Foundations of the Aged Care Act

Joint Submission

National organisations working with older people and carers

September 2023

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Council on the Ageing (COTA) Australia | peak body representing 9 million Australians over 50.

Older Persons Advocacy Network (OPAN) | peak body for aged care individual advocacy.

Association of Independent Retirees (AIR) | advancing the independence of those fully or partly self-funded in retirement.

Carers Australia | peak body representing Australia's unpaid carers.

Dementia Australia | supporting and empowering people living with dementia.

Elder Abuse Action Australia (EAAA) | acting to eliminate elder abuse.

Federation of Ethnic Communities' Councils of Australia | peak body for people from culturally and linguistically diverse backgrounds.

Legacy | supporting the partners and children of veterans.

LGBTIQ + Health Australia | peak body for LGBT and intersex organisations.

National Seniors Australia | advocating for better outcomes for older Australian members.

National Association of People With HIV Australia | Advocacy, representation, policy & health promotion for people with HIV.

PICAC Alliance | unified body of Partners in Culturally Appropriate Care (PICAC) funded organisations.

The Returned and Services League of Australia (RSL) | supporting people who have served or are serving in the Australian Defence Force.

1. Introduction

"I don't have the power to change anything".
(Resident, RAC, Brisbane)

"[These rights are] not worth the paper they are written on unless they are applied in practice".
(Older Person, Newcastle)

A human rights-based aged care act is essential. It is only then that the rights, preferences, and needs of the older person will be at the core of the aged care system. It is imperative that this Act is backed by an aged care system that articulates, enables, protects and enforces the human rights of older people as well as recognising and supporting their families and carers. This must also include having an enabled workforce with the right numbers and skill mix to meet the needs of each older person.

The new rights-based Aged Care Act must include mechanisms for monitoring and enforcing the rights of older people and there must be consequences for breaching these rights. The governance model of aged care must reflect this with appropriate mechanisms to monitor, respond and ensure the rights of older people are upheld. This must include direct engagement with older people themselves, and carers, and the organisations and people that represent them.

Rights must be framed to support active, informed and empowered citizenship for older people. This includes the right to equitable access and outcomes, the right to exercise choice, the right to autonomy, the right to the presumption of legal capacity, and in particular the right to make decisions about their care and the quality of their lives and the right to social participation and enjoyment as well as the right to fair, equitable and non-discriminatory treatment in access to the provision of care.

In addition, the new Act must include a direction to review the Act every three years, or sooner if legislative changes are made that impact on the Act. The new Act is a major shift away from how the sector currently operates and any issues or unintended consequences need to be resolved early and not allowed to continue unresolved A review is particularly important with the potential

implementation of a Human Rights Act, which is currently being considered by the Australian government. There is also the possible development of an International Convention on the Human Rights of Older Persons that will mean the Act will need to be re-written to meet obligations under a legal and international instrument. It will be important for the Act to align with new Human Rights legislation in Australia and a new international convention.

Our submission reflects the experiences and wants of older people, that they, carers and family members have shared with consumer organisations and through the consultations held across Australia by OPAN and COTA. It reflects our knowledge and experience in supporting and advocating with and on behalf of older people and carers. And it responds to, and makes recommendations about, the issues raised in the A New Aged Care Act: the foundations, Consultation Paper No.1.

1.1 Recommendations

General

1. That information, education and training on rights and the implementation of the new Aged Care Act must commence from 1 January 2024 for older people and participants, families, representatives, aged care workers and providers.
2. A 3-year review of the Act must be embedded within the Act.
3. That the Inspector General of Aged Care be required to provide an annual report on the operations of the Aged Care Act.
4. The Act clearly demonstrates/legislates how it will be applied throughout later life for people accessing Home Care, Residential Care, NATSIFlEX and other aged care services; and a palliative approach/care for older people at end of life.

Exposure Draft

5. The Government must ensure the proposed "rules" are included in the exposure draft consultation foreshadowed in December 2023 – February 2024.
6. That the Government provide a minimum 8-week period of consultation on the Exposure Draft of the new Aged Care Act.
7. That the legislation is developed as a single piece of legislation (including the Inspector General of Aged Care within the new Aged Care Act), and a single group of 'rules. Such an approach with topic-based

chapters of the “rules” will ensure consistent understanding of all obligations in a single location.

a. If the Inspector General of Aged Care Act were not to be included, consequential amendments to the Inspector General Act must be included to ensure the Inspector General is to have regard of:
    i. Statement of Rights
    ii. Statement of Principles
    iii. Purpose/Object.

2. Summary of Recommendations

2.1 General

1. That information, education and training on rights and the implementation of the new Aged Care Act must commence from 1 January 2024 for older people and participants, families, representatives, aged care workers and providers.
2. A three-year review of the Act must be embedded within the Act. (The new Act is a major shift away from how the sector currently operates and any issues or unintended consequences need to be resolved early and not allowed to continue unresolved.)
3. That the Inspector General of Aged Care be required to provide an annual report on the operations of the Aged Car Act.
4. The Act clearly demonstrates/legislates how it will be applied throughout later life for people accessing Home Care, Residential Care, NATSIFlEX and other aged care services; and a palliative approach/care for older people at end of life.

2.2 Exposure Draft

5. The Government must ensure the proposed "rules" are included in the exposure draft consultation foreshadowed in December 2023 – February 2024.
6. That the Government provide a minimum 8-week period of consultation on the Exposure Draft of the new Aged Care Act.
7. That the legislation should be developed as a single piece of legislation (including the Inspector General of Aged Care Act within the new Aged Care Act), and a single group of 'rules'. Such an approach with topic-based chapters of the rules will ensure consistent understanding of all obligations in a single location.

    a. If the Inspector General of Aged Care Act were not to be included, consequential amendments to the Inspector General must be included to ensure the Inspector General is to have regard to:
        a. Statement of Rights
        b. Statement of Principles
        c. Purpose/Object

2.3 Purpose and Objectives

8. That the Act and its reliance on external affairs powers are expanded beyond the "other relevant instruments" to specifically reference the following international documents:

    a. International Covenant on Civil and Political Rights (ICCPR) – to ensure Freedom from discrimination; Right to equality between men and women; Right to be treated with humanity in detention; Freedom of movement; Right to privacy; Freedom of religion and belief; Freedom of association; and Right to participate in public affairs are incorporated into the Act.
    b. Convention against Torture and Other Forms of Cruel Inhuman or Degrading Treatment or Punishment and the Optional Protocol to the Convention Against Torture – in recognition that a place of detention under OPCAT includes aged care facilities.
    c. United Nations Declaration on the Rights of Indigenous Peoples
    d. Universal Declaration of Human Rights
    e. Convention on Elimination of All Forms of Discrimination against Women.

9. The Purpose and Objectives must align with the rights and principles of the Act, so that each reinforces the other and there is no inconsistency.
10. That the object and purpose of the Act be combined into one section of the Act to remove the risk that the narrower purpose will have a primary role when the legislation is interpreted (noting there was some support for the purpose to be retained during consultations). This could simply be done by including the purpose statement as an introductory paragraph to the list of objects or including the purpose as an object.
11. That the purpose and objects should be re-written as indicated below in Section 4 below (Structure, Purpose and Constitutional Foundation of the Act), in particular to:

    a. Recognise the role of the Act to provide disability supports to people over the age of 65 who are not NDIS participants. It is inappropriate to diminish the person's specific disability into a generic aged related 'care needs', they have 'disability supports' needs as well.
    b. Legislate a recognition of a 'carer of a participant' in the same way the NDIS Act section 3, Item 3 does so by reference to "the Carer Recognition Act 2010."

2.4 Rights

2.4.1 Individual Rights

12. The Department works with participant peaks to ensure the wording of the rights is "right". We have made suggested changes below, based on consultations, in Section 6 (Statement of Rights) but welcome the opportunity to work on these further with you.
13. Rights must be legislated across the aged care system from the delivery of individual care by a personal care worker, up to the system governor, including the regulator and Inspector General. In other words, the obligation to comply with human rights applies not only to providers and others involved in the provision of services, but to the government and the regulator as well.
14. The following rights – a non-exhaustive list - must be included:

    a. The Right to Self Determination, Autonomy and Independence
    b. The Right to High Quality Care
    c. The Right to Health (including oral, sensory, psychological, and emotional)
    d. The Right to Freedom of Movement
    e. The Right to social participation, leisure and lifestyle activities
    f. The Right to pet companions.
    g. The Right to spirituality and wellbeing
    h. The Right to a named visitor at all times.

15. The word "inappropriate" to be removed from Right 7 so that it reads "freedom from the use of restrictive practices".
16. Any "qualifiers" such as "reasonable" are removed from the rights (see wording in Section 6 – Statement of Rights).
17. Ensure that rights are applicable to both those receiving aged care, along with those seeking to receive aged care services. If some rights only apply to those receiving aged care, split the list of rights to make this clear.
18. Consideration is given as to how rights may be grouped so key themes are highlighted.
19. A re-wording of the rights is needed (see wording in Section 6 – Statement of Rights).

2.4.2 Breaches of Rights

20. That the legislation includes or identifies pathways for seeking remedies for breaches of rights that are system wide, to include breaches as a result of acts or omissions by the government or regulators, e.g. what is the forum and procedure for raising a breach by the system governor or the regulator? It must be clear where participants can go to seek remedies for alleged breaches of rights.

2.4.3 Implementation of Rights

21. Legislation must include clear implementation timelines, monitoring and evaluation and the development of a culture change plan for the aged care sector.
    a. This includes developing a transition and implementation plan for providers including information, education and training

22. A change culture implementation plan must be released with the commencement of the Act to outline how the ACQSC, System Regulator and Aged Care Providers will embed rights in daily operations, including rights education measurements and implementation.
23. The ACQSC Quarterly Sector Report will include a regular report on the number of complaints against each right that have been received to measure whether a rights-based measure has been achieved.
24. A communication strategy on the new Act and what it means must be implemented prior to the commencement of the new Act.
25. If possible, rights should be written in plain English in the Act. If this is not feasible, a plain English and alternate versions (e.g. in language, visual) of the Rights must be available.

2.5 Complaints

26. The complaints system must be person-centred, robust and effective as such a system is an essential component of giving effect to a human rights-based approach in the aged care sector.
27. Alternate responses (A range of remedies that are flexible and adapted to resolving any allegations of violations of rights) must also be established and can be overseen by the new Complaints Commissioner.
28. The Aged Care Act should provide for the appointment of a statutory Complaints Commissioner with powers/responsibilities independent of the System Regulator.

2.6 Principles

29. The Act contains both Rights and Principles. The Principles must link to the rights and must not dilute the protections provided by the Statement of Rights.
30. The word “should” to be deleted and replaced with “is”, “will” or “must.”
31. A re-wording of the principles is needed, see Section 8 below (Principles).

2.7 High Quality Care

32. High Quality Care must link directly to the rights and principles in the Act.
33. The definition of High Quality Care should be re-worked with participant representatives and participants. We have provided suggested wording changes in Section 9 (High Quality Care).
34. The obligation to ensure High Quality Care must apply across the aged care sector from provider to regulator to System Governor.

2.8 Duty of Care

35. That Duty of Care applies to the responsible person and the governing bodies of aged care providers.
36. Duty of Care is applied to Personal Care Workers and other non-governed professionals (noting the duty of care of nurses, allied health professionals etc. is regulated by AHPRA) with the following limitations:

    a. The penalties should not be more onerous than a duty placed on other professionals regulated by AHPRA.
    b. The Duty does not apply, or is limited, where it can be demonstrated that the Provider has not met their duty of care to the staff member through appropriate onboarding and ongoing education and training, resourcing and the provision of a safe environment and equipment.
37. Duty of care should align with the obligations and responsibilities included within Work Health and Safety legislation, rather than duplicating this.
38. Introduce a separate duty on organisations that provide enabling services where the organisation is responsible for supplying workers to deliver the service (distinct from those who facilitate independent contractors who would independently be required to assess their own suitability for the services requested).

2.9 Penalties and Compensation

39. The payment of compensation does not stop action being taken to change the system (e.g. non-disclosure agreements or 'gag orders' cannot be applied to agreements involving compensation payments)
40. It must be clearly legislated that compensation payments, made through this process, must not be included within individual means-testing for aged care contributions (as currently happens with National Redress Scheme payments, noting we recommend that this practice ceases.)
41. Consideration should be given to how to support smaller and specialist providers that may face higher insurance charges as a result of these changes (but this must not be used as a reason to not implement these changes).

2.10 Whistleblowers

42. The Department must develop a guiding policy on Whistleblowers, with key principles and actions that Providers must include within their own Whistleblower Policies.
43. Whistleblowers must have multiple pathways available to them, not just directly to the provider.
44. The Act must clearly state that Whistle Blower protections include those that may be "whistleblowing" on another's behalf e.g. a family member or advocate, and that the Whistleblower protections applies equally to both parties.
45. That Whistleblower protections include priority access to timely assistance for participants who fear retribution to change aged care providers.
46. That clarification is provided in legislation for Whistleblowers who may have been involved in the misconduct and who then come forward.

2.11 Supported Decision-Making

2.11.1 Principles

47. Supported Decision-making must be the foundation of decision-making in aged care, as it is in disability support.
48. The proposed Supported Decision-Making model must be amended to reflect the Supported Decision-Making Framework recommended by the

Disability Royal Commission in its Report" Diversity, dignity, equity and best practice: a framework for supported decision-making".

49. The Act must use the terminology of "capability' or "ability" rather than capacity.
50. That in the current 3rd dot point of the Supported Decision-Making Principles the word "harm" must be changed to "serious harm".

2.11.2 Supporters and Representatives

51. Greater clarification is provided on how the proposed framework intersects with and applies to existing State and Territory decision-making frameworks including Power of Attorney, Guardian, medical treatment decision maker.
    a. Where people have an existing appointed POA or Guardian, then that person should automatically become the Representative and must work under the Supported Decision-Making Model.

52. The term Supporter should not be used, rather they should be referred to as an "information nominee" who must also work under the Supported Decision-Making Model where the older person requests this assistance.
53. If the role of Representative is to continue then consideration must be given to sub-categories of Representatives as not every person will have the time, skills and/or knowledge to assist a person with decisions across all areas of their life. For example, these could be:
    a. financial
    b. legal
    c. medical/health
    d. social.

2.11.3 Disputes and Reviews

54. Appropriate alternate dispute resolution processes are implemented so that disputes between the various decision-makers appointed by an older person can be resolved.
55. Similar appeal mechanisms, as available under State and territory laws, must be implemented.

2.11.4 Choosing a Representative

56. Establishing a clear pathway, and service, which could be based within the Regulator, to assist people in appointing a representative or nominee, or in the case where the person is assessed as unable to make

this decision, helping appoint a representative for that person. This service:

a. would ensure appropriate safeguards are in place to ensure there are no inappropriate nominee appointments.
b. will also provide the older person with the reasons for the appointment, the process that has undertaken to search for someone who could act as a supported decision maker for that person, whether an older person has the right to an advocate and legal representation, the process for appeal and/or to revoke the appointment.
c. The Secretary of the Department, or any delegated person, should not be the person choosing a representative or nominee as they have no connection, knowledge or understanding about that person and therefore cannot appoint someone who knows the person's wishes and preferences.

2.11.5 Further Work

57. Further engagement with participants and consumer representative groups to address the concern and confusion caused by this proposal and consider and address unintended consequences.
58. Establish a body to monitor and provide support, advice and education on the roles and responsibilities of being a representative and working within a supported decision-making framework.

2.12 Eligibility

59. Eligibility for people aged 50 – 64 years must be more flexible and include eligibility for those with younger onset dementia, found not eligible for the NDIS, or whose needs cannot currently be met by the disability system, those that have early onset of age-related health issue and those living with HIV.
    a. Flexibility must allow people under 65 being able to have a physiological test and if they are assessed as experiencing early ageing then they should be able to access aged care services.

3. Structure, Purpose and Constitutional Foundation of the Act

"The Act must take a life course approach and ensure that it is applicable across all aged care service types and palliative care."

(Aged Care Advocate)

We are uncertain as to the extent to which Commonwealth drafting practice is to include both a purpose and objects. The Commonwealth drafting style does not appear to use a "purpose" heading as this is usually indicated in the long title of the Act and in the "Objects" provisions. We note that Objects are common, but not so much Purpose. Purpose can be considered a higher-level Object with "Objects" a more detailed, non-exhaustive breakdown of specific goals that will contribute to the achievement of the overall purpose.
The Office of Parliamentary Counsel state:

"*Objects provisions*: *These are used to give readers a general understanding of the purpose of legislation, or to set out general aims or principles that help readers to interpret the detailed provisions of legislation*."[1]

During consultations with older people, it was indicated that there is some support for a clear Purpose being included within the Act. However, concerns remain that there is a risk that the narrower Purpose will have a primary role when the legislation is interpreted. This could simply be addressed by including the Purpose statement as an introductory paragraph to the list of objects or including the Purpose as an object.

There must also be a clear flow from Purpose, if kept, to Objects to Statement of Rights to Principles and that one does not over-ride the others.

3.1 Purpose

Current: facilitate access by older people to quality and safe, funded aged care services, based on their individual needs, with the aim of assisting them to continue to live active, self-determined and meaningful lives as they age.

[1] Australian Government Office of Parliamentary Counsel, *OPC's drafting services: a guide for clients,* 7th edition, July 2022, https://www.opc.gov.au/sites/default/files/2023-01/s13ag320.v55.pdf

Proposed Amendment: support the rights of older people accessing and receiving aged care and enable them to have the highest attainable health and wellbeing, autonomy and self-determination by delivering a safe, high quality, equitable, accessible and person-centred aged care system.

3.2 Objects

The objects need to give a general understanding of the purpose of the legislation. The current objects don't link fully to the rights in the Act nor the purpose of the Act. The following wording changes have been proposed:

Current: *gives effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities, the International Covenant on Economic, Social and Cultural Rights, and other relevant instruments.*

Proposed: gives effect to Australia's obligations under the Universal Declaration of Human Rights, Convention on the Rights of Person*s with Disabilities, International Covenant on Economic, Social and Cultural Rights, International Covenant on Civil and Political Rights, Convention against Torture and Other Forms of Cruel Inhuman or Degrading Treatment or Punishment, Optional Protocol Against Torture, Convention on the Elimination of Discrimination Against Women, International Convention on the Elimination of All Forms of Racial Discrimination, the UN Declaration on the Rights of Indigenous Persons and other relevant instruments.

Current: *assists older people to live active, self-determined and meaningful lives.*

Proposed: assists people to live active, autonomous, self-determined and meaningful lives and to retain choice and control in the planning and delivery of their care.

Current: *ensures equitable access to, and flexible delivery of, funded aged care services that takes into account the individual needs of older people, including people of diverse backgrounds and needs and vulnerable people.*

Proposed: ensures equitable access to, and flexible delivery of, funded aged

care services that meets the individual needs of people, including carers, people with disability and people from diverse and marginalised groups.

Current: *assists older people to effectively participate in society on an equal basis with others, which will help promote positive community attitudes to ageing.*

Proposed: ensures people accessing or receiving funded aged care services continue to enjoy the rights to social participation on an equal basis with members of society more generally.

Current: *enables older people accessing available funded aged care services to choose who will deliver their services, and when and how they do so.*

Proposed: enables people accessing or receiving funded aged care services to choose who will deliver their services, and when and how they do so. Where services are not available (e.g. in rural, remote areas) the government will provide services directly to those people.

Current: *ensure people accessing funded aged care services are free from mistreatment and neglect, and harm from poor quality or unsafe care.*

Proposed: protect and advance the rights of people receiving aged care to be free from mistreatment and neglect, and harm from poor quality or unsafe care.

Current: *provides and supports education and advocacy arrangements that can assist older people to access funded aged care services, understand their rights, make decisions, and provide feedback on the delivery of their services without reprisal.*

Proposed: provides and supports education and advocacy arrangements that assists older people accessing or receiving funded aged care services to understand their rights, make decisions, raise complaints and provide feedback on the delivery of their services without reprisal.

Current: *promotes innovation in aged care based on research and supports continuous improvement.*

Proposed: promotes innovation in aged care based on evidence-based research and supports continuous improvement.

Additional Objects:

- To meet the disability support needs of people aged over 65 who are not NDIS participants.
- Legislate a recognition of a 'carer of a participant' in the same way the NDIS Act section 3, Item 3 does so by reference to "the Carer Recognition Act 2010."

3.3 Recommendations

8. In relation to the constitutional foundations of the proposed new Act, the Consultation Paper refers only to the external affairs power. Presumably the intention is to rely on other heads of legislative power as well, in particular the corporation's power, in order to give the legislation a firm constitutional basis. So far as reliance on the external affairs power as a constitutional basis or interpretive aid, the refences should be expanded beyond the "other relevant instruments" to specifically reference the following international documents:

    a. International Covenant on Civil and Political Rights (ICCPR) – to ensure the right not to be arbitrarily deprived of one's life, Freedom from discrimination; Right to equality between men and women; Right to be treated with humanity in detention; Freedom of movement; Right to privacy; Freedom of religion and belief; Freedom of association; and Right to participate in public affairs are incorporated into the Act.
    b. Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and the Optional Protocol to the Convention Against Torture – in recognition that a place of detention under OPCAT includes aged care facilities.
    c. United Nations Declaration on the Rights of Indigenous Peoples
    d. Universal Declaration of Human Rights
    e. Convention on Elimination of Discrimination against Women

f. International Convention on the Elimination of All Forms of Racial Discrimination.

9. The Purpose and Objectives must align with the rights and principles of the Act, so that each reinforces the other and there is no ambiguity.
10. That the object and purpose of the Act be combined into one section of the Act to remove the risk that the narrower purpose will have a primary role when the legislation is interpreted (noting there was some support for the purpose to be retained during consultations). This could simply be done by including the purpose statement as an introductory paragraph to the list of objects or including the purpose as an object.
11. That the purpose and objects should be re-written as indicated below in Section 4 below (Structure, Purpose and Constitutional Foundation of the Act), in particular to:

    a. Recognise the role of the Act to provide disability supports to people over the age of 65 who are not NDIS participants. It is inappropriate to diminish the person's specific disability into a generic aged related 'care needs', they have 'disability supports' needs as well.
    b. Legislate a recognition of a 'carer of a participant' in the same way the NDIS Act section 3, Item 3 does so by reference to "the Carer Recognition Act 2010."

4. Constitutional Foundations

"[Older people have the] right to all human rights under various conventions".

(Advocate)

We note and welcome the inclusion of rights from the Convention on the Rights of Persons with Disability and the International Covenant on Economic, Social and Cultural Rights. However, in consultations with older people across Australia there have been repeated calls for inclusion of rights from the International Covenant on Civil and Political Rights, Convention on the Rights of Persons with Disabilities? and the United Nations Declaration on the Rights of Indigenous Peoples. Many people also raised inclusion and reference to the Convention against Torture and the Optional Protocol to the Convention against Torture, the Universal Declaration of Human Rights and the Convention on Elimination of Discrimination against Women and the International Convention on the Elimination of All Forms of Racial Discrimination.

5. Statement of Rights

"Rights are wonderful, but you need to take them in consideration of the realistic situation that a lot of these rights are unattainable in the current system".
(Older person, Hervey Bay)

"We need a campaign as effective as the "slip, slop, slap campaign" so that everyone knows their rights".
(Community member, Brisbane)

"We keep talking about linkages between societal (de)valuing of seniors/ageism, abuse, and expectations around human rights."
(Community member, Perth)

The first recommendation of the Royal Commission into Aged Care Quality and Safety (the Commission) Final Report was a new Aged Care Act, specifically a rights-based Act. Placing this as the first recommendation highlighted the importance and centrality of this new Act to truly transforming the current aged care system. It also emphasised the importance of placing the older person, and their rights, as 'central' to aged care.

The Royal Commission recognised the recipients of aged care, in all their diversity, as the centre of service delivery, regulation, quality assurance and funding. They also acknowledged that family and friend carers are the bedrock of a sustainable aged care system. They noted that carers' needs for support, and their relationship with the person receiving aged care, should be recognised and nurtured. The first recommendation of the Commission identifies the definition of aged care under the Act as:

a. support and care for people to maintain their independence as they age, including support and care to ameliorate age-related deterioration in their social, mental and physical capacities to function independently.
b. supports, including respite for informal carers of people receiving aged care.

In addition, in the rights that the Commission noted as forming the basis of this Act they included "*for people providing informal care, the right to reasonable access to supports in accordance with needs and to enable reasonable enjoyment of the right to social participation*".

The Commission identified a range of rights for people accessing and receiving aged care including the right to equitable access, the right to exercise choice, the right to liberty, freedom of movement, and freedom from restraint and the right of autonomy. The intent behind all these rights was to lay the foundations of an aged care system which addressed instances and patterns of neglect, inequities, lack of consideration, inadequacies and, in some cases, abuse of older people accessing aged care as revealed to the Royal Commission. In addition, it was to ensure that older people are recognised and treated as valuable, empowered members of society regardless of their diversity, disability, chronic condition, their life span, their backgrounds, their socioeconomic status, their beliefs, and their cultures.

During consultations older people identified several rights that they wanted to see included within the Act including the right to health care and the right to appropriate medications and end-of-life options including Voluntary Assisted Dying, as well as various changes to the language and wording used within the Rights. Older people also commented that the language used within the document was quite complex and legalistic, noting this would make it difficult for people to know and express their rights. The key themes identified by older people and community members will be addressed in full in the Consultation Report, however we have included some key wording changes below.

It is also our view that some additional rights should be identified in the Statement of Rights and that some wording changes are needed.

5.1 Recommended Additional Rights

"Since COVID residential care have locked doors for convenience of staff not residents. Freedom of movement."
(Older person, Sydney)

"Everyone has the right to live how they wish, without control over the way they choose to live."
(Older person, Canberra)

"I have the freedom to be myself."
(Resident, RAC, Newcastle)

We welcome the inclusion of rights based on those in the Convention on the Rights of Persons with Disabilities and the International Convention on Economic, Social and Cultural Rights. However, we note that some of the rights from the CRPD have been "watered down" in the proposed Statement of Rights and we have been unable to clearly map the rights in the ICESCR to the rights listed in the Statement of Rights.

In consultations we heard that older people, carers and community members also wanted to see rights from the International Covenant on Civil and Political Rights and the UN Declaration on the Rights of Indigenous Peoples included. There were also calls for the inclusion of rights and protections in the Universal Declaration of Human Rights, the Convention against Torture and Optional Protocol on Torture and the Convention on the Elimination of Discrimination Against Women. We would argue the following rights from the ICCPR must be included in the Statement of Rights:

- The Right to individual Self Determination (CRPD, ICCPR and ICESCR)
- The Right to Freedom of Movement.
- The Right to be treated with humanity in detention.
- The Right to freedom of thought, conscience and religion
- The Right to freedom of association
- The Right to participate in public affairs.

We have not identified which rights from the UN Declaration on the Rights of Indigenous Peoples should be added. First Nations peoples must be consulted on which rights they would like to have included.

Other additional rights raised during consultations for inclusion in the Statement are:

- The right to social participation, leisure and lifestyle activities (ICESCR - The States Parties to the present Covenant recognize the right of everyone: To take part in cultural life)
- The right to individual autonomy and independence (CRPD - Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons)
- The Right to High Quality Care
- The Right to pet companions
- The Right to spirituality, holistic care and wellbeing.

Consumer Peaks also note these additional rights for inclusion:

- The right to access the necessities of life including access to high quality nutrition and protection from the elements. Protection from the elements should include such things as shelter and protection from heat and cold.

- The right to the highest attainable standard of physical, psychological, sensory, oral, emotional and mental health. (ICESCR - The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health).

- For people providing informal care, the right to reasonable access to supports in accordance with needs and to enable reasonable enjoyment of the right to social participation.

With respect to carers, the right above was identified in the Royal Commission's list of rights for inclusion in the Act and can also be linked to the rights identified in the ICESCR. Noting also that carers receive aged care services in the form of respite, education and training, some one-to-one support such as through the Dementia Behaviour Management Advisory Service (DBMAS) and some advocacy support.

The CPRD also confers rights on families in Article 28.3:
"*To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related*

expenses, including adequate training, counselling, financial assistance and respite care".

However, not all carers are family members, and a number of these supports should be available to carers whether or not they live in poverty.

The Royal Commission also identified that: "*The inclusion of entitlements for informal carers in the [proposed]new Act is consistent with the principles expressed in the Carer Recognition Act 2010 (Cth). However, unlike the Carer Recognition Act, the new Act should provide means of enforcing those entitlements*."

5.1.1 Restrictive Practices

The starting point of the NDIS Act is that there are no restrictive practices. Then, if these are needed, there are processes to implement the use of restrictive practices. Older people must have the same starting point. There is no justifiable reason for older people to be treated differently simply because of their age. This is ageism. In addition, while Australia continues in effect to exclude Residential Aged Care from under the United Nation's Optional Protocol to the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT), to which it is a party, by classifying them as not being 'primary places of detention' falling with the jurisdiction of the Australia's National Preventive Mechanism. Further, locked dementia units continue to be considered "appropriate" restrictive practices without proper consideration of the social, emotional, psychological and general wellbeing of people living with dementia in these units.

5..1.2 Freedom of Association

We have concerns over the use of the word "reasonable" in the recommendation on visitation – see amended wording below. This has very different meanings to different people. For example, during consultations many raised the issue of only being able to visit a family member at night but, the doors were locked at 7pm. Some family members wanted to maintain traditions of watching late night shows together but were prevented from staying until 10pm. While we acknowledge that consideration must be given to other participants this can be addressed through having protocols about noise. Restricting the right of older people to see their family, at a time that suits both them and their family, is discriminatory and places restrictions on the older person that they would not have if they lived in the community.

Those we consulted were still deeply impacted by lock downs that occurred during COVID, especially those living in Residential Aged Care or those that had family members living in Residential Aged Care. The social, emotional and psychological toll, and indeed physical impacts, are well documented. That is why participants must never again be completely banned from seeing anyone and that a named visitor is able to visit at all and any times (of course with safe practices in place).

Additionally, participants at end of life in Residential Aged Care should never be prevented from having family members and/or friends beside their bed.

5.2 Changes to the Current Rights in the Statement of Rights

"Rights are written in a way that is airy-fairy. Look like policy statements not procedural requirements."

(Resident, RAC, Darwin)

"Older people need to know they have rights and have confidence to pursue them".

(Older Person, Melbourne)

"Rights are only meaningful if you have capacity to understand, interpret and claim them".

(Advocate)

The following are proposed wording changes to strengthen the Statement of Rights. Note that some rights have been split to provide greater clarity. The wording changes are based on feedback from consultations with older people and community members.

1. The right to autonomy, independence and self-determination.
   Older people have the right to exercise choice and make decisions that affect their lives and the manner of their death; have access to independent support to make those decisions where necessary, and have

those decisions respected and followed, including where they involve personal risk.

2. The right to social participation, leisure, cultural, spiritual and lifestyle activities and to enter into intimate and sexual relationships.

3. The right to equitable access to services, and timely access to assessment and re-assessment as their physical, psychological, and emotional needs change or progress, which is done in a culturally appropriate manner.

4. The right to exercise choice between available aged care services, they have been assessed as needing, and how these services are delivered. (**Note:** questions were raised as to how this right will be upheld where choice and availability is limited, especially in regional, rural and remote areas. Processes need to be in place so that choice is not limited in these areas).

5. The right to communication and information in their preferred language or method of communication, with access to interpreters, preferred support person or advocate, and communication aids as required.

6. The right to be treated with dignity and respect, to live the life one chooses and to be listened to and heard.

7. The right to freedom from all forms of abuse and sexual assault, degrading or inhumane treatment, violence, coercion, exploitation, and neglect.
   (**Note:** people raised the issues of the right to feel safe in residential aged care and the right to be free from systems abuse).

8. The right to be free from restrictive practices.

9. The right to safe, fair, equitable and non-discriminatory treatment in accessing and receiving aged care services.

10. The right to equitable access to timely palliative and end of life care, including appropriate medications and end of life options (Voluntary Assisted Dying).

11. The right to freedom of expression, including the right to exercise their rights and voice opinions.

12. The right to make complaints without fear of reprisal, and have their complaints dealt with effectively, promptly and to the person's satisfaction.

13. The right to have their identity, culture, spirituality, and diversity valued and upheld when accessing or receiving aged care services.
    Aged care services should:
    a. respond to people's needs that are disability-related as well as age-related.
    b. ensure the practice and connections of Aboriginal and Torres Strait Islander peoples are upheld.
    c. be culturally appropriate, person-led, trauma aware and healing informed.
    (**Note:** there is ongoing discussion about the use of "culturally appropriate" versus "culturally safe". Culturally safe is seen as applying to First Nations peoples. This being the case then this right needs to include both "culturally appropriate and culturally safe".

14. The right to have one's personal privacy respected and the privacy of one's personal information protected.

15. The right to information. The right to be provided with one's personal and financial information held by Commonwealth agencies and registered providers and the right to information about aged care services they access.

16. The right to education and advice about one's rights and to have one's rights upheld.

17. The right to have important connections acknowledged, supported and respected, including relationships with significant others, including unpaid carers, spouse/partners and pet companions.
    (**Note:** Older people commented that pets are critical to health and wellbeing for many and that opportunities and assistance to maintain a relationship with a companion animal should be listed here as a right. This

should include assistance in caring for their companion animal if they are no longer able to and for the pet to accompany the older person if they need to move into residential aged care).

18. The right to an independent advocate or support person of their choice

19. The right to freedom of association and taking part in public life.

    a. be supported and assisted to stay connected with family members, spouses/partners and other significant persons in their life, including safe visiting by family members, advocates and friends in residential care homes, including at end-of-life.
    b. be able to be always visited by a named visitor with 24/7 access rights.
    c. Be able to participate in activities, community events and other activities external to the residential aged care home.

5.3 Simplification, Implementation and Enforcement

"Rights need to be enacted and not kept in a cabinet. They have to be seen to be enacted".
(Older Person, Darwin)

"What are the consequences for breaches?"
(Older Person, Hobart)

It remains unclear as to the consequences for breaching rights. During consultations many raised concerns around enforcement; it's good to have rights but if they can't be enforced what is the purpose of having them? The Act should include clear pathways to address breaches of rights.

Rights also need to be actionable and practical. The translation of rights into practice was also a key theme of consultations.

It was noted that appropriate funding and resourcing needs to follow the rights so that rights can be enacted. For example, the ability to exercise choice of

services is dependent on the availability of those services. In Darwin and Perth for example there are long wait times for accessing aged care assessments and for both home care and residential care. This means you must choose the first available service rather than having a genuine choice about the service you want.

We also note that the language used for the rights is more legalistic for the purpose of the Act. A simplified plain English version will need to be developed and made available for older people to help them understand their rights (including in other languages and formats).

5.4 Recommendations

5.4.1 Individual Rights

12. The Department works with participant peaks to ensure the wording of the rights is "right".
13. Rights must be legislated across the aged care system from the delivery of individual care by a personal care worker, up to the system governor, including the regulator and Inspector General.
14. The following rights must be included:

    a. The Right to Self Determination, Autonomy and Independence
    b. The Right to High Quality Care
    c. The Right to Health (including oral, sensory, psychological and emotional)
    d. The Right to Freedom of Movement
    e. The Right to social participation, leisure and lifestyle activities
    f. The Right to pet companions.
    g. The Right to spirituality and wellbeing.

15. The word "inappropriate" to be removed from Right 7 so that it reads "freedom from the use of restrictive practices".
16. Any "qualifiers" such as "reasonable" are removed from the rights.
17. Ensure that rights are applicable to both those receiving aged care, along with those seeking to receive aged care services. If some rights only apply to those receiving aged care, split the list of rights to make this clear.
18. Consideration is given as to how rights may be grouped so key themes are highlighted.
19. A re-wording of the rights is needed.

5.4.2 Breaches of Rights

20. That the legislation includes or identifies pathways for seeking remedies for breaches of rights that are system wide, to include breaches as a result of acts or omissions by the government or regulators, e.g. what is the forum and procedure for raising a breach by the system governor or the regulator? It must be clear where participants can go to seek remedies for alleged breaches of rights.

5.4.3 Implementation of Rights

21. Legislation must include clear implementation timelines, monitoring and evaluation and the development of a culture change plan for the aged care sector.
    a. This includes developing a transition and implementation plan for providers including information, education and training.
22. A change culture implementation plan must/should be released with the commencement of the Act to outline how the ACQSC, System Regulator and Aged Care Providers will embed rights in daily operations, including rights education, measurements and implementation.
23. The ACQSC Quarterly Sector Report will include a regular report on the number of complaints received broken down by references to each right allegedly breached in order to measure whether a rights-based approach is being achieved.
24. A communication strategy on the new Act and what it means must be implemented prior to the commencement of the new Act.
25. If possible, rights should be written in plain English in the Act. If this is not feasible, a plain English and alternate versions (e.g. in language, visual) of the Rights must be available.

6. Complaints

The Aged Care Quality and Safety Commission (ACQSC) is responsible for the enforcement of aged care provider responsibilities under the current Aged Care Act 1997 as set out in the current Aged Care Quality and Safety Commission Act 2018 and the Aged Care Quality and Safety Commission Rules 2018. The ACQSC is able to accept complaints regarding Government-funded aged care services delivered by Government-approved providers. The ACQSC Regulatory Strategy states that the information obtained during the complaints resolution processes is used to inform the ACQSC's regulatory and education functions. In addition, people can contact the ACQSC and give feedback about the quality of care and

services they have received which may inform accreditation, assessment and monitoring of services.

The ACQSC's approaches to complaints resolution are outlined on the ACQSC's webpage 'The complaints process' which states the ACQSC may 'assist you to resolve your concern directly with the service provider' (also referred to by the ACQSC as 'early resolution') or they may select one or more of the following approaches to resolve the complaint: conciliation, investigation, service provider resolution or mediation.

Older people have stated, and OPAN advocates have directly observed that the current ACQSC regulatory approach does not provide a sufficient range of approaches and powers to ensure the promotion of older people's rights and to remedy breaches of these rights by providers. There must be an increased range of approaches and powers when dealing with 'lower risk' complaints regarding rights breaches and transparent public reporting against these. Additionally, complaints and breach response processes must be dementia friendly and accessible to people with a cognitive impairment, and with capacity for independent advocates/ chosen supporters to make complaints on the person's behalf.

6.1 Creating a range of actions to ensure rights are upheld in aged care

The Australian Human Rights Commission (AHRC) undertook its Free and Equal project: A National conversation on human rights from 2019-2021. In 2021, the AHRC released its Position Paper 'Free and Equal: A reform agenda for federal discrimination laws'. The differences in coverage between the state and territory laws and federal laws and the complexity of this legislation is acknowledged as a repeated theme in reform reviews by the AHRC.
The AHRC noted that "*These different obligations reflect that there is no one single action that can fully protect human rights or remedy a breach of human rights. It requires a mixture of actions ranging from legal protections, complaint and compensatory processes, educative measures, community-based programs and social services, for example*." (p.16)

It is against the backdrop of broader discrimination and rights legislation reform in Australia that we call for the creation of an independent Complaints Commissioner with the powers, functions and approaches to provide a regulatory body complementary to the ACQSC capable of promoting and

enforcing human rights in aged care. We believe this specific pathway for human rights breaches in aged care is warranted due to the frequency, breadth, and pervasiveness of rights breaches across the aged care sector.

6.2 Specified and enhanced pathways for 'lower risk' breaches of rights

The range of regulatory approaches presented by the Aged Care Quality and Safety Commission (ACQSC) and the frequency of different actions as portrayed by the regulatory diamond, provides a solid foundation for further enhancing approaches to rights breaches. This can include provision for the Complaints Commissioner to specifically handle 'lower risk' breaches of human rights, with a clearly articulated remit and ability to cooperate with, and escalate to, the ACQSC if needed.

Our position is that a specified pathway, which is appropriately resourced, and a broader range of actions need to be clearly articulated to provide adequate regulatory responses to what currently are considered 'lower risk' breaches of human rights. Such 'lower risk' breaches may include, for example, aged care service provider approaches reinforcing paternalistic, ageist and ableist approaches to service delivery, or a failure of aged care services providers to allow an older person to express their religion, culture, gender, and/or sexuality.

The range of approaches for addressing 'lower risk' breaches of rights should include early resolution, conciliation, investigation, and mediation, as in the current ACQSC approach. However, the processes for handling and resolving complaints using these approaches must be overhauled and improved. Furthermore, we believe that 'service provider resolution' should no longer be an option, as this does not promote restorative justice approaches and dialogue between the involved parties.

6.3 'Lower risk' does not equate to low impact on people whose rights have been breached

We note that risk level is currently largely determined by an immediate risk to life (including risk of suicide), or significant measurable effects on people's physical health and therefore a risk of legal action against the provider. We use the term 'lower risk' as a reflection of this current context. However, these 'lower risk' breaches can have significant and long-term effects on people's wellbeing and mental health, as well as flow-on effects to the broader public, and are

therefore in no way less impactful or 'risky' in reality. We will continue to advocate for a future where risk is defined more broadly to reflect the true impact of breaches of older people's human rights.

6.4 Focus on restoration rather than retribution.

In the justice system, restorative approaches embody the foundational principles '*cause no further harm; work with those involved and set relations right*.' Although the outcomes of restorative and retributive justice may be the same (e.g. result in sanctions/limitations and fines), the process and motivations differ.

We call for a focus on restoration to repair harm to those immediately impacted and involvement of the broader community in searching for reparation for aged care service providers breaches of older people's rights.
Restorative principles can be embedded throughout all approaches to complaints resolution including early resolution, conciliation, investigation, and mediation.

6.5 High-quality early resolution, conciliation, and mediation approaches

High-quality early resolution, conciliation and mediation approaches are key to ensuring that a restorative and educative approach is achieved.

As a starting point, the approach to early resolution, conciliation and mediation should build on the well-established resolution approaches of the Australian human rights and anti-discrimination entities. In particular, the approach to human rights complaints adopted by the Queensland Human Rights Commission which allows for a flexible approach to resolution spanning early intervention (referred to here as 'early resolution') and conciliation. However, our position is there must be the opportunity to escalate rights breach complaints that are not resolved through early resolution, conciliation or mediation and for enforceable actions to be imposed.

6.6 Determination of approach to be taken

The approach to resolution of a complaint regarding a 'lower risk' breach of rights should consider, in particular:

- The extent to which this issue relates to a single or few individuals or the entire service provider's approach (e.g. a single worker at the service, or a service-wide policy).

- Whether complaints regarding the same or substantially similar issues have been received against the provider in the past (including by other complaints handling entities).
- The provider's willingness to engage with the complainant or the Complaints Commissioner to resolve the issue, including any response they have made to the complaint either directly to the complainant or to the Commissioner or ACQSC's initial notification.
- Escalation for investigation of matters unable to be resolved through early resolution, conciliation or mediation.
- If a matter cannot be resolved via early resolution, conciliation or mediation, there must be escalation to a formal investigation by the ACQSC. The formal ACQSC investigation process should include a detailed examination, or all relevant information provided to date and an opportunity for all parties involved to be heard. The ACQSC must have the powers to compel the provision of any further information by providers to assist in resolving the matter.
- A failure of providers to provide the required information or cooperate in the investigation process should result in enforceable actions, including sanctions and fines.

Based on the outcome of a formal investigation of human rights complaint, there must be the opportunity for the full range of outcomes, including enforceable actions by the ACQSC. This may include the ACQSC imposing an enforceable action such as a fine or sanction if they conclude following an investigation that the matter could have been resolved through early resolution, conciliation, or mediation, but this was not possible because of the provider's conduct (e.g. the provider refused to engage in these processes through a respectful dialogue and/or sharing of information).

All actions that result from a resolution of a complaint must be enforceable, but this can be achieved through a staged approach. For example, if a provider commits to revising its policies and procedures through an early resolution approach but is later found to have not undertaken this response, then this should result in escalation to an action that is enforceable which may include a sanction.

There must be the option for the Complaints Commissioner to escalate to enforceable actions, including sanctions, if providers are found not to undertake agreed outcomes of early resolution, conciliation or mediation processes.

There are a number of opportunities for the Complaints Commissioner and the ACQSC to identify providers who do not undertake agreed outcomes of early resolution, mediation and conciliation approaches. These include ensuring any agreed outcomes are addressed during ACQSC audits, comparing future complaints against records of early complaints to assess any lack of change in behaviour, attitudes and processes, and allowing individuals and other bodies to report if they are aware of providers not following through on an agreed outcome.

6.7 Recommendations

26. The complaints system must be person-centred, robust and effective as such a system is an essential component of giving effect to a human rights-based approach in the aged care sector.
27. Alternate responses (A range of remedies that are flexible and adapted to resolving any allegations of violations of rights) must also be established and can be overseen by the new Complaints Commissioner.
28. The Aged Care Act should provide for the appointment of a statutory Complaints Commissioner with powers/responsibilities independent of the System Regulator.

7. Statement of Principles

"How do these service principles correlate to the rights of the end user?"
(Older person, Canberra)

"I don't think it has an appreciation that the aged care system sits within a much broader community and those links with the broader community need to be encouraged because otherwise you're going to get a very isolated aged care."
(Community member, Newcastle)

"These principles should apply to all aged care service delivery, not just what is funded."
(Older person, Sydney)

We support the Statement of Principles being more clearly aligned with the Statement of Rights and seek greater clarity on the complementary nature of the Rights afforded to aged care participants and the obligations under the stated Principles on individual providers, the regulator and the system governor to promote and protect those Rights.

As such the Statement of Principles should be categorised into:

- Service Delivery Principles (1 and 2)
- System Governance Principles (3 to 11, and 15)
- Regulatory Principles (12, 13 and 14)

We acknowledge that the current numbering of the proposed principles is for ease of reference only. We consider that overlap between service delivery, system governance and regulatory principles is both necessary and desirable to indicate to aged care participants the shared responsibility for promoting and protecting their rights under the new Act. Principle 15 is a case in point as learning from complaints and establishing and maintaining a positive complaints culture should extend across registered providers, the system regulator and the system governor.

Older people reacted strongly to principles referring to them as vulnerable and considered this was inconsistent with the focus on human rights. Within the social model of health, there are environmental risk and protective factors that influence aged care outcomes for older people. Rather than locating the source of vulnerability within the individual, we recommend locating the problem within their environment. We therefore support removal of the word 'vulnerable' when referring to people and replacing it with the phrases 'marginalised', 'experiencing disadvantage' and/or 'at risk of social exclusion'.

Older people reacted negatively to the concept that it was inappropriate for aged care services to be used to fill 'gaps'. They felt strongly that where service gaps exist in other systems, or where older people have less access to these services than others, that the aged care system should play a role in addressing these gaps at an individual level, while working at a policy level to ensure such systemic gaps are closed.

There was strong agreement among those participating in face-to-face consultations (older people, their families and carers, service providers and community members) that the principles would be strengthened by either

leaving out or changing each instance of the word ‘should’ to ‘is’, ‘are’, ‘will’ or ‘must’. While it was recognised the principles in the consultation document have been written in future tense to refer to proposals for a future aged care system, there was strong support for changing the principles to present tense.
We propose rewording the principles as follows.

7.1 Service Delivery Principles

Principle 1:

The human rights of older people to self-determination, autonomy, dignity, health, wellbeing, safety and quality of life are the primary consideration in the delivery of funded aged care services.

Principle 2:

Aged care service delivery must promote and protect the human rights of older people to self-determination, autonomy, dignity, health, wellbeing, safety and quality of life, by providing care that:

- supports dignity of risk, and the preferences, individual needs, goals and aspirations of older people
- is free from any form of discrimination, abuse and neglect, including all forms of illegal or unauthorised restraint
- treats older people as unique individuals, and treats them and their significant others with kindness, dignity and respect
- supports older people’s personal connections to their spiritual, cultural and language communities and countries of origin; and
- for First nations people, supports their personal connection to community and Country.

7.2 System Governance Principles

Principle 3:

The aged care system is adequately funded to put older people first, and supports older people who access funded aged care services being:

- able to live at home if that is their choice, or, where that is not possible, in a setting appropriate to their circumstances, that is recognised as their home.

- able to exercise individual responsibility and make decisions that enable them to lead active and fulfilling lives, including by engaging in their community and maintaining relationships, including intimate and sexual relationships, with people of their choice.
- active and informed partners in decision-making as they wish about the funded aged care services delivered to them
- able to maintain or improve their physical, mental and cognitive capabilities for as long as possible, with a focus on enablement.
- able to refuse treatment and make end of life decisions, including a palliative approach to their care, or other end of life options.
- aware of and able to exercise their rights when accessing funded aged care services.

Principle 4:

The aged care system will fund accessible, culturally appropriate and trauma informed services for all older people, regardless of their location, including people with disability, from diverse and marginalised groups, people with alternative service needs and people at risk of social exclusion.

This includes, but is not limited to:

- people living with dementia
- First Nations people
- peoples from culturally, ethnically and linguistically diverse backgrounds
- people who live in rural or remote areas
- people who are financially or socially disadvantaged
- veterans
- forgotten Australians
- parents separated from their children by forced adoption or removal
- people who are homeless or at risk of becoming homeless, and
- people who identify as lesbian, gay, bisexual, trans or gender diverse, intersex or queer.

Principle 5:

The aged care system is transparent and provides public access to meaningful and readily understandable information about aged care, including in languages other than English.

Principle 6:

Government funding of aged care services must be used to support access to, delivery and regulation of services which provide individualised care and support in response to older people's identified needs.

Principle 7:

The aged care system will only be used to address service gaps in other care sectors or systems, where such gaps are preventing older people from getting the best available care to meet their individual needs, goals and preferences.

Principle 8:

The aged care system is designed to support the diverse needs of older people, including those groups listed in Principle 4. For younger people, alternative community-based health, mental health, disability and residential support services should be available to meet their needs.

Principle 9:

The aged care system funds essential aged care services according to prioritised needs. To achieve this, the aged care system takes an equitable approach to the individual needs of older people, including disability supports, and to assessing the financial means of older people expected to meet some of the costs of services they use.

Principle 10:

The aged care system is funded to incorporate effective service networks to support:

- continuity of care for older people accessing funded aged care services, and
- access to integrated services that older people may require over time, with strong links to and effective inter-governmental agreements with the health, mental health, disability and community services sectors.

Principle 11:

A constructive and successful aged care system must prioritise relationships of trust between older people, their families and carers, the aged care workers who support them and the registered providers they choose to provide their care. The foundations of this are a well-trained and appropriately skilled workforce. The aged care system must:

- ensure that provider's employment and contractual arrangements empower aged care workers to effectively contribute to the delivery of high-quality care.
- support the ongoing governance and business improvement of providers operating in a diverse and sustainable aged care sector.
- recognise and support the important roles of volunteers in enhancing the experience of aged care.
- recognise and support unpaid family and friend carers as partners in care.

7.3 Regulatory Principles

Principle 12:

Feedback and complaints about the delivery and accessibility of funded aged care services are used to inform and promote continuous improvement in registered provider's service delivery, regulation and governance across the aged care system.

Principle 13:

Regulation of the aged care sector will:

- be undertaken collaboratively with older people seeking and using aged care services
- promote innovation, continuous improvement and contemporary evidence-based best practice within the aged care system,
- identify failures and risks of failures within the aged care sector, with a view to prevention and timely action
- be responsive, risk proportionate, and principles based,
- focused on the health and safety of older people, and prioritised to areas of highest impact on older people,
- promote delivery of high quality, person-centred, trauma informed and culturally appropriate care to people accessing aged care services, and
- strive for regulatory alignment with other care and support sectors where it is appropriate to do so and will benefit older people and the aged care sector.

Principle 14:

The aged care regulator will undertake its functions, including its financial and prudential regulation functions, in a way that has the rights of older people at its centre and seeks to prompt and encourage registered aged care providers to

operate viable services that ensure continuity of quality, safe care for people using them.

7.4 Additional Principle

We support the inclusion of the principle referenced by the Royal Commission with respect to carers that:

Principle 15:

Informal carers of older people have certainty that they will receive timely and high quality supports in accordance with assessed need.

7.5 Recommendations

29. The Act contains both Rights and Principles. The Principles must link to the rights and not dilute or undermine the protections guaranteed in the Statement of Rights or the obligations of those subject to the Act.
30. The word "should" to be deleted and replaced with "is", "will" or "must."
31. A re-wording of the principles is needed as proposed above.

8. Definition of High-Quality Care

"High-quality care means seeing it being 'delivered' not just reading a booklet about how services should be delivered".

(Older person, Melbourne)

"I can tell you what high-quality care is not – it is not having to go through all the steps that I had to, to (navigate the system) and get the care I needed."

(Older person, Newcastle)

"The definition of high-quality care is a wonderful wish list."

(Older person, Brisbane)

We are pleased to see that the definition has been altered from that proposed in the New Model for Regulating Aged Care Consultation Paper No.2 and that there is no longer a qualifier on supporting a person to enhance their physical and cognitive capacities and mental health 'where possible'.

8.1 The proposed definition

> *"Well, it's [high quality care] when you've identified whether the person who's giving the care is caring about it".*
>
> (Resident, RAC, Darwin)

While there was overall support for the focus on care processes over care outcomes, older people have expressed mixed views about this definition. Some supported the reality that it was an improvement on the current system that the new Act should legislate provision of adequate, minimum standard care, accompanied by mechanisms for increasing the incidence of high-quality care over time. Some raised concerns that if there is not a suitably aspirational definition, it would be better not to have one at all. While others felt this is a significant opportunity that must not be missed to embed a right of older people accessing funded aged care services to receive high quality care.

Others recognised that what is considered high quality care relates to both the subjective experience of care and objective measurement of care processes. There was agreement that despite individual differences, the assessment of what constitutes high-quality will change over time, citing care practices that were once considered best practice that are no longer current due to improvements in evidence. They would like to see a strong statement that high quality care is evidence-based care and significantly increased support for translating research on improved care processes into practice.

Overall, we consider there is scope to include both care processes and some care outcomes such as quality of life in the definition, together with structural indicators, such as reduced waiting times for access to care and the right aged care staffing and skills mix to provide high quality care. [2]

[2] Mant, J. (2001). Process versus outcome indicators in the assessment of quality of health care. *International journal for quality in health care*, *13*(6), 475-480.

8.2 Reviewed Definition

While the Statement of Rights is correctly focused on the individual, the definition of high-quality care should be focused on the aged care participant population. Therefore, high quality is defined as a well funded aged care system delivering subsidised aged care services to the eligible population of older people by providing evidence-based care that is:

- **Rights-based**
- **People-centred** – with respect for everyone, their life experiences, autonomy, self-determination and dignity, and their quality of life
- **Equitable** – that does not vary in quality due to a person belonging to a diverse or marginalised group or their gender, disability, geographic location, age, or socio-economic status.
- **Enabling** - supporting participants to enhance their physical, mental, psychological and cognitive health and wellbeing
- **Responsive** – to each participant's expressed personal needs, aspirations, and preferences regarding the way services are delivered to them
- **Participatory** – supporting each participant's cultural, recreational, spiritual and social connections and contribution to their community
- **Integrated** - integrating and meeting each participant's holistic needs including physical, psychosocial, spiritual and relational needs
- **Relational** – delivered in the context of a relationship of trust and partnership between participants, their families and carers and their chosen aged care providers
- **Compassionate** - providing aged care services that are culturally safe, trauma aware and healing informed
- **Timely** - reducing episodes of delayed or missed care and reducing waiting times for access to services that can cause harm
- **Consistent** – provided by skilled staff, with low variability from shift to shift, day to day and care worker to care worker
- **Continuous** – maximising continuity of staffing and effective handover between care workers and between care providers
- **Adaptive** - facilitating regular reviews to ensure that services and supports continue to reflect individual participant needs

- **Coordinated** - from the first engagement with the aged care system, through care transitions to end of life care
- **Safe** – delivered with a systematic approach to avoiding preventable causes of harm to participants
- **Efficient** - maximising available resources for the benefit of participants and avoiding low value care.

Delivery of high-quality care is dependent on an enabling environment that reduces barriers to high quality care through supporting care providers to develop trusting relationships and care for the whole person. High quality care is care that is measurable at the population level largely using care process quality indicators, complemented by some care outcome quality indicators and structural quality indicators.

Older people would like to see the right to high quality care as the first right listed in the Statement of Rights. They strongly support a focus on the right to high-quality care to address the hazards of low expectations of care processes and outcomes for older people. Low expectations of the importance of aged care processes and of physical, cognitive, and mental health outcomes for older people living with multiple health conditions and disabilities is ageism. If outcomes are poor, these are too easily attributed to the characteristics of the individual, rather than to poor quality care processes or episodes of care that were or were not provided. A focus on population level care processes, outcomes and structures in the definition helps make measurement of high-quality care more objective while also recognising everyone's subjective experience of care quality.

8.3 Recommendations

32. High Quality Care must link directly to the rights and principles in the Act.
33. The definition must be re-worked with participant representatives and participants. We have provided suggested wording changes below in Section 9 (High Quality Care).
34. High Quality Care must apply across the aged care sector from provider to regulator to System Governor.

9. Duty of Care

"We think mainly that's not clear enough and it does affect situations such as when people aren't being fed properly when they need assistance with eating. So, it might not be classed as an injury or serious harm, but it can lead to a death."

(Community member, Brisbane)

"Does harm include psychological abuse? This can be more impactful than physical harm."

(Provider, Perth)

"The duty of care should be on government to fund aged care services."

(Community member, Sydney)

We welcome the opportunity to comment on the statutory duty of care on registered providers that will deliver on the Government's 2022 election commitment and recommendations 14 and 101 of the Royal Commission. However, we are dismayed that the statutory duty of care will not be linked to a requirement to deliver high quality care. Instead, the high quality of care definition will not be relevant to the statutory duty and its penalties.

The table below attempts to consolidate our understanding of the various regulations and their associated penalties that will occur in the new aged care act, explained as:

Regulation	Penalties / Enforcement	Penalties applies to		
		Provider	**Responsible Persons**	**Aged Care Worker**
Statement of Rights	Unclear from discussion paper what penalties for breach of rights apply.	Yes	Unclear	Unclear

Quality Care Regulations (incl. Quality Standards, Category Registration condition, and Individual Provider Registration Condition)	• vary, suspend, or revoke a provider's registration.
	• issue an infringement notice,
	• enter into enforceable undertakings, or
	• apply for civil penalties.
	• in critical failures scenarios:
	  ○ appoint a statutory manager or
	  ○ voluntary administrator
	• possibly a sanction action
		Yes	No	No

Code of Conduct	Issue banning orders for providers and individual workers.	No	Yes	Yes
Statutory Duty "Serious failure" to act in a manner consistent with the duty "to take reasonable steps to avoid their actions adversely affecting	"Where a failure to take reasonable steps results in a risk to, or actual serious illness, injury or death of an individual to whom the duty is owed" the	Yes	Yes	Proposed

Regulation	Penalties / Enforcement	Penalties applies to		
		Provider	Responsible Persons	Aged Care Worker
the health and safety of persons in their care".	following penalties may apply. Civil Penalties Compensation Criminal penalties			
High Quality Care	Nil – aspirational only, no enforcement of breeches of high-quality care	n/a	n/a	n/a
Breaches of other laws (Consumer protections, Crimes Act, WHS laws)	Various -civil or criminal dependent on the other legislation	Yes	Yes	Yes

We note that the current information on the regulatory obligations and penalties for failure to adhere to the various regulatory requirements are not consolidated in one location. We strongly urge the Government to ensure it clearly articulates the various regulatory requirements and specific possible penalties associated with those requirements as part of its exposure draft of the legislation. Without a clear understanding of how the government is delivering a "tough cop on the beat", the exclusion of high-quality care and the narrow grounds on which compensation may be granted is likely to yield confusion and concern amongst participants.

9.1 Support for a Statutory Duty of Care

We support a new statutory duty of care in the new Act in principle. We note that the intention of the new duty is not to displace existing duties including those currently available through common law, workplace health and safety laws, and other state/territory laws. Nevertheless, it will be necessary to review the exposure draft legislation before ascertaining whether the legislation meets expectations.

We are dismayed that there will be no penalties associated with the failure to implement high quality care because of its decoupling from the duty. Further we note that the disconnectedness of the duty from other regulatory mechanisms makes it unclear how integrated, or disconnected the various regulatory

mechanisms will be. For example, a technical breech of a quality standard would be noted in the system with presumably no regulatory response; however, where the breach leads to harm, it may be subject to a non-compliance notice and further, if it were to amount to a serious breach of the duty, it may result in civil or criminal penalties. The ability to explain how the scale of regulatory penalties may apply and at which point those possible penalties occur will be necessary to satisfy participants and their families who put their faith in the regulatory system to protect them.

One area of possible unintended consequences we identified relates to the financial compensation potentially available for a breach of the duty. In other industries, we have seen examples of the cost of insurance rising, or its availability restricted following such regulation. For many aged care providers, especially those run largely by volunteers, if the cost of insurance became prohibitive, their ability to operate would be significantly affected. Government must assure itself and the sector of the impact of the exposure draft legislation and release advice about its final proposed approach to give confidence to the sector so that smaller, unique aged care providers will not be inappropriately affected by its introduction.

9.2 Related Duties

We fully support related duties being placed on the owners, the executive managers, and the governing persons of aged care providers. We note that consideration will need to be given as to what level of management is intended to be captured by the term 'responsible person'. The current explanation of the potential to include "people (that) have responsibilities, as well as the potential to strongly influence the culture and accountability of a registered provider, through their decisions and behaviours" may be too opaque. Is it intended to include team leaders or only facility managers? Does it include the entire people and culture team at all levels given their responsibility for organisational culture? While we recognise that the legislation itself will need to be necessarily broad, clarity of the Government's intent in the explanatory memorandum will be necessary.

9.3 Duty on Aged Care Workers

We have significant reservations about the inclusion of aged care workers (i.e. those who are not a responsible person) under a related duty. If government

were to maintain the inclusion of the duty, we note our concern with the way the duty is proposed to be drafted.

Aged care workers should not be subject to financial penalties either via compensation or via civil penalties. Such a punitive approach will likely further exacerbate the perception that aged care is not a good place to work. We further note that the inclusion of financial penalties would be above the obligations placed on AHPRA registered professionals: we consider this to be inappropriate.

We note the duty is proposed to relate to "serious" breaches, however the related duty for an aged care worker would be restricted to "very serious" breach.

If a related duty were to be included, we note our concern with the current draft that appears to be simply framed as grounds on which an aged care provider may shift their obligations onto the aged care worker for failure to adhere to policies outlined by the provider.

9.4 Separate Duty for organisations that provide enabling services/facilitate access to aged care workers

We note that there is a range of organisations that provide services and facilitate access to aged care workers. Where such an organisation provides the worker for a specific service (for example, agency staff), the organisation should be under an obligation to ensure the worker has the "experience, qualifications, skills and training to perform the particular personal care or nursing care work the person is being asked to perform"[i].

For organisations that facilitate access to aged care workers (e.g. online platforms) it is necessary to consider whether the organisation is engaging the person to provide the service (which would fall under the above obligation) or is facilitating individual contractors to assert their own appropriateness for the work that is to be performed. In this latter case it is more appropriate that such obligations be included in the registration of online platforms outlined in regulation paper 2. In this scenario we note the individual worker would continue to have the obligations discussed above, including as a registered provider proposed under the future registration model.

9.5 Recommendations

35. That Duty of Care applies to the responsible person and the governing bodies of aged care providers.
36. Duty of Care is applied to Personal Care Workers and other non-governed professionals (noting the duty of care of nurses, allied health professionals etc. is regulated by AHPRA) with the following limitations:

    a. The penalties should not be more onerous than a duty placed on other professionals regulated by AHPRA.
    b. The Duty does not apply, or is limited, where it can be demonstrated that the Provider has not met their duty of care to the staff member through appropriate onboarding and ongoing education and training, resourcing and the provision of a safe environment and equipment.
37. Duty of care should align with the obligations and responsibilities included within Work Health and Safety legislation, rather than duplicating this.
38. Introduce a separate duty on organisations that provide enabling services where the organisation is responsible for supplying workers to deliver the service (distinct from those who facilitate independent contractors who would independently be required to assess their own suitability for the services requested).

10. Penalties and Compensation

"My thought is also penalties must impact star ratings".
(Older person, Sydney)

We note that the proposed compensation pathway would "complement, not replace, existing compensation arrangements for personal injury" and restrict our comments only to the new compensation pathway. During consultations with older people and their families there was broad support in principle for compensation.

However, some participants raised concerns about the impact of a compensation scheme, noting concerns about the possible increased insurance and other costs resulting from the need to respond to [vexatious] compensation claims. Participants cited other industries that have seen the inclusion of compensation schemes resulting in insurance and operating costs

making the cost of delivering a service prohibitive for smaller operators. Accordingly, they cautioned against actions that would lead to smaller niche providers being pushed out of the aged care service delivery. Signatory organisations felt that Government must ensure it has appropriately engaged with the insurance industry to assess the impact of their proposed changes to mitigate against this risk.

Notwithstanding common law provisions, it may be appropriate for compensation under the Aged Care Act to require participants to have participated in a mediation and/or conciliation process by the lower cost jurisdiction of the Aged Care Quality and Safety Commission's complaints process before being entitled to seek compensation. This may reduce vexatious claims via a private right of action of damages.

We also caution against compensation payments being included in aged care means test assessments that could result in people who have been harmed having to pay more for their care. For example, Forgotten Australians who have received payments under the National Redress Scheme, which provides compensation for survivors of institutional child sexual abuse, currently face having this payment included under the assets means test for aged care fees.

10.1 Recommendations

39. The payment of compensation should not prevent action being taken to change the system (e.g. gag orders cannot be applied to compensation payments).
40. It must be clearly legislated that compensation payments, made through this process, must not be included within individual means-testing for aged care contributions (as currently happens with National Redress Scheme payments, noting we recommend that this practice ceases).
41. Consideration is given to how to support smaller and specialist providers that may face higher insurance charges as a result of these changes (but this must not be used as a reason to not implement these changes).

11. Disclosure Protections for Whistleblowers

"My experience has shown that there's been too many cover-ups of mistakes. I've reported abuse and nothing's been done. They hide it, don't even follow through. It just needs to be simplified so the regulator takes (and acts on) the Whistleblower's disclosure."
(Carer, Adelaide)

"Add to illegal, unsafe or fraudulent a term like 'harmful' or 'abusive' to cover all the negative impacts on an older person and others."
(Community member, Hobart)

"The more we can make it possible for people to report, the better off everyone will be."
(Community member, Canberra)

Current whistleblower provisions are extremely limited, and we strongly support increasing both the range of matters that whistleblowers can report and increasing protections for whistleblowers. We support consistency of these provisions with the whistleblower protections contained in the *Corporations Act 2001*, the NDIS Act and the new *Inspector-General of Aged Care Act 2023*. We strongly support inclusion of qualifying disclosures by independent advocates. We support the system regulator offering whistleblower protections for any individual holding a reasonable and honest belief that a serious breach of aged care legislation has occurred. This should include the ability for an individual to maintain anonymity when making a disclosure and for whistleblowers who disclose their identity to the Commission or the Department to have this protected from the organisation they work for and from the public.

Older people repeatedly raised that while they supported the addition of whistleblower provisions, there was a lack of detail in the paper on the difference between 'regular' complaints and whistleblowing and under what circumstances the Complaints Commissioner would translate a serious complaint to a whistleblower disclosure. They also strongly supported a focus

on significant improvement to existing complaints processes in addition to whistle-blower provisions in the new Act.

11.1 Who can make a qualifying disclosure?

Independent advocates assisting clients via the National Aged Care Advocacy Program are in a unique position to identify serious breaches of aged care legislation at the individual and the provider level. As above, we strongly support independent advocates being able to make qualifying disclosures. We support the proposed list of people who can make a qualifying disclosure but query the limitation to persons with a contract for supply of goods or services to or on behalf of a provider. We seek clarification of whether for example, a doctor providing a visiting GP service that is billed to Medicare is considered to have a contractual relationship with the provider or with the resident and therefore if they are considered eligible to make a qualifying disclosure? Given the different circumstances and service environment of home care, we recommend that anyone who visits in any capacity to residential aged care homes, whether under a contractual arrangement or not, is eligible to make a qualifying disclosure.

We propose that many individuals concerned about making a qualifying disclosure will need substantial information, education, and support, including where they have already made a complaint to another person or entity.

11.2 Who can receive a qualifying disclosure?

We support that disclosure can be made to a range of officials including staff of the Commission or the Department, aged care workers, governing or responsible persons of registered providers, police officers, and anyone else authorised to receive that information. We consider that 'anyone else' should include a range of other Commonwealth, State and Territory regulatory, statutory, and legal bodies. These should include relevant State and Territory health and consumer complaint bodies and ombudsmen, as well as ASIC, ACCC and the ACNC.

We consider there should be additional statutory obligations on the Aged Care Quality and Safety Commission, and Aged Care Complaints Commissioner to accept, investigate and act on disclosures from whistleblowers. As a result of relevant investigations, these actions should include the power to refer and/or consult with other Commonwealth, State and Territory regulatory, statutory, and

legal bodies. These should include relevant State and Territory health and consumer complaint bodies and ombudsmen, as well as ASIC, ACCC and ACNC. The regulator should also accept referrals from and be consulted by these agencies and others.

For example, the Commission receives allegations of misappropriation of government subsidies and charging participants for services not delivered from an aged care employee seeking whistleblower protection. On investigation, they identify the potential fraud includes systemic under-payment of staff. The regulator should support the employee by providing this information to the Fair Work Ombudsman (FWO) on their behalf.

For example, a state health complaints commission, on receiving a complaint from an aged care participant about their emergency department treatment, identifies they have also made allegations of systemic substandard aged care leading to a high rate of hospital transfers. With the consent of the participant, the aged care regulator could receive a qualifying disclosure from the health complaints commission and extend whistleblower protection to the aged care participant.

11.3 Protections for whistleblowers

We support retention of existing protections against victimisation in addition to proposed protections against civil, criminal and administrative liability and contractual or other remedies. However, we recommend strengthening existing protections against victimisation, as reprisal can be subtle, such as not responding to a call bell or overt, such as refusing a family member's entry to a residential aged care home. Any participant or representative whistleblower in fear of retribution should be offered timely support and priority access to change aged care providers if they wish.

11.4 Confidentiality of whistleblowers

"People will still be fearful and if you're known and regular visitor and something gets reported [the] provider will work out that it's you and do something to you or loved one."

(Carer, Hervey Bay)

We are concerned that the proposal for the disclosure of a whistleblower's identity to the responsible person of a registered aged care provider would act as a significant disincentive to employees and contractors becoming whistleblowers due to fear of negative consequences for their employment or service contract. We consider this provision would be an additional disincentive to aged care participants, their carers and family members. We recommend that any such disclosure must only be made with the informed consent of the whistleblower.

Older people have repeatedly raised concerns that in instances where the whistle blower is a carer, family member or advocate of an aged care participant, the person receiving care could be subject to retribution if they are not also protected by confidentiality. Whistleblower protections must apply not only to the person making the disclosure but to the individual aged care participant the disclosure applies to.

11.5 Obligations of Aged Care Providers

We support providers being required to have an internal whistleblower policy, to publicise it, to train staff receiving disclosures and to escalate disclosures to the Department or Commission. Older people participating in consultations strongly supported a standardised approach to internal whistle-blower policies, with a template provided by the Aged Care Quality and Safety Commission and auditing of provider compliance with the standard policy. We strongly support the intent to make people feel confident to raise issues and for these provisions to lead to effective change. However, as stated above, individual staff, volunteers, participants and family members need access to readily understandable information, education and support to make a qualifying disclosure. We consider the National Aged Care Advocacy Program is ideally placed to offer education to groups and information and support to participants, their carers and families.

Analysis of aged care complaints data indicates there is currently a high proportion of anonymous complaints, largely from staff, some of whom may be eligible for whistleblower protections. We recommend the new whistleblower provisions must be subject to robust data collection and evaluation. This should include evaluation of the actions of the regulator in providing education and support for providers to achieve a positive complaints culture[3] e.g. assessing

[3] UK Care Quality Commission: Rapid Literature Review: Improvement cultures in health and adult social care settings

and inspecting for evidence of an environment where people feel they can speak up and that their voice will be heard, and public reporting of the number of anonymous complaints and aged care staff seeking whistleblower protection.

Older people participating in consultations expressed strong support for whistleblower protections for staff, except in instances where a staff member, responsible person or member of a governing body has participated or been complicit in the wrongdoing they have disclosed. Older people want assurance that extension of select whistleblower protections such as anonymity, do not preclude civil or criminal penalties applying to whistleblowers found to have engaged in illegal or fraudulent activity.

11.6 Recommendations

42. The Department must develop a guiding policy on Whistleblowers, with key principles and actions that Providers must include within their own Whistleblower Policies.
43. Whistleblowers must have multiple pathways available to them, not just directly to the provider.
44. The Act must clearly state that Whistleblower protections include those that may be "whistleblowing" on another's behalf e.g. a family member or advocate, and that the Whistleblower protections applies equally to both parties.
45. That Whistleblower protections include priority access to timely assistance for participants who fear retribution to change aged care providers.
46. That clarification is provided in legislation for Whistle Blowers who may have been involved in the misconduct and who then come forward.

12. Supported Decision-Making Arrangements

"I don't have anyone in my life I can ask to be my supporter or representative – what should I do?"
(Resident, RAC, Perth)

"A diagnosis of dementia doesn't mean someone else has to step in to make all the decisions".
(Community member, Perth)

"I have a (state) Guardian and I'm on a budget (Administration). I want my aged care supporter to be someone who knows me and who I can trust".
(Resident, RAC, Melbourne)

We support the implementation of obligations under the Convention on the Rights of Persons with Disabilities (CRPD) in relation to supported decision-making, and particularly, **Article 12: Equal Recognition before the law**. While we agree with the urgent need to cease the current use of substitute decision-makers in Australia to reduce the abuse of older people, we recognise that substitute decision-making may still be required in rare and exceptional cases where all possible options to support an older person to make their own decisions have been exhausted or are impossible.

The proposed nominee framework for the aged care sector potentially adds another layer of substitute decision making to existing substitute decision making systems, if the "supported decision-making" approach is not properly monitored and nominees are not adequately educated and supported.
We have developed the following foundational statements regarding older people and decision-making, using the terms 'capability' or 'ability', rather than the term 'capacity':

1. As with all adults, older people have the right to make decisions about the care and services they receive and the risks they are willing to take.
2. The presumption must always be that older people have the ability to make decisions.

3. A reduction in decision-making ability is not a result of ageing:

    a. Most people have the ability to make decisions about all aspects of their life until their death.
    b. Some adults of any age may want and/or need support in making certain types of decisions.
    c. Only in rare cases will adults require support in making all decisions.

4. Decision-making ability is complex, fluctuating, and difficult to assess. Decision-making ability depends on many factors, including but not limited to:

    a. the quality of information provided and the suitability of the format provided
    b. available supports to make a decision
    c. the person's confidence and/or knowledge relating to the decision topic
    d. the person's communication modes and preferred language, cultural differences in expressions and values
    e. the type of decision made
    f. fluctuating abilities with time.

5. The presumption of decision-making ability should only be diverged from when the complex nature of decision-making ability has been fully considered and all possible options to support a person to make their own decisions have been exhausted or are impossible (e.g., if the person is in a coma).

We recommend that the Act should use the similar terminology of 'capability' or 'ability' rather than capacity.

We also note that people with very advanced dementia will also likely need a substitute decision maker, who ideally would be someone who knows the person well, has been the supported decision maker and is able to make decisions on behalf of the person informed by previous decisions and their will and preferences.

12.1 Lack of alignment with existing state and territory guardianship and administration laws

During consultations older people consistently commented that this model was confusing. Adding another layer of decision making on top of existing substitute decision making regimes that are in place across Australia, will result in consumers being subjected to multiple and conflicting decision-making systems, and providers being required to know the various decision makers for all the different types of decisions an older person may make within aged care. With the creation of different decision makers for different types of Commonwealth services that overlap with existing state and territory based-substitute decision makers, this will be unworkable and will result in increased risk of harm to older people.

Clarification is needed where the domains of the appointed representatives under the new Act and those of guardians appointed under State and Territory law overlap. To take but one example, the NSW Government provides the following information with respect to guardianship:

"*A guardian makes healthcare, lifestyle, and medical decisions for a set period of time. Their primary role is to ensure the person has access to the same care, treatment, and services as the rest of the community. The types of decisions they may need to make for the person can include:*

- *where they live*
- *what services they receive*
- *consenting to their medical and dental treatment*."

It should also be made clear that Powers of Attorney in relation to financial transactions will continue to rely on State and Territory legislation if this is the case. One matter of concern is where the State or Territory framework under which an appointment has been made is not consistent with the supported decision-making framework required by the Convention on the Rights of Persons with Disabilities and the appointment permits the exercise of substitute decision-making where that is not in line with the CRPD.

Implementing supported decision making will require a concerted effort to increase community and sector awareness of supported decision making across Australia. Without dedicated funding for service providers to implement via training for staff, we are concerned that staff of service providers will seek

and consult a "representative" under the proposed nominee framework or a substitute decision maker under the relevant guardianship and administration scheme, rather than use supported decision making as it will take too much time for staff to undertake.

In addition, it is essential that nominees are educated and skilled in using supported decision making. This includes where someone appointed as a Guardian or Power of Attorney is also appointed as a nominee and must move from a substitute decision making model "in the best interests" to a supported decision-making model "the person's will and preferences".

12.2 Lack of safeguards in the proposed nominee framework.

The proposed nominee framework for aged care does not provide adequate safeguards for older persons. Any restrictions on an older person's exercise of legal capacity should have a range of safeguards that apply, in order to protect the older person's human rights. Article 12 of the CRPD states that[4]:

States Parties shall ensure that all measures that relate to the exercise of legal capacity (a holder of rights which entitles persons to full protection of their rights by the legal system) provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent, and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

Adequate safeguards are needed to ensure there are no inappropriate nominee appointments and to minimise potential harm caused by a nominee. There is a lack of detail provided about safeguards for the process for appointment of a nominee, for example details on whether the older person are given the reasons for the appointment, the process that has been undertaken to search for someone who could act as a supported decision maker for an older person,

[4] UN General Assembly (2007). Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106.

whether an older person has the right to an advocate and legal representation, the process for appeal, or to revoke the appointment etc. A system for monitoring nominees is also not included in the proposed nominee framework and must be in place.

12.3 The support needs for First Nations people will not be met by this framework.

The proposed nominee framework is predicated on the individualistic nature of a culture, versus a culture that is based on the collective. First Nations' cultural norms are based on group decision making and the concept of reciprocity. The proposed framework does not allow for collective responsibilities, such as the pooling of funds for use across a group of people or a community. There is often collective ownership of funds and financial assets in First Nations' families and communities. This type of functional interdependence between family and community members is not catered for in the proposed nominee framework for aged care.

Queensland research has found that there are fundamental incompatibilities between substitute decision making schemes and First Nations people's values and culture.[5] All participants in the Queensland research revealed that substitute decision making schemes are inherently complex for all people but are even more complex when allowing for cultural differences. Another example of these cultural differences is the First Nations' cultural concept of 'shame', particularly about telling your business to someone else, and particularly a non-Indigenous person:

> *There is a stigma for Indigenous people about having other people making their decision, particularly white people. The process can be extremely damaging, they feel shame and humiliation.*

[5] Cadet-James, D., Cadet-James, Y., Chenoweth, L., Clapton, J., Clements, N., Pascoe, V., Radel K., & Wallace V. (2011). Impaired decision-making capacity and Indigenous Queenslanders, final report. School of Human Services and Social Work, Griffith University, Brisbane; The Office of the Public Advocate (2013). Research Insights Aboriginal and Torres Strait Islander Queenslanders with impaired decision-making capacity.

In addition, there is an understandable lack of trust by First Nations' people in protectionist policies and programs implemented by government agencies, due to past injustices such as Stolen Wages and the Stolen Generation.
The proposed nominee framework makes no mention of how cultural considerations will be addressed. An example of this type of safeguard is section 11b of the *Guardianship and Administration Act 2000* (Qld), which requires consideration of culture:

5 Maintenance of an 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.

12.4 Lack of detail on alignment with the NDIS framework for supported decision making.

The consultation paper frequently states that the proposed nominee framework for aged care will have similar requirements to the NDIS supported decision making framework. Without clarification of how much it will align, it is difficult to make comment on the suitability of the NDIS framework for aged care. In addition, the NDIS supported decision making framework implementation plan identifies a range of issues where further work is required to successfully implement the policy, such as: how to conduct supported decision making for NDIS participants with complex communication needs; developing a clear position on consent and on conflict of interest, and the independence required when interacting with participants[6]. It is unclear from the consultation paper whether the government will undertake similar activities for the proposed nominee framework for aged care, in order to implement a system that is safe for older people and workable for all involved in the aged care sector.

The NDIS supported decision making policy outlines that NDIS participants can access 'reasonable and necessary' decision making supports through funding in their NDIS plans, such as training for participants to build their capacity to

[6] National Disability Insurance Agency (2023). NDIS Supported Decision Making Implementation Plan.

make decisions, training for carers or family to build their skills around supporting participants to make their own decisions, and trained facilitators to support participants to be heard in decision-making processes.[7] This consultation paper does not outline similar supports that will be funded in the aged care sector to assist older people to make decisions. In addition, whether these and other types of supports for supported decision making in aged care are currently available in the market for older persons to access, and whether they are best practice, is not stated.

Without work done to build the unpaid networks for consumers who have no one to act as a 'supporter' or 'representative', it is unclear how appointing someone as a supporter or representative who does not have an existing relationship with an older person, will enable an older person's will, preferences and wishes to be realised.

Concerns were also raised by older people that the decision to appoint someone as their supporter or representative should be made in a well-considered way, and not be subject to undue influence due to time pressure at the point of entry to residential aged care or coercion to appoint a particular person.

12.5 Changes to the Proposed Supported Decision-Making Model

We provide the following changes to the proposed Supported Decision-Making model:

- The model should align with the Supported Decision-Making framework/Model being proposed by the Disability Royal Commission so that supported decision making is consistent across the disability and aged care sectors.
- The eight National Supported Decision-Making principles proposed by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability should be included within the Aged Care Act.
- The inclusion in legislation of advance directives/advance social directives/advance living directives (older people have spoken of these under a range of names) outlining the will and preferences of the individual to assist in decision-making. These advance directives may

[7] NDIS Review Panel (2023). Safeguarding paper: NDIS Participant Safeguarding Proposals Paper on Participant Safeguarding, Independent Review of the National Disability Insurance Scheme.

also specify supporters and substitute-decision makers and should specify the point(s) at which a person wants supported decision-making or substitute decision-making to be in force.
- A requirement that criteria used in assessments of decision-making abilities must be continually revised and improved through explorations of how they are implemented in real-life decisions.
- An ability to appoint multiple representatives dependent on the decisions to be made e.g. financial, legal, medical, social.

In addition, aged care legislation and policies, plus individual aged care service provider policies, must explicitly state and address how they will enable and support older people and decision-making.

We believe that the following initiatives are needed to enforce the rights of older people to make decisions in aged care:

- There must be a process for the older person to be able to revoke the appointment of a nominee.
- There must include a specified body with the powers to enforce relevant charges and sanctions for individuals and entities (including aged care service providers) who do not uphold the supported decision-making principles.
- All providers of aged care services, including screening and assessment services, must ensure access to supported decision-making, independent of the service, to all individuals who want or need this support.
- Aged Care Quality and Safety Commission quality audits must include specified requirements for aged care services to produce substantial evidence of:
    - how their workers implement supported decision-making principles in day-to-day practice, and
    - how they provide access to independent supporters.

The Australian Government should also consider current legislation and support decision making frameworks (SDM) internationally and use these to frame the SDM framework in the Aged Care Act.

12.6 Appointment by the Secretary of the Department of Health and Aged Care

Older people were emphatic during consultations that the proposed model for appointment of a nominee by the Secretary was not appropriate. They questioned the ability of the secretary to appoint someone who knew the older person's wishes and preferences. This issue is further exacerbated where there could be cultural considerations and/or previous life experiences of trauma at the hands of the "state".

We have been unable to come to a clear decision on who could or should be able to appoint a nominee and encourage further discussion with older people on what an appropriate model would be.

12.7 Example of a legislated Supported Decision-Making Framework - Ireland

A concise summary of the Republic of Ireland's supported decision-making legislation (namely the *Assisted Decision-Making (Capacity) Act 2015*). The Citizens Information Board is 'the national agency responsible for supporting the provision of information, advice and advocacy on social services.

Key aspects of the Ireland legislation that came into effect on 26 April 2023 are:

- A presumption of capacity to make decisions and a *functional test* for assessment of decision-making capacity based on the decision that has to be made at that time.
- A new range of decision support arrangements:
    - *Decision-making assistance agreement* where the person requiring support making some of their own decisions nominates someone to support them in making decisions for themselves through gathering information and helping them understand it.
    - *Co-decision-making agreement* where a person who finds it difficult to make certain decisions on their own, or may shortly be unable to do so, chooses someone to make decisions jointly with them.
    - *Decision-making representation order* where a person can't make certain decisions on their own or with somebody else's support, the Circuit Court may appoint a decision-making representative.
- Abolishment of the 'ward of court' system.

- The establishment of a Decision Support Service that will:
    - regulate and register decision support arrangements
    - supervise the actions of decision supporters
    - maintain a panel of experts who will act as decision-making representatives, special and general visitors
    - review and investigate complaints made under the Act
    - promote awareness and provide information about the Act.
- The introduction of specific criminal offences relating to decision support arrangements, enduring powers of attorney and advance healthcare directives.

12.8 Recommendations

47. Supported Decision making must be the foundation of decision-making in aged care, as it is in disability support.

48. The proposed Supported Decision-Making model is amended to reflect the Supported Decision-Making Framework recommended by the Disability Royal Commission in its Report" Diversity, dignity, equity and best practice: a framework for supported decision-making".

49. The Act must use the terminology of "capability' or "ability" rather than capacity.

50. That in the current 3rd dot point of the Supported Decision-Making Principles the word is changed from "harm" to "serious harm".

12.8.1 Supporters and Representatives

51. Greater clarification is provided on how the proposed framework intersects and applies within existing State and Territory decision making frameworks including Power of Attorney, Guardian, medical treatment decision maker etc.
    a. Where people have an existing appointed POA or Guardian that that person automatically becomes the Representative and must work under the Supported Decision-Making Model

52. The term Supporter should not be used, rather they should be referred to as an "information nominee" who must also work under the Supported Decision-Making Model where the older person requests this assistance.

53. If the role of Representative is to continue then consideration must be given to sub-categories of Representatives as not every person will have the time, skills and/or knowledge to assist a person with decisions across all areas of their life.
    For example, these could be:
    a. Financial
    b. Legal
    c. Medical/Health
    d. Social

12.8.2 Disputes and Reviews

54. Appropriate alternate dispute resolution processes are implemented so that disputes between the various decision-makers appointed by an older person can be resolved.

55. Similar appeal mechanisms, as available under State and territory laws, must be implemented.

12.8.3 Choosing a Representative

56. Establishing a clear pathway, and service, which could be based within the Regulator, to assist people in appointing a representative or nominee, or in the case where the person is assessed as unable to make this decision, helping appoint a representative for that person.

    This service:
    a. would ensure appropriate safeguards are in place to ensure there are no inappropriate nominee appointments.
    b. will also provide the older person with the reasons for the appointment, the process that has undertaken to search for someone who could act as a supported decision maker for that person, whether an older person has the right to an advocate and legal representation, the process for appeal and/or to revoke the appointment.
    c. The Secretary of the Department, or any delegated person, should not be the person choosing a representative or nominee as they have no connection, knowledge or understanding about that person and therefore cannot appoint someone who knows the person's wishes and preferences.

12.8.4 Further Work

57. Further engagement with participants and consumer representative groups to address the concern and confusion caused by this proposal and consider and address unintended consequences.

58. Establish a body to monitor and provide support, advice and education on the roles and responsibilities of being a representative and working within a supported decision-making framework.

13. Eligibility for Funded Aged Care Services

"I'm over 80, and individuals aged 65 and over is an undifferentiated group".

(Older person, Sydney)

"Physiological ageing is more important than chronological ageing".

(Older person, Canberra)

"Forgotten Australians are often prematurely aged and have been forgotten here too".

(Older person, Melbourne)

We welcome the intent, directions and approach proposed for a new single-entry point into the aged care system, with common eligibility requirements and a single assessment framework, giving expression to Recommendation 25 of the Royal Commission.

The streamlined, simplified approach outlined in the consultation paper – if delivered effectively and in a timely manner – should make a major, positive difference to the experience of initial engagement with the aged care system for large numbers of older people and their families and friends who support them in this process.

We also believe that if this new approach functions as intended, it is likely to generate better outcomes for older people through more accurate assessment

of needs and matching with services and supports from first contact by older people with the system.

In general, we believe the combination of proposed access and eligibility arrangements and definitions set the bar for entry to the aged care system at an appropriate level. However, we raise some concerns, questions and suggestions regarding particular components in discussion below.

13.1 Application Process

The proposal that the application process is free of charge is a welcome starting point that signals an important aspect of equity of access to the system.

However, clarification is required as to what is meant by the application will be able to be made verbally. Does 'verbally' in this case mean 'orally' by telephone or in-person? Does it mean that there will be a written application as the default, but individuals can, if needed, make a 'verbal' application?

We welcome flexibility in the application process, including the capacity to make applications in-person or over the telephone, but this will need to be properly resourced and managed.
Government over the counter and telephone access arrangements across the board have degraded beyond recognition over recent years (in favour of written, digital communications) and current standards of service would not be acceptable for a new application process in aged care. Significant resources, appropriate management information systems and staff skills would need to be applied to this arrangement.

We also welcome the capacity for a person to receive access to care services prior to assessment in emergencies or delays outside their control.
The proposed threshold eligibility test appropriately recognises that a person's own declaration of need or professional referral is a valid starting point to initiate the process. A clear and accessible definition of needs against which older people themselves and their supporters can assess their eligibility will be a critical piece of information in this pathway.

Overall, we support the proposed definition of care needs for the new Act.

However, we request that the terminology 'cognitive' be added to "physical, mental or social" in dot point 1 and to "physical, psychological or social" in dot point 2. This recognises a crucial driver for many people seeking support through aged care services and is not captured by the current language.

13.2 Eligibility Criteria

We generally accept the proposed age eligibility criteria in the consultation paper, with the range of provisos and safeguards suggested.

In addition, we welcome the continued recognition of the specific needs of some First Nations people and some people who are homeless or at risk of homelessness. The age threshold of 50 for persons in these groups to access aged care is appropriate and strongly supported.

However, given real world situations, we also envisage the need for some flexibility taking account of exceptional circumstances for some other groups and individuals under the age of 65. We suggest the need for the creation of age exception pathways and supporting guidance and evaluation of assessment processes and decisions relating to these instances, that could address this concern in rare situations.

There was a great deal of concern expressed during the consultations that the support needs of younger people excluded from the NDIS due to having lower levels of functional impairment will fall through the gaps of both systems, especially in relation to access to assistive technology.

Examples raised with us in our consultations, where there may be a strong case for exemption to made to the 65 age barrier, include some populations who may experience an early ageing process due to particular personal attributes or medical issues. Examples of this include some people with HIV (not eligible for support under the NDIS) and some veterans or Forgotten Australians. The assumption that either the NDIS or the healthcare system will cater fully for all those under the age of 65 is challenged by many of our stakeholders.

The needs of people living with younger onset dementia were raised at every consultation. Many people in the early stages of dementia do not meet the eligibility criteria for the NDIS but would benefit from access to community based cognitive rehabilitation and other supports, including carer supports that

may prevent or delay their entry to residential aged care. We also note that the disability service system is currently not always able to meet the needs of people living with younger onset dementia, and that they should not be refused access to funded aged care supports if required. We strongly support policies to prevent anyone aged under 65 entering residential aged care but consider that anyone aged 50-64 with care and support needs who has applied for and been denied access to the NDIS or whose needs cannot currently be met by the disability system should have expedited access to an age exception pathway to access home and community based aged care services.

We also note that a number of people raised concerns about the eligibility age being 65, when people now retired at 67 and/or were more physically active in later age. However, any change in age would require a change in age across all intersecting care systems, especially disability so that people were not unintentionally left without access to services.

13.3 Recommendations

59. Eligibility for people aged 50 – 64 years must be more flexible and include eligibility for those with younger onset dementia, found not eligible for the NDIS, or whose needs cannot currently be met by the disability system, those that have early onset of age-related health issue and those living with HIV.

    b. Flexibility must allow people under 65 being able to have a physiological test and if they are assessed as experiencing early ageing then they should be able to access aged care services.

[i] Aged Care Royal Commission Recommendation 14