A Human Rights Perspective on Aged Care

Submission to the Royal Commission into Aged Care Quality and Safety

18 July 2019
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1 Introduction

1. The Australian Human Rights Commission (the Commission) welcomes the opportunity to provide this submission to the Royal Commission into Aged Care Quality and Safety (the Royal Commission).
2. The Commission is Australia’s National Human Rights Institution, with recognised independent status and roles in United Nations human rights fora. The Commission’s purpose is to provide independent and impartial services to promote and protect human rights and fundamental freedoms. The Commission undertakes a range of policy development and research tasks that aim to promote compliance with Australia’s human rights obligations, while also investigating and conciliating complaints of unlawful discrimination and breaches of human rights.

3. A focus on the human rights of older Australians is particularly important at this time when Australia, along with many other nations, faces an ongoing increase in its ageing population. While increased life expectancy is a cause for celebration, it also presents particular challenges, including in relation to the provision of aged care services.

4. Examinations of aged care in Australia, such as the Productivity Commission’s 2011 inquiry, have identified numerous challenges facing the sector which relate to the ongoing demographic, economic, social and cultural changes in Australian society. These challenges include:

- a significant increase in demand for aged care services arising from the ageing of the Australian population
- an associated relative decline in the number of people working which will impact on the aged care workforce
- the need for more complex and higher levels of care to support people with chronic diseases, such as dementia, that are associated with increased longevity
- a decline in the availability of informal carers, such as family members, due to changes in the social and economic circumstances, and reductions in the size of families
- a shift in expectations and preferences regarding the type of aged care services that are provided, with an increased focus on independent living and in-home services
- the diverse geographical spread of the Australian population
- the social, cultural, linguistic and religious diversity of the Australia population.

5. Inquiries and reviews of the aged care sector over recent years have highlighted various weaknesses including:

- a system that is complex and difficult to negotiate
- inequities in accessing information and services for particular sectors of the population
issues relating to quality of care including neglect, overmedication and use of restraints

• associated failures in regulatory mechanisms

• workforce issues connected with ongoing low wages and inadequate education and training.²

6. These inquiries and reviews have also been the catalyst for positive reforms that have been, or are in the process of being, implemented such as:

• the ‘My Aged Care’ information gateway

• the establishment of the Aged Care Quality and Safety Commission

• the introduction of the Aged Care Diversity Framework

• the implementation of unannounced site audits for residential aged care services

• regulatory changes in relation to the use of restraints.³

7. The Royal Commission provides a significant opportunity to identify ongoing issues across the aged care sector and recommend additional reforms to prepare better for the future, including reforms that respect, protect and fulfil human rights.

8. While the Commission does not have extensive knowledge of, or expertise in, the specifics of aged care services, the Commission is uniquely placed to provide input regarding the human rights of older Australians.

9. It is the Commission’s view that a human rights based approach to aged care—that is, an approach where human rights norms and principles are integrated in the planning, provision and monitoring of services—is fundamental to addressing systemic problems and improving aged care.⁴

10. This submission provides: an overview of the international and domestic human rights framework relevant to the provision of aged care; an overview of the key principles underpinning a human rights based approach; a human rights perspective on particular issues relevant to the Royal Commission’s Terms of Reference; and recommendations which reflect human rights principles and standards.

1.1 Enhancing person-centred care, autonomy and independence

11. Central themes have emerged in the Commission’s discussions with people interacting with the aged care system, many of which have related to the
delivery of person-centred aged care, and autonomy and independence of aged care users.

12. The Commission recognises the broader issues affecting access to quality services and person-centred care, for example, relating to funding and availability of services, staffing levels and regulatory mechanisms, but also acknowledges there are other groups more appropriately placed to make specific recommendations on these matters.

13. The Commission also recognises that while there are legitimate criticisms relating to the quality and safety of aged care, these do not necessarily apply to all providers.

14. The submission includes a number of practical suggestions to enhance autonomy, independence and person-centred care. While not exhaustive, these measures should be considered by the Royal Commission when formulating recommendations.

2 Summary of recommendations

15. Recommendation 1: The Royal Commission consider international human rights instruments relevant to the rights of older persons with a view to ensuring its recommendations align with Australia’s obligations under these instruments.

16. Recommendation 2: The Australian Government adopt a human rights based approach to the planning, provision and monitoring of aged care services, which builds on recent innovations such as the Aged Care Diversity Framework and connects the new Charter of Aged Care Rights and the new Aged Care Standards with the domestic and international human rights framework.

17. Recommendation 3: The Australian Government fund and facilitate the development and implementation of training for the aged care workforce to address ageism and educate them about the human rights of older persons.

18. Recommendation 4: The Australian Government invest in public awareness campaigns and associated programs which focus on the rights of older people and address negative stereotypes of ageing.

19. Recommendation 5: The Australian Government commit to ongoing funding of appropriate outreach and navigator services to ensure all older people and their families, including Aboriginal and Torres Strait Islander peoples and people from other diverse communities, can
access information to assist them make informed decisions about aged care services.

20. **Recommendation 6:** The Australian Government improve the accessibility of the ‘My Aged Care’ website by ensuring it is compatible with Web Content Accessibility Guidelines 2.1.


22. **Recommendation 8:** The Australian Government commit sufficient resources to ensure that aged care service users and providers are educated about the Aged Care Diversity Framework and associated Action Plans, including the underpinning human rights principles and legal framework.

23. **Recommendation 9:** The Australian Government take action to ensure that service providers’ accreditation is contingent on their implementation of the Aged Care Diversity Framework and Action Plans, including requiring that reaccreditation considers the provider’s performance against outcomes in the Action Plans with a particular focus on:
   - service user/community co-design in the planning, development, implementation and evaluation of services
   - the use of culturally appropriate assessment methods and tools
   - training for aged care workers in cultural safety, anti-discrimination and trauma informed service delivery
   - the recruitment and retention of culturally competent and appropriately skilled aged care workers.

24. **Recommendation 10:** The Australian Government commit sufficient resources to ensure that aged care service providers utilise the available care leaver resources and training materials and aged care user resources are developed to support care leavers to access aged care.

25. **Recommendation 11:** The Australian Government commit sufficient resources to support Indigenous community-controlled and mainstream organisations to deliver aged care services, including investment in training and employment opportunities for Indigenous aged care workers, and the collection of appropriate data to enable an evidence-based approach to Aboriginal and Torres Strait Islander aged care policy and practice.
26. Recommendation 12: The Australian Government commit sufficient funding for infrastructure and aged care services in rural and remote areas where access is currently lacking or inadequate, with a particular focus on the provision of services to Aboriginal and Torres Strait Islander peoples.

27. Recommendation 13: The Royal Commission closely consider the ALRC’s recommendations in its Report No 124 Equality, Capacity and Disability in Commonwealth Laws as a means to provide clear statutory guidance for decision-making in the context of aged care.

28. Recommendation 14: The Aged Care Act 1997 (Cth) should be amended to include provisions dealing with supporters and representatives consistent with the Commonwealth decision-making model, as recommended by the Australian Law Reform Commission in its Report No 124 Equality, Capacity and Disability in Commonwealth Laws.

29. Recommendation 15: The Australian Government invest in public awareness campaigns and associated programs to:
   - increase knowledge about enduring documents and advance care planning by aged care workers, attorneys and the community generally, including the applicability and limitations of these documents and the relevant rights of older persons
   - encourage the use of advance care planning preferably prior to or at the point of access to aged care.

30. Recommendation 16: The Australian Government fund and facilitate the development and implementation of training for the aged care workforce in relation to supported decision-making and the applicability, limitations and appropriate use of enduring documents.

31. Recommendation 17: The Australian Government ensure sufficient quantities and levels of in-home age care packages are progressively made available to respond to identified needs.

32. Recommendation 18: The Australian Government update aged care legislation to regulate the use of restrictive practices in residential aged care in line with recommendations made by the ALRC and in the Review of National Aged Care Regulatory Processes. Any restrictive practice should be the least restrictive and used only:
   - as a last resort, after alternative strategies have been considered, to prevent serious physical harm;
   - to the extent necessary and proportionate to the risk of harm;
• with the approval of a person authorised by statute to make this decision;
• as prescribed by a person’s behaviour support plan; and
• when subject to regular review.

33. Recommendation 19: The Australian Government consider further safeguards in relation to the use of restrictive practices in residential aged care, including:
• establishing an independent Senior Practitioner for aged care, to provide expert leadership on and oversight of the use of restrictive practices;
• requiring aged care providers to record and report the use of restrictive practices in residential aged care; and
• consistently regulating the use of restrictive practices in aged care and the National Disability Insurance Scheme.

34. Recommendation 20: The Australian Government and the Council of Australian Governments should develop a national approach to the regulation of restrictive practices aged care.

35. Recommendation 21: The Australian Government ensure that the implementation of the National Plan to Respond to the Abuse of Older Australians:
• takes into account the needs of diverse communities, particularly as it relates to understanding and preventing elder abuse in those communities
• includes resources for further training for the aged care workforce in relation to identifying and responding to elder abuse and understanding privacy legislation and exemptions for reporting across aged care and health settings.

3 A human rights based approach to aged care

36. The language of ‘rights’ has been part of the aged care legislative framework for many years. The rights of users of aged care services are set out in the User Rights Principles 2014, made under section 96–1 of the Aged Care Act 1997 (Cth) (Aged Care Act), and the associated charters of rights and responsibilities for residential aged care, in-home aged care and short-term restorative aged care. The Commission notes the development of the new Charter of Aged Care Rights which will be operational as of 1 July 2019 and which provides one set of rights for all types of aged care.
37. These charters set out a broad framework of high-level rights. For example, the current ‘Charter of Care Recipients’ Rights and Responsibilities—Residential Care’ includes:
   - the right to be treated with dignity and respect and to live without exploitation, abuse or neglect
   - the right to privacy
   - the right to live in a safe, secure and home-like environment, and to move freely both within and outside the residential service without undue restriction
   - the right to live without discrimination.7

38. Despite these articulations of service user rights, concerns continue to be raised about the translation of these rights into practice, particularly in relation to how care is provided in residential aged care facilities.8

39. A human rights based approach to aged care is a person-centred approach which aims to see the language of rights meaningfully connected with practice.

40. A human rights based approach sets out the existing rights and responsibilities of stakeholders with reference to the universal, legitimate framework of domestic and international human rights law and requires that human rights standards and principles are embedded in all aspects of service planning, policy and practice. It is an approach that addresses both processes and outcomes, and provides a consistent framework for monitoring and evaluation.9

41. Overseas research supports that a human rights based approach to service delivery can have numerous benefits including increased user satisfaction, reduced complaints, improved risk management and decision-making, and greater transparency and accountability.10

3.1 Human rights and responsibilities

42. Central to a human rights based approach to aged care is an understanding of relevant human rights and the associated requirements to respect, protect and fulfil these rights.

(a) The international and domestic human rights framework

43. Human rights are basic rights and freedoms that belong to every person which are set out in international treaties and conventions. Australia has
ratified a range of international human rights instruments that contain important provisions relevant to older people. These include:

- the Constitution of the World Health Organization\textsuperscript{11}
- the International Covenant on Civil and Political Rights (ICCPR)\textsuperscript{12}
- the International Covenant on Economic, Social and Cultural Rights (ICESCR)\textsuperscript{13}
- the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)\textsuperscript{14}
- the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)\textsuperscript{15}
- the International Covenant on the Elimination of All Forms of Racial Discrimination (ICERD)\textsuperscript{16}
- the Convention on the Rights of Persons with Disabilities (CRPD).\textsuperscript{17}

44. Australia has also endorsed the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP).\textsuperscript{18}

45. The international human rights instruments referenced above require that States:

- respect the relevant human rights—that is, not interfere directly or indirectly in the enjoyment of the rights
- protect the relevant human rights—that is, prevent third parties (including business enterprises) from interfering or breaching human rights
- fulfil the relevant human rights by adopting appropriate measures to fully realise rights.

46. The rights set out in the abovementioned international instruments include:

- the right to liberty and security—Article 9 ICCPR
- the right to liberty of movement and freedom to choose one’s residence—Article 12 ICCPR
- the right to freedom from torture or cruel, inhuman or degrading treatment or punishment—Article 7 ICCPR
- the right to freedom from arbitrary or unlawful interference with privacy, family and home—Article 17 ICCPR
- the right to freedom of thought, conscience and religion, including the freedom to manifest one’s religion or belief in worship, observance, practice and teaching—Article 18 ICCPR
• the right to equality before the law without discrimination —Article 26 ICCPR
• the right for persons from ethnic, religious or linguistic minorities to enjoy their own culture, to profess and practise their own religion, or to use their own language—Article 27 ICCPR
• the right of everyone to the enjoyment of the highest attainable standard of physical and mental health—Article 12 ICESCR
• the right of persons with disabilities to be protected from all forms of exploitation, violence and abuse—Article 16 CRPD
• the right of persons with disabilities to live independently and be included in the community—Article 19 CRPD
• the right to freedom from discrimination on the basis of sex, including in relation to the provision of goods, services and facilities—Articles 12 and 13 CEDAW
• the right to freedom from discrimination on the ground of race, colour, descent, or national or ethnic origin, including in the provision of goods, services and facilities—Article 5 ICERD
• the right of Indigenous peoples to maintain their health practices and have access, without any discrimination, to all social and health services—Article 24 UNDRIP
• the right of Indigenous peoples to the enjoyment of the highest attainable standard of physical and mental health—Article 24 UNDRIP.

47. There are also a number of non-binding instruments at the international level that address the rights of older people. These include:

• the Vienna International Plan of Action on Ageing, endorsed by the United Nations General Assembly in 1982

• the United Nations Principles for Older Persons, adopted in 1991, which set out 18 principles to be incorporated into national policies that promote the independence, participation, care, self-fulfilment and dignity of older persons

• the Madrid International Plan of Action on Ageing, adopted in 2002, which requires that States take measures to address ageing so that a society for all ages can be achieved.

48. The United Nations Principles for Older Persons include the following principles that governments are encouraged to incorporate into programs:

• Older persons should be able to live in environments that are safe and adaptable to personal preferences and changing capabilities

• Older persons should be able to reside at home for as long as possible
- Older persons should have access to social and legal services to enhance their autonomy, protection and care
- Older persons should be able to utilise appropriate levels of institutional care providing protection, rehabilitation, and social and mental stimulation in a humane and secure environment
- Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives
- Older persons should be able to live in dignity and security and be free of exploitation and physical or mental abuse
- Older persons should be treated fairly regardless of age, gender, racial or ethnic background, disability or other status and be valued independent of their economic contribution.

49. Australia’s ratification of international instruments is reflected in a framework of legislation at the national level to protect human rights. This legislation includes the following:

- the Racial Discrimination Act, 1975 (Cth) which deals with discrimination on the grounds of race, colour, descent, or national or ethnic origin and racial hatred
- the Sex Discrimination Act, 1984 (Cth) which deals with discrimination on the grounds of pregnancy, marital or relationship status (including same-sex de facto couples) status, breastfeeding, family responsibilities, gender identity, intersex status, sexual orientation and sexual harassment
- the Disability Discrimination Act, 1992 (Cth) which deals with discrimination on the grounds of disability
- the Age Discrimination Act, 2004 (Cth) which deals with discrimination on the grounds of age
- the Australian Human Rights Commission Act, 1986 (Cth) which provides limited rights in relation to specific international instruments such as the ICCPR and the CRPD.

50. Federal anti-discrimination law provides people with the right to make a complaint to the Commission about unlawful discrimination, and where that complaint cannot be resolved by conciliation, the possibility of pursuing the matter to the Federal Court of Australia or the Federal Circuit Court for an enforceable remedy.

51. Australia has also agreed to be subject to United Nations complaint mechanisms associated with a number of ratified treaties. These complaint mechanisms which relate to the ICCPR, ICERD, CEDAW, CRPD and CAT, are
distinct from the complaint mechanisms under national human rights and anti-discrimination laws.

52. On 21 December 2017, Australia also ratified the optional protocol to CAT (OPCAT). Countries that have ratified OPCAT must introduce a system of regular visits or inspections in all places where people are deprived of their liberty in order to prevent torture and other ill-treatment. Australia’s OPCAT inspection regime is likely to rely, in large part, on current inspectorate and monitoring bodies. However, it is clear that the functions and powers of some of these bodies may have to be amended in order to become OPCAT compliant.

53. In addition, ratifying OPCAT involves agreeing to allow periodic inspections of Australia’s places of detention by the United Nations Subcommittee on Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment.

54. **Recommendation 1:** The Royal Commission consider international human rights instruments relevant to the rights of older persons with a view to ensuring its recommendations align with Australia’s obligations under these instruments.

(b) **Younger people in aged care and the relevance of the CRPD**

55. While at this time, there is no international convention dealing specifically with the rights of older persons, the CRPD is relevant to issues of aged care for people with disability. The context of how the CRPD relates to violence, abuse and neglect of people with disability in institutional and other settings will be discussed in more detail in the Commission’s upcoming submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, which may be useful for this Royal Commission to consider in forming recommendations.

56. In the Terms of Reference b(i) of this Royal Commission, the requirement to inquire into the matter of ‘how best to deliver aged care services to people with disabilities residing in aged care facilities, including younger people’ includes the implicit assumption that there is a place for young people in aged care. This assumption is misguided. The Commission is strongly of the view there is no place for young people in aged care in Australia and extensive regulatory safeguards and provision of age appropriate care should be put in place to prevent that occurrence.
3.2 Underpinning principles of a human rights based approach

(a) PANEL principles

57. While the specifics of a human rights based approach may vary in different contexts, the approach is characterised by five underpinning human rights principles. These are known as the 'PANEL principles'—Participation, Accountability, Non-discrimination and equality, Empowerment, and Legality. A statement of each principle and comments on the relevance of the principle to the provision of aged care services is provided below.

- **Participation**: People should be involved in decisions that affect their rights. In the context of the provision of aged care services, this principle requires that those who are receiving services should be able to participate in decisions about the care and support they are receiving. Participation must be active, free and meaningful and give attention to issues such as accessibility of information, including in a form and language that can be understood. The methods for undertaking participation are context dependent, but steps must be taken to develop and ensure mechanisms are in place to enable participation.

- **Accountability**: There should be monitoring of how people’s rights are being affected and remedies provided for when things go wrong. In the context of the provision of aged care services, this principle requires the development of appropriate indicators and processes to enable effective monitoring of compliance with human rights standards. There must also be appropriate policies, procedures and mechanisms in place to enable redress, where a breach of human rights has occurred.

- **Non-discrimination and equality**: All forms of discrimination must be prohibited, prevented and eliminated and those people who face the most significant barriers to realising their rights, should be prioritised. In the context of the provision of aged care services, this principle requires that those in receipt of services are not treated less favourably because of attributes such as their race, colour, sex, religion, disability, age, sexual orientation or gender identity. Aged care services should recognise that older people are not a homogeneous group and difference and diversity must be respected. It also requires that attention be given to the needs of more marginal groups, with policy and practice promoting equality rather than perpetuating inequality.

- **Empowerment**: Everyone should understand their rights and be fully supported to take part in developing policy and practices which affect their lives. In the context of aged care services, it requires that older persons are provided with information about their rights and how they can
exercise their rights, which may involve the provision of appropriate advocacy or communication supports.

- **Legality:** Actions should be grounded in the legal rights set out in domestic and international laws and reflect associated principles about the application of rights. For example, the principles of legality, legitimacy and proportionality should be considered in relation to potential restriction of rights and the principles of progressive realisation and non-retrgression in situations of limited resources.30

(b) **Core components of the right to health**

58. Also relevant to the provision of aged care services are the core components of the right to health in Article 12 of the ICESCR as defined by the United Nations Committee on Economic, Social and Cultural Rights.31 The Committee states that the right to health contains the following interrelated and essential components: availability, accessibility, acceptability and high quality. The PANEL principles are the core enablers of achieving health care services that are available, accessible, acceptable, and of high quality. An explanation of each component is provided below.

- **Availability:** This refers to the need for functioning health care facilities, goods and services and programs to be available in sufficient quantity.

- **Accessibility:** This requires that health facilities, goods, and services must be accessible to everyone. Accessibility has four overlapping dimensions:
  - **non-discrimination:** that is, that they are accessible to all, without discrimination, especially the most marginalised sections of the population
  - **physical accessibility:** that is, that they are within physical reach of all sections of the population, including marginalised sections of the population, and also accessible for people with disability
  - **economical accessibility:** that is, that they are affordable for all, including those socially disadvantaged groups, with payment based on the principle of equity
  - **information accessibility:** this includes the right to seek, receive and impart information and ideas about health issues without impairing the right of have personal health data treated with confidentiality.

- **Acceptability:** This requires that all health facilities, goods and services and programmes are people-centred and cater for the specific needs of diverse population groups and accord with international standards of medical ethics, including confidentiality and informed consent.
Australian Human Rights Commission
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- **Quality**: Health facilities, goods and services must be scientifically and medically appropriate and of good quality. Quality health services should be:
  - **safe**: avoiding injuries to people for whom the care is intended
  - **effective**: providing evidence-based healthcare services to those who need them
  - **people-centred**: providing care that responds to individual preferences, needs and values
  - **timely**: reducing waiting times and sometimes harmful delays
  - **equitable**: providing care that does not vary in quality on account of gender, ethnicity, geographic location, and socio-economic status
  - **integrated**: providing care that makes the full range of health services available throughout the course of life
  - **efficient**: maximising the benefit of available resources and avoiding waste.

3.3 Implementing a human rights based approach

59. Scotland, England and Wales have implemented a human rights based approach in the provision of health services, including in the provision of residential mental health services. Information about these programs support that the steps involved in implementing a human rights based approach include:

- tailored training for people with responsibilities for service planning and policy development to ensure they are aware of human rights and associated principles
- the incorporation of human rights standards and principles in the strategic objectives of services and organisations and the development of appropriate indicators and measures to assess performance
- review of policies and procedures to ensure conformity with human rights standards and principles
- tailored training for service providers to ensure they are aware of human rights and their associated responsibilities, and understand how human rights principles can assist daily practice
- tailored training for service users to ensure they are aware of their rights and how to exercise them
- development and implementation of appropriate feedback mechanisms to obtain feedback from users and staff with a view to facilitating ongoing improvements in service delivery
• development and implementation of appropriate complaint mechanisms to deal with possible breaches of rights and provide remedies where required.

60. **Recommendation 2:** The Australian Government adopt a human rights based approach to the planning, provision and monitoring of aged care services, which builds on recent innovations such as the Aged Care Diversity Framework and connects the new Charter of Aged Care Rights and the new Aged Care Standards with the domestic and international human rights framework.

4 **Improving aged care—a human rights perspective**

61. This section of the submission highlights some particular issues that are relevant to the Royal Commission’s Terms of Reference, and that the Commission considers are important to address in order to build on recent reforms and improve and strengthen aged care in Australia.

62. The discussion and recommendations highlight how a human rights based approach can assist in providing a framework for integrating norms, principles and standards that are essential to the provision of safe, high quality aged care.

4.1 **Addressing ageism**

63. Ageism can be defined as ‘discrimination against people based on their age, manifested through negative stereotypes and perceptions’. Ageism undermines the human rights of older Australians and is an obstacle to achieving an aged care system that respects and supports human rights.

64. Ageist attitudes arise from negative beliefs about older people and ageing. This can include generalised negative views of older people as less deserving, incapacitated, burdensome and needing protection—views which are often generated and reinforced in popular culture and the media.

65. Ageist attitudes can have a broad-range of impacts on individuals and the community. For individuals, ageism can lead to discrimination, marginalisation, isolation and disempowerment.

66. A 2013 Commission study found that over 70% of all Australians feel age discrimination is common; and that almost half of all Australians feel discrimination is present within the healthcare system, within government policy and in access to services.
67. Individuals working in health and aged care services can reinforce and perpetuate ageism and discrimination based on age, often through unconscious bias. This may be demonstrated in the types of services available to older people, language used when interacting with older people, and in assumptions about older people’s preferences and capabilities.

68. The link between ageism and elder abuse has also been noted in a number of reports, in that discriminatory attitudes towards ageing can contribute to trivialising, excusing or justifying such abuse. Elder abuse is further discussed later this submission.

69. Ageism may manifest in a ‘benevolent’ form, where restrictive assumptions and stereotypes lead to an overly protective response towards older people in aged care. While often well meant, this nonetheless undermines the capability and the dignity of older people, diminishing their sense of autonomy and control over their lives and leading to patronising, even infantilised, treatment.

70. At times, ageism manifests overtly and malevolently through fear and dislike of older people, devaluing them and leading to neglect and abuse. Ageism can result in older people disengaging, or being excluded from decision-making regarding the care they receive and from active participation in the planning and monitoring of services. It can also result in older people feeling they cannot exercise their rights and/or their concerns not being appropriately acknowledged and addressed.

71. Research commissioned by the World Health Organization indicates that interventions, which educate people about and/or establish contact between people of different generations can reduce ageism and improve participants’ knowledge of ageing. In addition to fostering more intergenerational programs, other initiatives to reduce ageism could include furthering of public awareness campaigns, such as EveryAge Counts, education for aged care workers and health professionals on ageism and its consequences, and monitoring and reviewing services to identify and address ageism.

72. **Recommendation 3:** The Australian Government fund and facilitate the development and implementation of training for the aged care workforce to address ageism and educate them about the human rights of older persons.

73. **Recommendation 4:** The Australian Government invest in public awareness campaigns and associated programs which focus on the rights of older people and address negative stereotypes of ageing.
4.2 Ensuring access to information

(a) Human rights standards

74. Article 12 of the ICESCR refers to the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. With reference to the core components of the right to health, as defined by the United Nations Committee on Economic, Social and Cultural Rights, information about health services should be accessible to all without discrimination.

75. Access to information about services is essential in order for older people to be empowered to participate in decisions concerning the services they receive.

(b) Accessibility of information about aged care

76. The Commission acknowledges the value of ‘My Aged Care’ as a single gateway for information about aged care, and the ongoing work that has been undertaken to improve the service. However, concerns continue to be raised regarding a lack of community awareness about ‘My Aged Care’, difficulties accessing information and the overall complexity of the aged care system. These include particular difficulties experienced by Aboriginal and Torres Strait Islander peoples and other diverse communities.

77. The Consumer Directed Care model that has been a focus of aged care reform has sought to reflect the language of ‘positive ageing’, describing older people as engaged, active ‘consumers’ who make choices and negotiate about the care that they receive. However, this representation ignores the real issues some older people, especially those with limited family supports, may face in accessing information and navigating the aged care system. As noted in a recent hearing before the Royal Commission, the provision of information via a call centre and online does not meet the needs of many older people who are not computer literate or have a disability such as a hearing impairment.

78. The Commission also notes that the ‘My Aged Care’ website appears not to be compatible with the Web Content Accessibility Guidelines 2.1 which set the standard for web content that is accessible for people with disability.

79. Ongoing aged care reforms need to strive to make the system as streamlined and user-friendly as possible and be supplemented with accessible information and resources. These resources should seek to increase individual and family members’ understanding of the aged care system before a person requires care.
80. The Commission welcomes the Aged Care System Navigator Trials being conducted across all states and territories and which will be evaluated independently at the end of June 2020.\(^\text{60}\)

81. The Commission notes the importance of long-term funding commitments to ensure appropriate outreach and navigator services are available. The Commission also suggests that consideration be given to larger scale public education campaigns and digital literacy education to support people to understand, prepare for, and access further information about aged care services they may need in the future.

82. **Recommendation 5:** The Australian Government commit to ongoing funding of appropriate outreach and navigator services to ensure all older people and their families, including Aboriginal and Torres Strait Islander peoples and people from other diverse communities, can access information to assist them make informed decisions about aged care services.

83. **Recommendation 6:** the Australian Government improve the accessibility of the ‘My Aged Care’ website by ensuring it is compatible with the Web Content Accessibility Guidelines 2.1.

84. The issue of accessibility of aged care services for diverse communities is also discussed below.

### 4.3 Recognising and responding to diversity

**\(a\)  Human rights standards**

85. A human rights perspective requires recognition that older people are not a homogeneous group and that difference and diversity must be respected. It also requires that there is no discrimination in the provision of services, including in terms of access to services and how services are provided, and a focus on equity of access and outcomes with reference to those members of the community.

**\(b\)  Supporting diverse communities in accessing and using aged care services**

86. Challenges faced by particular sections of the population in accessing and using aged care services, including ‘people with special needs’ recognised in the Aged Care Act, have been identified in various research and reports.

87. For example, particular challenges relevant to Culturally and Linguistically Diverse (CALD) communities include: a lack of knowledge of available services; the complexity of the aged care system; different cultural views of
ageing and caring; language barriers; and a lack of culturally and linguistically appropriate aged care services.\textsuperscript{50}

88. Challenges for Lesbian, Gay, Bisexual, Trans and Gender Diverse and Intersex (LGBTI) communities include: a lack of awareness of the needs of LGBTI communities in the aged care sector; a mistrust of mainstream services related to histories of discrimination; generic responses that fail to meet the unique needs of LGBTI people and communities; a failure of services to recognise the individual’s ‘family of choice’; and other risks of abuse, including threats to ‘out’ a person or of family member denying the individual’s LGBTI status.\textsuperscript{51}

89. Challenges faced by care leavers, also known as ‘Forgotten Australians’, ‘Former Child Migrants’ or ‘Stolen Generations’ may include distrust and fear of aged care institutions and challenges relating to the loss of privacy and loss of control.\textsuperscript{52} Similarities between childhood and aged care settings including dependence on others for daily needs, disempowering structures and compromised autonomy can revive memories of childhood trauma and can place survivors at risk of re-traumatisation.\textsuperscript{53}

90. The 2017 report of the Aboriginal and Torres Strait Islander Ageing Advisory Group and the Australian Association of Gerontology highlighted the numerous challenges in assuring equity of access and quality outcomes in aged care for Aboriginal and Torres Strait Islander peoples.\textsuperscript{34} Due to multiple health and social disadvantages, Aboriginal and Torres Strait Islander peoples are more likely to develop serious medical conditions earlier in life, have a lower life expectancy than their non-Indigenous counterparts and are able to, and also more likely to, access aged care services earlier in life than the non-Indigenous population. Aboriginal and Torres Strait Islander peoples also have a higher need for dementia services and a younger onset of the disease.\textsuperscript{55}

91. Despite this higher level of need, Aboriginal and Torres Strait Islander peoples are underrepresented in aged care.\textsuperscript{56} The particular barriers Aboriginal and Torres Strait Islander peoples face in relation to aged care services include: difficulties navigating the aged care system and meeting the cost of quality care; a lack of culturally appropriate assessment tools and methods; and a lack of culturally appropriate and trauma informed services.\textsuperscript{57} Particular issues also arise for Aboriginal and Torres Strait Islander peoples living in more remote and regional areas where there is a general lack of services, including general health services such as doctors, dental services and dialysis, and limited access to technology, and in relation to cultural expectations relating to kinship structures, and sharing and reciprocity.\textsuperscript{58}

92. Strategies to address the abovementioned issues have been part of the ongoing reforms in the aged care sector. These reforms have included expansion of the National Aboriginal and Torres Strait Islander Flexible Aged
Care Program and the development and implementation of the Aged Care Diversity Framework.

93. The Commission notes that there is no specific action plan under the Aged Care Diversity Framework that addresses the unique barriers and challenges faced by older people with disability. Approximately 50% of men and 52% of women aged 65 years and older have a disability. For people 85 years and older, 78% of men and 80 percent of women have a disability.

94. The Commission considers an action plan for older people with disability would enhance the human rights approach being adopted under the Aged Care Diversity Framework. A dedicated action plan would assist aged care service providers and governments address the specific barriers and challenges experienced by older people with disability in the context of aged care and to ensure their rights are realised. The action plan should include important cross-cutting concepts such as accessibility, non-discrimination, reasonable adjustments and supports for people with disability, and should also incorporate the National Decision-Making Principles and Guidelines recommended by the ALRC which are discussed further below.

95. Governments and service providers should also understand the gendered nature of ageing and plan and evaluate policy and service delivery accordingly. For example, women’s experience of, and access to, quality and appropriate aged care services can differ significantly to the experience of men. As recognised by the Committee on the Elimination of Discrimination Against Women, the impact of gender inequality throughout a woman’s lifespan is exacerbated in old age and is often based on deep-rooted cultural and social norms. Women generally have a higher life expectancy than men, and are therefore more likely to need aged care support. The gender pay gap and less time spent in the workforce can lead to lower retirement incomes, financial insecurity and increasing rates of homelessness for older women, which can also detrimentally impact their access to quality aged care services. Women, along with a number of other vulnerable groups, also have heightened vulnerability to elder abuse.

96. In applying a human rights based approach to the planning, provision and monitoring of aged care services, the Australian Government should adopt gender-sensitive and age-specific policies and measures and collect, analyse and disseminate data disaggregated by age and sex, to ensure it has information on the situation of older women and their particular experiences of aged care services.
The Aged Care Diversity Framework

97. The Commission welcomes and endorses: the Aged Care Diversity Framework (Diversity Framework) that was introduced in 2017 and the recently released action plans for CALD and LGBTI communities, and Aboriginal and Torres Strait Islander peoples. The Commission also supports the human rights based approach evident in the Diversity Framework and the recognition of diversity within communities and issues of intersectionality.

98. The Commission notes the importance of sufficient resources being allocated to educate service users and providers about the Diversity Framework, associated action plans and underpinning human rights principles, as well as the connections between the Diversity Framework and the new Aged Care Quality Standards.

99. It is the Commission’s view that the following actions are essential in ensuring inclusive and non-discriminatory aged care for diverse communities:

- the involvement of service users and their communities in identifying and addressing barriers to accessing services
- the ongoing participation of service users and their communities in the planning, design and evaluation of services
- the use of culturally appropriate assessment tools and methods, to address assessment needs identified by the Australian Association of Gerontology and the Aboriginal and Torres Strait Islander Ageing Advisory Group
- strategies to ensure the recruitment and retention of a sufficient number of culturally competent and appropriately skilled age care workers; including strategies to increase Aboriginal and Torres Strait Islander representation in the aged care workforce
- mandatory training for the aged care workforce in cultural safety, anti-discrimination and trauma informed service delivery
- appropriate data collection to enable an evidence-based approach to policy and practice.

100. Recommendation 7: The Australian Government develop an action plan for older people with disability under the Aged Care Diversity Framework in consultation with people with disability.

101. Recommendation 8: The Australian Government commit sufficient resources to ensure that aged care service users and providers are educated about the Aged Care Diversity Framework and associated Action Plans, including the underpinning human rights principles and legal framework.
102. **Recommendation 9:** The Australian Government take action to ensure that service providers’ accreditation is contingent on their implementation of the Aged Care Diversity Framework and Action Plans, including requiring that reaccreditation considers the provider’s performance against outcomes in the Action Plans with a particular focus on:

- service user/community co-design in the planning, development, implementation and evaluation of services
- the use of culturally appropriate assessment methods and tools
- training for aged care workers in cultural safety, anti-discrimination and trauma informed service delivery
- the recruitment and retention of culturally competent and appropriately skilled aged care workers.

103. **Recommendation 10:** The Australian Government commit sufficient resources to ensure that aged care service providers utilise the available care leaver resources and training materials and aged care user resources are developed to support Care Leavers access aged care.

104. **Recommendation 11:** The Australian Government commit sufficient resources to support Indigenous community-controlled and mainstream organisations to deliver aged care services, including investment in training and employment opportunities for Indigenous aged care workers, and the collection of appropriate data to enable an evidence-based approach to Aboriginal and Torres Strait Islander aged care policy and practice.

105. **Recommendation 12:** The Australian Government commit sufficient funding for infrastructure and aged care services in rural and remote areas where access is currently lacking or inadequate, with a particular focus on the provision of services to Aboriginal and Torres Strait Islander peoples.

4.4 Respecting autonomy and decision-making capacity

(a) Human rights standards

106. The United Nations Principles for Older Persons states that older persons should: (i) have access to social and legal services to enhance their autonomy, protection and care; and (ii) be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility,
including the right to make decisions about their care and the quality of their lives.

(b) Supported decision-making

107. The Commission notes and supports the various references to a person's right to have control and make decisions about their care and other aspects of their life in the new single Charter of Aged Care and the associated Aged Care Quality Standards.

108. However, the Commission is concerned that the decision-making capacity of some older people receiving aged care may be limited or denied in certain situations. This is particularly a concern for people with dementia, people with intellectual disabilities and people with psychosocial disabilities.

109. Supported decision-making gives primacy to the person's autonomy and preferences and recognises that individuals should be empowered with information to make decisions, including the right to take risks and make mistakes. It encompasses a spectrum of informal and formal supports and support arrangements which provide assistance to obtain and understand information, evaluate possible alternatives and consequences of a decision, express and communicate a decision, and/or implement a decision. Examples include support networks, formally recognised support agreements, peer and self-support groups, support for self-advocacy, independent advocacy and advance directives.

110. In 2014, the Australian Law Reform Commission (ALRC) undertook a comprehensive inquiry to consider how Australia could give effect to the requirements around supported decision-making in the CRPD. The ALRC considered aged care as part of its inquiry. The ALRC recommended that all relevant Commonwealth, state and territory laws be reformed to be consistent with the following National Decision-Making Principles:

- **Principle 1: The equal right to make decisions**
  All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

- **Principle 2: Support**
  Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

- **Principle 3: Will, preferences and rights**
  The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.
• **Principle 4: Safeguards**

Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.  

111. The ALRC recommended a new Commonwealth decision-making model to encourage supported decision-making in line with the National Decision-Making Principles, based on the positions of ‘supporter’ and ‘representative’.

112. The ALRC also recommended that the Aged Care Act be amended to include provisions dealing with supporters and representatives consistent with the Commonwealth decision-making model. The ALRC repeated this recommendation as part of its inquiry into elder abuse.

113. **Recommendation 13:** The Royal Commission closely consider the ALRC’s recommendations in its Report No 124 Equality, Capacity and Disability in Commonwealth Laws as a means to provide clear statutory guidance for decision-making in the context of aged care.

114. **Recommendation 14:** The Aged Care Act 1997 (Cth) should be amended to include provisions dealing with supporters and representatives consistent with the Commonwealth decision-making model, as recommended by the Australian Law Reform Commission in its Report No 124 Equality, Capacity and Disability in Commonwealth Laws.

(c) **Enduring documents and advance care planning**

115. Enduring documents such as enduring powers of attorney, enduring guardianship or advance care directives are examples of ways in which older people can document their will and preferences should there be a time in the future when they are unable to directly communicate their will and preferences.

116. Powers of attorney are a traditional and legal way to appoint someone to look after your financial affairs in given circumstances. Other enduring documents, such as Enduring Powers of Attorney, enduring guardianship and advance care directives have evolved to differentiate the subject matter dealt with in the documents and the circumstances under which they take effect. Despite this, surveys indicate the use of powers of attorney and advance care directives is relatively low, which may partly be due to a lack of knowledge and/or an unwillingness for people to discuss issues related to illness or mortality.
117. It is important that older Australians are encouraged to have enduring documents in place as far in advance as possible—well before they require an attorney or need to access aged care. Early documenting of these arrangements may reduce any doubt about a person’s capacity and the validity of the documents at the time of signing.

118. While enduring documents can promote the autonomy and independence of older people, a lack of understanding about the scope and limitations of enduring documents, or the misuse of these documents, can limit or preclude decision-making capacity.

119. It is important that individuals, attorneys, aged care staff and other professionals are fully informed about the rights of older people to make decisions, and the scope and limitations of enduring documents and the role of attorneys. It is also important to increase community awareness about arrangements that they can put in place to limit or qualify the powers held by an attorney and when the attorney’s powers commence.

120. Training and education of the aged care workforce so they understand the scope and limitations of enduring documents is critical to uphold the rights of older Australians to make decisions and to give effect to their preferences where they have appointed an attorney.

121. Recommendation 15: The Australian Government invest in public awareness campaigns and associated programs to:

- increase knowledge about enduring documents and advance care planning by aged care workers, attorneys and the community generally, including the applicability and limitations of these documents and the relevant rights of older persons
- encourage the use of advance care planning preferably prior to otherwise or at the point of access to aged care.

122. Recommendation 16: The Australian Government fund and facilitate the development and implementation of training for the aged care workforce in relation to supported decision-making and the applicability, limitations and appropriate use of enduring documents.

4.5 Promoting independence and inclusion in the community

(a) Human rights standards

123. With reference to Article 12 of the ICESCR, States are required to take steps to ensure the progressive realisation of the right to the highest attainable level of mental and physical health through the provision of a sufficient quantity of services that are accessible to all who need them, including in
terms of geographical location, affordability and accessibility for people with disability.

124. The United Nations Principles for Older Persons provide that older persons should be able to: (i) reside at home for as long as possible; (ii) live in environments that are safe and adaptable to personal preferences and changing capabilities; and (iii) enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.

(b) In-home aged care

125. A 2015 Productivity Commission survey found that 83% of people aged 60 and over would prefer to remain in their own home as they age.  

126. There are a number of identified benefits for a person 'ageing in place' within their community. This approach enables the older person, including older people with disability, more easily to participate in the community and remain engaged with family, friends, neighbours, peers and others who can assist with care. It also facilitates the provision of support in a way that is culturally sensitive, leverages existing social networks, local skills and resources, and includes the person in the design and provision of the services.

127. Reforms in aged care have included an emphasis on supporting people to live independently at home and in the community for as long as possible. However, concerns continue to be raised by stakeholders about waiting times and high fees for in-home aged care packages. Issues regarding fees have included concerns about unreasonably high administration costs imposed by some providers and the costs of aged care packages in regional and remote areas where higher costs in providing care related to the higher costs of food, transport and staff training, means that fewer hours of actual care can be provided.

128. Department of Health data released in March 2019 shows that while people may be allocated an interim in-home aged care package within three to six months, they may have to wait much longer for a package at the appropriate level. For example, those with higher needs may wait up to two years for an appropriate package to match their assessed needs. As at 31 December 2018, 73,978 people were waiting for an in-home aged care package and had not been offered one and an additional 53,770 people had been offered a lower level interim package while they wait for a package at their approved level.

129. Concerns have been raised that a lack of suitable in-home aged care means that people are being inappropriately hospitalised or prematurely moved to residential care. Unsuitable in-home care can include care packages that that
do not adequately respond to the specific disability-related needs of older people with disability such as the need for particular equipment to assist independence.82

130. The Commission welcomes the Government’s announcements in January 2019 to further increase in-home aged care services, reduce the maximum contribution that people can be asked to make, and support rehabilitation and reablement programs.83

131. However, the Commission considers that more needs to be done to address the current unmet need for in-home services, and to explore options for expanding the in-home care system for people with higher level needs. For example, this may include expanding the availability of interim in-home support or home care packages or adding a further level of in-home care with funding commensurate with residential care, as previously recommended in the Legislated Review of Aged Care.84

132. **Recommendation 17:** The Australian Government ensure sufficient quantities and levels of home care packages are progressively made available to respond to identified needs.

(c) **Residential aged care**

133. Some older people may choose to live in residential care facilities or may be required to do so in situations where there is a lack of available and accessible in-home are and/or community supports.

134. Traditionally, aged care residential facilities have been modelled on acute medical care facilities in terms of both the physical layout and the manner in which care is provided. This means that they have been designed to facilitate the work practices of staff rather than facilitating the physical, psychological and social needs of residents.85

135. The lifestyle of people who live in aged care facilities is often characterised by a level of isolation and segmentation from the community; a lack of privacy and a lack of control about many aspect of their lives—such as with whom they live, who provides their care, what they can own and use, and their daily schedule including when and what they can eat and drink.86 As prefaced earlier, the Commission recognises that this statement is not relevant to all aged care providers.

136. A tool kit for a human rights based approach to long term residential aged care has been developed by the European Network of National Human Rights Institutions.87 This resource outlines the case for a human rights based approach for long term aged care and explains steps in embedding human rights within the culture of a facility. The resource also provides examples of
actions that can be taken to support human rights in residential aged care by ensuring dignity, privacy, participation and increased control for residents. Possible actions might include:

- changing the size and design of buildings to allow for smaller facilities, within communities that resemble a real home environment, including kitchen areas and appropriate individual privacy
- increasing staff to resident ratios
- including actions that support a person’s autonomy and independence in individual care plans
- increasing the flexibility of daily routines to accommodate individual preferences
- providing meal options
- involving residents in decisions about the services that are provided
- facilitating activities that enable residents to maintain connections with the community
- allowing residents to take trips away from the residential facility to stay with friends and family members.

137. Issues regarding the admission to, and treatment within, residential aged care facilities are discussed later in this submission.

4.6 Preventing ill-treatment

(a) Human rights standards

138. Article 9 of the ICCPR and Article 14 of the CRPD refer to the right to liberty and security and the right not to be arbitrarily or unlawfully deprived of liberty. The CRPD also states that the existence of a disability does not justify the deprivation of liberty.

139. Article 7 of the ICCPR and Article 15 of the CRPD refer to the right to freedom from torture, or cruel, inhuman or degrading treatment or punishment.

140. Article 16 of the CRPD states that people with disability have the right to be protected from all forms of exploitation, violence and abuse.

141. Article 25 of the CRPD states that persons with disabilities have the right to the enjoyment of the highest attainable standard of health, and health professionals are required to provide care of the same quality as they provide to others, including on the basis of free and informed consent.
142. The United Nations Principles for Older Persons include that older persons should be able to: (i) utilise appropriate levels of institutional care providing protection, rehabilitation, and social and mental stimulation in a humane and secure environment; and (ii) live in dignity and security and be free of exploitation and physical or mental abuse.

(b) Regulating the use of restrictive practices

143. The Commission is concerned that older people, and in particular older people with disability, such as dementia, are at heightened risk of being restrained inappropriately or confined in aged care facilities.

144. If an older person is placed in an aged care facility without their free and informed consent or is not free to leave the aged care facility, they are deprived of their liberty. Deprivation of liberty occurs not only where there is a physical barrier to exit such as a locked dementia ward, but also applies to practices where a person is physically or chemically restrained, or subjected to isolation or solitary confinement in an aged care facility or their own home.88

145. The Commission is aware of the decision-making tool developed by the Department of Health to support aged care providers deliver care in a restraint free environment. The Decision-Making Tool: Supporting a Restraint Free Environment in Residential Aged Care acknowledges that "[a] restraint free environment is seen as a basic human right for all residents living in a residential care setting."89 The Commission commends the acknowledgement of this human rights principle but notes that further work and regulatory mechanisms are needed to embed practices.90

146. Support for adequate regulation of restrictive practices is furthered by the fact that the use of restrictive practices may at times amount to elder abuse.91

147. The Commission supports recommendations made by the ALRC and in the Review of National Aged Care Regulatory Processes for the regulation of restrictive practices in residential aged care and the development of a national approach to the regulation of restrictive practices in aged care.92

148. These recommendations are intended to limit and carefully regulate the use of restrictive practices and provide a high standard and appropriate safeguards for the use of restrictive practices. Under the proposed arrangements, restrictive practices should be the least restrictive and only used as a last resort, to the extent necessary and proportionate to the risk of harm, with the approval of an authorised decision-maker, as prescribed by a person's behaviour support plan and when subject to regular review.93

149. The Commission notes amendments have been made to the Quality of Care Principles, which seek to address incidents of overuse of physical and
chemical restraints in aged care. However, the amendments do not reflect the full extent of the ALRC recommendations, with many key features absent in the amended Principles that the Commission views are required to establish high standards and appropriate safeguards for the use of restrictive practices in residential aged care.

150. **Recommendation 18:** The Australian Government update aged care legislation to regulate the use of restrictive practices in residential aged care in line with recommendations made by the ALRC and in the Review of National Aged Care Regulatory Processes. Any restrictive practice should be the least restrictive and used only:

- as a last resort, after alternative strategies have been considered, to prevent serious physical harm;
- to the extent necessary and proportionate to the risk of harm;
- with the approval of a person authorised by statute to make this decision;
- as prescribed by a person’s behaviour support plan; and
- when subject to regular review.

151. **Recommendation 19:** The Australian Government should consider further safeguards in relation to the use of restrictive practices in residential aged care, including:

- establishing an independent Senior Practitioner for aged care, to provide expert leadership on and oversight of the use of restrictive practices;
- requiring aged care providers to record and report the use of restrictive practices in residential aged care; and
- consistently regulating the use of restrictive practices in aged care and the National Disability Insurance Scheme.

152. **Recommendation 20:** The Australian Government and the Council of Australian Governments should develop a national approach to the regulation of restrictive practices aged care.

(c) **Responding to elder abuse**

153. Elder abuse is defined by the World Health Organization as

a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person.
154. Elder abuse can take many forms: physical, psychological/emotional, sexual, and financial, or intentional or unintentional neglect. It may be perpetrated by family, friends, or carers, including paid carers providing care in a person’s home or in a residential care facility.

155. While the prevalence data on elder abuse is lacking (the government has announced that a prevalence study is soon to be undertaken), it is currently estimated that between 2% and 14% of older Australians experience elder abuse each year.

156. With the extension and increase of aged care in the home, preventative and responsive strategies need to address the potential for increases in the incidence of elder abuse in the home and community.

157. Cohorts of older people at higher risk of elder abuse include those with functional dependency on others, cognitive impairment, disability, poor health, isolation and those belonging to a marginalised group.

158. Elder abuse is a key priority in Dr Patterson’s term as the current Australian Age Discrimination Commissioner. Dr Patterson has been working with many sectors to increase awareness of elder abuse and develop supports to respond to, and prevent, elder abuse. Dr Patterson has also met with Attorneys-General across jurisdictions to encourage and contribute to the implementation of the recommendations in the ALRC’s report Elder Abuse—A National Legal Response.

159. The ALRC report made 43 recommendations, 14 of which related to aged care. These recommendations included among others, a national prevalence study of elder abuse to inform policy development; the harmonisation of enduring documents and a national register to reduce the potential for such documents to be misused; the establishment of a serious incident response scheme in aged care legislation; and reforms relating to the suitability of people working in aged care. The Commission understands that work is underway to respond to many of these recommendations and the Commission encourages their ongoing implementation.

160. The ALRC inquiry report also recommended a national plan to respond to elder abuse. The ‘National Plan to Respond to the Abuse of Older Australians’, launched by the Australian Government in March 2019, represents a significant step in understanding elder abuse and strengthening safeguards for older Australians. The Commission is of the opinion that in progressing the National Plan there needs to be a focus on consultations with diverse communities to understand how elder abuse may manifest in those communities and how contributing factors may be addressed. For example, the ALRC report referred to research which indicated that substantially more
work is required to understand and conceptualise elder abuse in Aboriginal and Torres Strait communities.\textsuperscript{101}

161. The ALRC report also noted the important role that health professionals can play in recognising and responding to elder abuse, and identified training as a means to assist health professionals in this regard.\textsuperscript{102} The ALRC stated its view that additional training for health professionals should be an important initiative under a National Plan.

162. The ALRC report on elder abuse outlines barriers for health (and other) professionals to identify and respond to elder abuse, including difficulty detecting elder abuse, limited knowledge of and access to appropriate referral pathways, and concerns that responding to elder abuse might result in a breach of privacy laws.

163. Elder abuse education and training for health professionals would assist them to identify and appropriately respond to elder abuse in community settings. Education and training should include clear guidance on the relevant privacy legislation and exemptions for disclosure, noting that legislation varies across states and can differ between public and private healthcare settings and could benefit from harmonisation.

164. Similar education modules to support the aged care workforce to identify and appropriately respond to elder abuse should also be a core component of training programs (including for incidents that do not require reporting under the Aged Care Act).

165. Recommendation 21: The Australian Government ensure that the implementation of the National Plan to Respond to the Abuse of Older Australians:

- takes into account the needs of diverse communities, particularly as it relates to understanding and preventing elder abuse in those communities
- includes resources for further training for the aged care workforce in relation to identifying and responding to elder abuse and understanding privacy legislation and exemptions for reporting across aged care and health settings.

5 Appendix A: Hyperlinks to international human rights treaties and other instruments
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<th>Link</th>
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<tr>
<td><a href="http://www.ohchr.org/en/professionalinterest/pages/cat.aspx">www.ohchr.org/en/professionalinterest/pages/cat.aspx</a></td>
<td>Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment</td>
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<tr>
<td>undocs.org/A/HRC/37/56</td>
<td>Report of the Special Rapporteur on the Rights of Persons with Disabilities</td>
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<tr>
<td><a href="http://www.ohchr.org/EN/ProfessionalInterest/Pages/OlderPersons.aspx">www.ohchr.org/EN/ProfessionalInterest/Pages/OlderPersons.aspx</a></td>
<td>United Nations Principles for Older Persons</td>
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5. Aged Care Act 1997 (Cth); *User Rights Principles 2014*.
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A Human Rights Perspective on Aged Care, 17 July 2019

23 Race Discrimination Act 1975 (Cth).
24 Sex Discrimination Act 1984 (Cth).
26 Age Discrimination Act 1999 (Cth).
30 The principles of legality, legitimacy and proportionality refer to the approach that must be taken in restricting any qualified human right. That is, there must be a clear legal basis and a legitimate aim for the restriction of an individual’s right and the restriction must be the minimum necessary to achieve the legitimate aim. The principle of progressive realisation means that a State’s compliance with the obligation to fulfil some rights, for example the right to health, is assessed in the light of available resources and progressive realisation of the right is allowed over time. However, States are required to ensure that there is non-retrogression of rights—that is, that there is no action that deprives people of rights they previously enjoyed.


For information on the EveryAge Counts campaign, see <https://www.everyagecounts.org.au/>.


See Web Content Accessibility Guidelines (WCAG) 2.1 at https://www.w3.org/TR/WCAG21/.


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35 Australian Association of Gerontology and Aboriginal and Torres Strait Islander Ageing Advisory Group, Assuring Equity of Access and Quality Outcomes for Older Aboriginal and Torres Strait Islander Peoples: What Needs to Be Done (7 November 2017) 8.
36 Australian Association of Gerontology and Aboriginal and Torres Strait Islander Ageing Advisory Group, Assuring Equity of Access and Quality Outcomes for Older Aboriginal and Torres Strait Islander Peoples: What Needs to Be Done (7 November 2017) 7.
37 Australian Association of Gerontology and Aboriginal and Torres Strait Islander Ageing Advisory Group, Assuring Equity of Access and Quality Outcomes for Older Aboriginal and Torres Strait Islander Peoples: What Needs to Be Done (7 November 2017) 7.
40 United Nations Committee on the Elimination of Discrimination Against Women, General Comment No. 27 on older women and protection of their human rights, 42nd sess. CEDAW/C/GC/27 (16 December 2010).
41 Australian Bureau of Statistics, Australian Demographic Statistics, ABS cat. no. 3101.0 (June 2016).
45 Australian Association of Gerontology and Aboriginal and Torres Strait Islander Ageing Advisory Group, Assuring Equity of Access and Quality Outcomes for Older Aboriginal and Torres Strait Islander Peoples: What Needs to Be Done (7 November 2017) 19.


Committee on the Rights of Persons with Disabilities, General Comment No.5 (2017) on Living Independently and Being Included in the Community, above n 71, 92.


European Network of National Human Rights Institutions, Respect My Rights: An ENNHRI Toolkit on Applying a Human Rights-Based Approach to Long-Term Care for Older Persons (October 2017).


The Commission notes that there are divergent views on whether the use of restrictive practices in aged care is justified in some circumstances. As outlined in the Royal Commission's Background Paper 4, there is an emerging body of evidence on strategies to negate the need for restraint by addressing the underlying causes of challenging behaviour. Reducing and eliminating the use of restrictive practices on older people with disability is also consistent with the CRPD, in particular to the right to liberty and security of person (Article 14), freedom from torture, cruel, inhuman or degrading treatment or punishment (Article 15) and freedom from exploitation, violence and abuse (Article 16).


Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019 (Cth).


