

Department of Health and Aged Care - New Aged Care Act
Consultation
GPO Box 9848
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Australia



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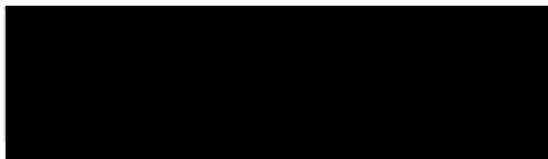
To whom it may concern,

We thank the Department of Health and Aged Care for the opportunity to provide comment on the exposure draft of the Bill for the new Aged Care Act (Hitherto referred to as "The Act").

Capacity Australia (capacityaustralia.org.au) is a-not-for-profit, human rights medico-legal organization with charity DGR status, led by senior legal, medical/psychiatric and allied health (social work, psychology and pharmacy) academics, clinicians and practitioners. We are committed to supporting the human rights of people with decision-making disability and vulnerable populations.

Please find our response to the exposure draft of the Bill for the Act below, on behalf of the Board of Capacity Australia.

Kind Regards,



Professor Carmelle Peisah
President, Capacity Australia



Section 5

We applaud Section 5 Objects of The Act in its active promulgation of human rights frameworks with specific articulation of relevant rights. We note that the new Act aims to create a simple, “rights-based legal framework” that focuses on the needs of older people.¹ Older persons, particularly those with disability (which by definition include those requiring aged care services),² continue to experience violations of their human rights, particularly in relation to equitable access to health care and meeting needs on account of disability, rights articulated in Article 25 of the Convention on the Rights of Persons with Disabilities (CRPD).³ Capacity Australia shares with its partner human rights organisations including but not limited to Rights of Older Persons Australia (ROPA)(rightsofolderson.org.au), and its international partners a mission of advocacy for rights-based healthcare embodied in legislation such as The Act.⁴ We also are strong advocates against ageism, supported by overwhelming scientific evidence with longstanding explicit and universal disavowal in all other legal, health, social and human rights contexts.⁵

Although purporting to be a rights-based framework, the Act seems to shy away from explicitly stating this. For example, in 5(b) (iv), the CRPD-19 enshrined right to

¹ See Australian Department of Health and Aged Care, *Exposure Draft – Aged Care Bill 2023*, December 2023, <https://www.health.gov.au/resources/publications/exposure-draft-aged-care-bill-2023> and *A new Aged Care Act: exposure draft, Consultation paper No. 2*, December 2023, <https://www.health.gov.au/sites/default/files/2024-02/a-new-aged-care-act-exposure-draft-consultation-paper-no-2.pdf>

² Peisah C, de Mendonça Lima C, Verbeek H, Rabheru K [IPA and WPA-SOAP joint statement on the rights of older persons with mental health conditions and psychosocial disabilities](#). *Int Psychogeriatr*. 2021 May 12:1-5

³ CRPD. (2016). [Convention on the Rights of Persons with Disabilities | OHCHR](#)

⁴ Peisah C, Sheppard A, de Mendonça Lima C, Ayalon L, Banerjee D, Rabheru K, (2023) Right to health and access to health services Response to the call from the of WPA-SOAP and IPA response to the call from the UN-OHCHR rapporteur for the 13th session of the OEWSG.

⁵ For Capacity Australia related references see:- Ayalon L, Peisah C, Lima CM, Verbeek H, Rabheru K. (2021) Ageism and the State of Older People With Mental Conditions During the Pandemic and Beyond: Manifestations, Etiology, Consequences, and Future Directions. *Am J Geriatr Psychiatry*. 29(10):995-999; also Wand A, Verbeek H, Hanon C, Augusto de Mendonça Lima, C, Rabheru K, Peisah C. (2021) [Is Suicide the End Point of Ageism and Human Rights Violations?](#) *The American Journal of Geriatric Psychiatry* 29(10):1047-1052; also Ayalon L, Peisah C, de Mendonça Lima, C, Verbeek, H, Rabheru K. (2021) Ageism and the state of older people with mental conditions during the pandemic and beyond: Manifestations, etiology, consequences, and future directions". Response to the call by the Independent Expert on the human rights of older persons, Office High Commissioner Human Rights (OHCHR) United Nations (UN) to inform the Expert's report to the 48th session of the Human Rights Council, UN. https://www.ohchr.org/_layouts/15/WopiFrame.aspx?sourcedoc=/Documents/Issues/OlderPersons/AgeismAgeDiscrimination/Submissions/NGOs/IPA-and-WPA.pdf&action=default&DefaultItemOpen=1.



inclusive community living is conflated with an obscure, apparent reference to ageism in relation to community attitudes:

While we applaud The Act's attempted stance against ageism, it is implicitly stated and obfuscated in in 5(b) (iv):

support individuals accessing funded aged care services to effectively participate in society on an equal basis with others, thereby promoting positive community attitudes to ageing.

Firstly, it is not a non-sequitur to talk about promoting positive community attitudes by supporting inclusiveness (i.e. inclusiveness does not promote positive community attitudes). The human right to live independently and be included in the community is moot here and should be specifically emphasised.

A rights-based Act must explicitly define and prohibit ageism. One way to combat ageism is to "promote positive community attitudes", but there are many other ways, such as promoting autonomous decision-making, involving older persons in making, communicating and participating in decisions that affect their lives. This must be included in the Act e.g. it could be linked to supported decision-making, which is also per se a right enshrined in Article 12 of the CRPD.

Furthermore, there is missed opportunity to prohibit elder abuse more explicitly. Capacity Australia has been active in the global battle against elder abuse and has provided consultation on elder abuse to both State government and the Australian Law Reform Commission.⁶ We suggest that for the same reason as above in relation to ageism, elder abuse is specifically referred to (and defined – see below) in the Act. This explicit prohibition is an imperative in an Act that purports to support human rights, particularly given the evidence provided to the Royal Commission into Aged Care Quality and Safety. We suggest expanding upon 5 (b) and (d):

⁶ [NSW Legislative Council General Purpose Standing Committee No. 2: Inquiry into Elder Abuse](https://www.parliament.nsw.gov.au/committees/DBAssets/InquiryReport/ReportAcrobat/6063/Report%2044%20-%20Elder%20abuse%20in%20New%20South%20Wales.pdf), evidenced by multiple references both to myself personally and to Capacity Australia (see Elder abuse in New South Wales / General Purpose Standing Committee No. 2 [Sydney, N.S.W.] : the Committee, 2016. [xx, 186] p. ; 30 cm. (Report no. 44 / General Purpose Standing Committee No. 2) and where endorsement and use of our tool was Recommendation 9 of the LC's final report. https://www.alrc.gov.au/sites/default/files/pdfs/publications/elder_abuse_131_final_report_31_may_2017.pdf; the ALRC enquiry into elder abuse; https://www.alrc.gov.au/sites/default/files/pdfs/publications/elder_abuse_131_final_report_31_may_2017.pdf f:-

ensure individuals accessing funded aged care services are free from elder abuse: i.e. mistreatment, neglect and harm from poor quality or unsafe care;



Section 7 Part 2 Definitions

We suggest that cognitive difficulties (better referred to as cognitive disorders) are referred to specifically and separate to mental difficulties (mental disorders). Many people with cognitive difficulties do not see themselves as having mental difficulties and along the same lines, we suggest that any reference to “*physical, mental or social*” be amended to “*physical, mental, cognitive or social*”.

Please define elder abuse, and use the World Health Organization definition:

*“A single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person. This type of violence constitutes a violation of human rights and includes physical, sexual, psychological and emotional abuse, financial and material abuse, abandonment; neglect; and serious loss of dignity and respect.”*⁷

Section 17

This remains an excellent nuanced approach to restrictive practices.⁸

Given Australia’s problem with obtaining consent for restrictive practices⁹ we suggest that the consent requirement (currently s17 1 (f)) be moved higher in the hierarchy, perhaps to s17 1 (b).

Section 19

This is an excellent description of high-quality care. Perhaps replace the word “*aspirations*” (line 32, page 27) with “*will*” [i.e. “*will and preferences*”] to make it more perfectly aligned with Article 12 CRPD.

We suggest the following be added:

⁷www.who.int/news-room/fact-sheets/detail/abuse-of-older-people

⁸ O’Neill N., Peisah C. (2021) Capacity and the law. 4th Edition Australasian Legal Information Institute ([AustLII](http://austlii.com.au)) Communities <http://austlii.com.au/wiki/Books/CapacityAndTheLaw/>.

⁹ Peisah C, Jessop T. (2021) Australia’s problem with obtaining consent for psychotropic use in older people Internal Medicine Journal. Intern Med J.;51(4):604-607.



(xii) supporting the individual to participate in meaningful, respectful and abuse-free relationships including, intimate relationships, consistent with their will and preferences.¹⁰

Part 3—Aged care rights and principles; Division 1—Aged care rights 20

Statement of Rights

This Part is excellent, and we applaud the reference to provision of palliative care.

Division 2 Statement of Principles

As above, comprehensive and well stated.

Part 4 Supporters and Representatives

While we applaud the reference to Supported Decision Making and strongly endorse its inclusion in all reformed legislation, this Part is overly complex and both overly prescriptive and proscriptive compromising its likely intended purpose. Firstly, the interface with other legislation including Guardianship and Administration legislation is very unclear. Notwithstanding the caveat *“If the System Governor intends to appoint a person as a supporter but there is already a representative of the individual, the System Governor must cancel the appointment of the representative: see subsection 388(3),”* there is no clear statement regarding which law overrides. There is limited discussion about what each descriptor means, nor does there seem any utility in generating so many roles (i.e. Guardians, Attorneys, Representatives, and Supporters). Given what we know about conflict in families,¹¹ this is likely to exacerbate such, when the roles, the responsibilities and hierarchy of decision making of Guardians, Attorneys, Representatives, and Supporters are all confused and weaponised.

¹⁰ Peisah C, Ayalon, L, Verbeek H, Benbow SM, Wiskerke E, Rabheru K, Sorinmade O (2021) [Sexuality and the human rights of persons with dementia](#) *The American Journal of Geriatric Psychiatry* 29(10):1021-1026.
Peisah C, Burns K., Edmunds S. Brodaty H. (2018) Rendering visible the previously invisible in health care: the ageing lesbian, gay, bisexual, transgender and intersex (LGBTI) communities *Medical Journal Australia* 6;209(3):106-108

¹¹ Peisah C. Brodaty H, Quadrio C. (2006) Family conflict in dementia: prodigal sons & black sheep *Int J Ger Psychiatry* 21(5):485-492



Secondly, the wording of Part 4, Division 1, s374 appears presumptuous, protectionist and ageist in the implication that the need for and decision to appoint a Supporter starts with and lies with the System Governor. Surely it starts with the person? We recognise that the appointment relies on the mutual consent of the person and the supporter, but this sounds more like assent.

Thirdly, the Act does not adequately address protection for an individual when an advocate or support person is engaged with assisting the individual in a supported decision-making process. The Act should embody the principles outlined in the Guardianship and Administration Act 2019 (Vic), including that role of the advocate or support person is limited to enabling the individual's understanding and communication of their own decision and not to act as a substitute decision maker (Section 20 (1)(b) and (10)).¹²

In conclusion, given our Federalism and other Guardianship and Administration laws in place, Capacity Australia recommends that the Act endorses supported decision-making as a national, principle-based process rather than creating new, confusing roles. This means, legislating for how to support, not who should support, as embodied in the General Principles of the Queensland Guardianship and Administration Act 2000 - S 11B (See Appendix 1).

Section 27 (5) is very unclear. How can anyone be compelled to “do a thing” (or make a decision?): *If an individual is required under, or for the purposes of, this Act to do a thing, failure by a representative of the individual to comply with the requirement on behalf of the individual is taken, for the purposes of this Act (other than this Part), to be a failure of the individual to comply with the requirement.*

Section 28 is very unclear.

¹² Oshea, B., Hunter, H., Bird, K., Saunders, D., Opazo, I. Supported Decision Making (2023) Law Institute Journal, November, p 18-21; *Guardianship and Administration Act 2009* (Vic), sections 3 and 90.

Section 106 is incomprehensible.



Appendix 1

Queensland GUARDIANSHIP AND ADMINISTRATION ACT 2000 - SECT 11B

General principles

11B General principles

(1) The principles (the "**general principles**") set out below must be applied by a person or other entity that performs a function or exercises a power under this Act.

(2) Also, a person making a decision for an adult on an informal basis must apply the [general principles](#) in making the decision.

(3) The community is encouraged to apply and promote the [general principles](#).
[General principles](#)

1 Presumption of capacity

An adult is presumed to have capacity for a matter.

2 Same human rights and fundamental freedoms

(1) An adult's inherent dignity and worth, and equal and inalienable rights, must be recognised and taken into account.

(2) The rights of all adults to the same human rights and fundamental freedoms, regardless of a particular adult's capacity, must be recognised and taken into account.

(3) The principles on which an adult's human rights and fundamental freedoms are based, and that should inform the way those rights and freedoms are taken into account, include—

(a) respect for inherent dignity and worth, individual autonomy (including the freedom to make one's own choices) and independence of persons; and

(b) non-discrimination; and

(c) full and effective participation and inclusion in society, including performing roles valued by society; and

(d) respect for difference and acceptance of persons with impaired capacity as part of human diversity and humanity; and

(e) equality of opportunity; and

(f) accessibility; and

(g) equality between all persons regardless of gender.

3 Empowering adults to exercise human rights and fundamental freedoms

The importance of the following matters must be taken into account—



(a) empowering an adult to exercise the adult's human rights and fundamental freedoms;

(b) encouraging and supporting an adult—

(i) to perform social roles valued in society; and

(ii) to live a life in the general community and to take part in activities enjoyed by the community; and

(iii) to achieve maximum physical, social, emotional and intellectual potential and to become as self-reliant as practicable;

(c) an adult's right to participate to the greatest extent practicable in the development of policies, programs and services for people with impaired capacity for a matter.

4 Maintenance of adult's existing supportive relationships

(1) The importance of maintaining an adult's existing supportive relationships must be taken into account.

(2) Maintaining an adult's existing supportive relationships may, for example, involve consultation with—

(a) the adult, to find out who are the members of the adult's support network; and

(b) any persons who have an existing supportive relationship with the adult; and

(c) any members of the adult's support network who are making decisions for the adult on an informal basis.

(3) The role of families, carers and other significant persons in an adult's life to support the adult to make decisions should be acknowledged and respected.

5 Maintenance of adult's cultural and linguistic environment and values

(1) The importance of maintaining an adult's cultural and linguistic environment and set of values, including religious beliefs, must be taken into account.

(2) Without limiting *subsection (1)*, for an adult who is an Aboriginal person or a Torres Strait Islander, the importance of maintaining the adult's Aboriginal or Torres Strait Islander cultural and linguistic environment and set of values, including Aboriginal tradition or Island custom, must be taken into account.

6 Respect for privacy

(1) An adult's privacy must be taken into account and respected.

(2) An adult's personal information, including health information, must be protected on the same basis as other people's personal information is protected.

7 Liberty and security

(1) An adult's right to liberty and security on an equal basis with others must be taken into account.



(2) An adult should not be deprived of the adult's liberty except in accordance with the law.

8 Maximising an adult's participation in decision-making

(1) An adult's right to participate, to the greatest extent practicable, in decisions affecting the adult's life must be recognised and taken into account.

(2) An adult must be given the support and access to information necessary to enable the adult to make or participate in decisions affecting the adult's life.

(3) An adult must be given the support necessary to enable the adult to communicate the adult's decisions.

(4) To the greatest extent practicable, a person or other entity, in exercising power for a matter for an adult, must seek the adult's views, wishes and preferences.

(5) An adult's views, wishes and preferences may be expressed orally, in writing or in another way, including, for example, by conduct.

(6) An adult is not to be treated as unable to make a decision about a matter unless all practicable steps have been taken to provide the adult with the support and access to information necessary to make and communicate a decision.

9 Performance of functions and exercise of powers

A person or other entity, in performing a function or exercising a power under this Act in relation to an adult, or in making a decision for an adult on an informal basis, must do so—

(a) in a way that promotes and safeguards the adult's rights, interests and opportunities; and

(b) in the way that is least restrictive of the adult's rights, interests and opportunities.

10 Structured decision-making

(1) In applying general principle 9, a person or other entity in performing a function or exercising a power under this Act in relation to an adult, or in making a decision for an adult on an informal basis, must adopt the approach set out in *subsections (2) to (5)*.

(2) First, the person or other entity must—

(a) recognise and preserve, to the greatest extent practicable, the adult's right to make the adult's own decision; and

(b) if possible, support the adult to make a decision.

(3) Second, the person or other entity must recognise and take into account any views, wishes and preferences expressed or demonstrated by the adult.

(4) Third, if the adult's views, wishes and preferences cannot be determined, the person or other entity must use the principle of substituted judgement so that if, from the adult's views, wishes and preferences, expressed or demonstrated when the

adult had capacity, it is reasonably practicable to work out what the adult's views, wishes and preferences would be, the person or other entity must recognise and take into account what the person or other entity considers the adult's views, wishes and preferences would be.



(5) Fourth, once the person or other entity has recognised and taken into account the matters mentioned in *subsections (2) to (4)*, the person or other entity may perform the function, exercise the power or make the decision.