(a) The duty to apply the presumption of capacity in relation to all decisions made by the individual; and*

The remainder of clause 26 should remain and be renumbered accordingly. The same amendment should be applied to subdivision (b) at clause 30, in relation to the duties of representatives.

With respect to the System Governor's ability to appoint a supporter or representative: ADA is generally supportive of the proposal for an existing informal support to be formally recognised through this process, when the supporter/representative has been selected or endorsed by the older person. However, the current drafting falls short of providing the protection presumably intended for the older person through this process, as it does not appear to require the System Governor (or presumably a delegate) to thoroughly consult with the older person and to take into account the older person's views and preferences, *prior* to making an appointment.

We also note with concern a document provided by the Department titled '*Steps for making a proposed nominee arrangement under the new Aged Care Act*'. The document contains a flow chart which is intended to provide further information about how the System Governor will go about appointing a supporter or representative. In relation to the appointment of a representative, the document states, *"System Governor must have regard to certain information when appointing someone as a representative. In particular where a person is appointed under State/Territory legislation as a Guardian/EPOA that person* ***will almost always be appointed*** *as a representative."* [our emphasis added].

Alongside the drafting in the Exposure Draft, this statement confirms our concerns that the proposed appointment system is unlikely to support an older person who seeks to be heard in relation to their own views and preferences, or to be recognised as their own decision-maker with capacity to make decisions regarding aged care services. Further, it indicates that the presumption of capacity is unlikely to be properly applied by the System Governor or their delegate.

As drafted, the appointment of a representative in circumstances where a guardian or EPOA has been appointed is at risk of becoming an automated exercise that does not apply the presumption of capacity or seek to uphold an older person's participation in these important decisions. It is also worth noting that simply because a guardian or EPOA is appointed by State or Territory legislation, that alone does not mean that the appointee is empowered to make decisions relating to aged care services (for example, accommodation decisions or healthcare decisions).

It is critical that the new Aged Care Act actively moves away from any system that reinforces ageism and diminishes the application of the presumption of capacity. ADA supports the recognition of an older person's chosen supporters and representatives. It is our view that the drafting and associated material do not align with the stated objectives of the legislation, or with the recommendations of the Royal Commission. We strongly suggest that, at a minimum, the section is amended to mandate both application of the presumption of capacity and for comprehensive consultation with the adult to take place before any appointment is made.

On a practical level, a comprehensive education program will be required to be delivered to the aged care sector and associated health, judicial and community agencies to ensure that the proposed model is understood and operates as intended. Without this, a multiplicity of potential decision-makers is likely to lead to confusion for all parties.

Recommendations for Chapters 1 – 3:

1) Amend the Objectives and Statement of Rights to include additional rights and clarify the scope of identified rights, in accordance with the above.
2) Remove clause 21(3).
3) Amend Chapter 4, Part 1, and Chapter 8 in relation to the proposed clauses regarding supporters and representatives as outlined above.
4) Remove provisions setting out the process of the System Governor appointing a supporter or representative from Chapter 8, and insert these (incorporating suggested amendments as above) into Chapter 1, where they will then be read in conjunction with the operative provisions of these roles. Making this change will also alert the reader that a supporter and/or representative is not a mandatory requirement for a person seeking or receiving aged care services.

Governance and regulatory interventions

The final report of the Royal Commission into Aged Care Quality and Safety (the **Royal Commission**) noted the regulatory shortcomings in the current system, stating:

> *"The regulatory framework is overly concerned with processes, not focused enough on outcomes, and does not provide enough safeguards to protect older people….."*[1]

[1] Aged Care Royal Commission*, A summary of the final report*, (2021) 76, https://www.royalcommission.gov.au/system/files/2021-03/final-report-executive-summary.pdf.

ADA supports the stated intention to improve and expand the regulatory oversight of the sector.

Role of the Regulator and Department

ADA supports the proposed revision of oversight, inspection and monitoring powers and functions by the Aged Care Commission (the **Commission**), to be carried out by a specialised team. The drafting suggests a proposed expansion that would appear to support a more comprehensive and thorough model for these critical functions, including an improved understanding within the regulator about systemic or broader risks in the sector. These changes, if appropriately resourced, will play an important role in identifying and reducing issues of concern at both an individual and systemic level.

However, some key changes are needed to ensure that these key roles operate as intended and in accordance with the objectives of the legislation.

This includes an increase in the independence of the newly created Complaints Commissioner. This important role should be directly appointed by, and report to, the Minister. It is not appropriate for the Complaints Commissioner to report to the Aged Care Commissioner, which will give rise to reasonable concerns about the independence of the role, including whether a conflict of interest may exist or could arise.

The independent Complaints Commissioner should work collaboratively with the Aged Care Commissioner to assist in identify systemic issues and patterns, and so that information can be appropriately shared with safeguards to ensure that critical information pertaining to an individual's complaint, wellbeing and safety is not siloed to the detriment of the individual.

Enforcement Powers and penalties

ADA supports the proposal to include mechanisms which ties obligations and non-compliance of an aged care services provider to registration.

However, this is insufficient and will not drive the significant cultural change which is required to implement the cultural change needed to herald in a strong rights-based aged care practice in alignment with community expectations.

As identified above, the rights set out in the Statement of Rights must be enforceable via a court or tribunal. If the government intends to adhere to the recommendations of the Royal Commission, the legislation must provide for an affected individual to seek to enforce the rights set out in the Statement of Rights by all recourses that are usually available to any person seeking to uphold a right or obligation, including utilising appropriate legal pathways. It is insufficient to assert that a right does not provide standalone protection for an individual, and can only be enforced in the event of identifying that the provider has not complied with another section of the act.

With respect to regulatory powers of enforcement, ADA is encouraged that the legislation includes the enforcement of civil penalties, infringement notices, enforceable undertakings, injunctions, action and compliance notices as some of the expanded powers available. However we note that critical failures powers are yet to be drafted.

It is encouraging that the draft refers to banning orders which may be imposed upon aged care entities as well as individuals as aged care workers and responsible persons. Further detail regarding the circumstances or examples that would be expected to lead to the use of this order would be welcome (noting that some general examples are helpfully included in clause 286(3)(a)-(h)), as well as an example to explain the intended application of the exemption to a banning order as referred to under clause 286(2).

It is concerning that referral pathways are not mentioned as a result of any investigation and enforcement functions being underway or completed by the regulator, such as to police as may be appropriate or required.

Role of providers, professional advocacy, supporting quality care and cultural change

ADA applauds the inclusion of a statutory recognition of the right to advocacy and inclusion of this right in the Objectives of the Exposure Draft. As mentioned above, we suggest further amendments to ensure that the legislation clarifies that the right to advocacy is available to an individual whether or not decision-making capacity is in question, and whether or not a supporter, representative, guardian, administrator or attorney is in place. A legislative provision to this effect will be in alignment with other human rights instruments, including the *Human Rights Act 2019* (Qld) and the CRPD.

In addition to aforementioned statutory reform and the introduction of a federal human rights-based framework, ongoing education programs and awareness campaigns targeting aged care providers, health care providers and the community are required to inform the sector and community about increased standards of practice, improved oversight and functions of the Department and the Regulator, and the need for a holistic human-rights based approach to be developed and delivered in policy and in practice.

ADA supports the stated objective to work with providers and help the sector to lift the quality and safety of aged care service delivery. The stronger responsibility on providers to continuously improve quality of care and services is important. Appropriate and regular oversight of this obligation will be required. There is significant work to be done in this space, particularly with respect to the use and management of restrictive practices. The implementation of star ratings is a welcome and important step in improving information about aged care and assisting people to make informed decisions.

To aid the objective of continuous improvement, ADA supports the proposal that the regulatory model include a requirement for residential aged care facilities to facilitate and undertake education sessions led by external advocacy organisations. The network of community advocacy organisations that are associated with the Older Persons Advocacy Network, of which ADA is a member, are funded to provide educations to the sector but currently residential facilities are not required to facilitate them. It would be appropriate to introduce a requirement to have an advocacy organisation provide an education session at least annually, and for compliance to be tied to accreditation of the provider.

To this point, the draft refers to the provision and support for education and advocacy arrangements in the objectives of the Exposure Draft but does not expressly provide a right of entry for accredited advocacy organisations to carry out these functions. The obligation to facilitate entry for these purposes should be recognised as an important aspect of supporting the system's governance

framework, and should be a requirement of registration and ongoing accreditation for service providers.

ADA suggest that an additional overarching obligation is included as a condition of registration with reference to the obligation to recognise, support and uphold the human rights of an individual who receives aged care, in accordance with the requirements of relevant laws.

An obligation to this effect will promote a human rights practice across the sector, and assist in adherence to the new Age Care act and other domestic and international instruments.

Recommendations for Chapters 5 - 6

1. Amend the Exposure Draft to ensure that the Complaints Commissioner is appointed by and reports directly to the Minister, not to the Aged Care Commissioner.
2. Provide additional examples and detail about what circumstances and degree of severity is likely to trigger different enforcement mechanisms.
3. Include a provision expressly referring to referral pathways *to relevant investigative authorities* as may be appropriate, such as to police or the ombudsman. Whilst this clarification should be expressly included in relation to the 'complaints functions' of the Aged Care Commissioner under clause 144, it should not solely sit here. Rather, the obligation to provide referral pathways to relevant investigatory bodies should be embedded as a responsibility of each person and entity associated with governance of the Act.
4. Insert a provision that clarifies the right of entry of a professional advocate to undertake education sessions, in support of the Aged Care Commissioner's education functions and to assist with the governance obligations of the Act.
5. Insert a provision setting out the right of entry of a professional advocate to undertake legal or general advocacy services, in support of the Objectives of the Act and to support the governance framework and responsibilities attributed to the System Governor, Aged Care Commissioner and the Complaints Commissioner.

While strongly supporting penalties and sanctions for breaches of human rights in aged care, ADA is pragmatic, noting that the achievement of a true rights-based system cannot and will not be achieved overnight given the current poor performance in this area. ADA would support a phased approach to the application of penalties and sanctions, perhaps over a 2-3 year period, to allow providers to meet the requirements of a truly rights-based Aged Care Act and supporting legislative framework.

Thank you again for the opportunity to comment. ADA would be pleased to further assist the Committee with its inquiry. Should you wish to discuss this submission, please do not hesitate to contact Vanessa Krulin, Solicitor and Senior Policy and Research Officer on [redacted] or via [redacted].

Yours faithfully

[redacted]

Geoff Rowe
Chief Executive Officer