

AUSTRALIAN LAW DURING COVID-19: MEETING THE NEEDS OF OLDER AUSTRALIANS?

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This article focuses on the interests of older Australians during the COVID-19 pandemic. It analyses aspects of Australian law by considering the implications of the pandemic for older Australians in order to evaluate the adequacy of existing laws in meeting their needs. We begin by analysing two important challenges. First, although we focus on the interests of older Australians, defining what is meant by ‘older’ can be challenging. Second, although we adopt a rights-based approach to our analysis, we recognise that there is no convention on the rights of older persons that clearly articulates the rights of older persons. In the remaining parts of the article, we examine different areas of law (antidiscrimination laws, responses to social isolation, and participation in medical research of individuals where capacity has been lost or is diminishing) as examples through which to analyse the impact of the pandemic on older Australians and to provide insights into the adequacy of current Australian laws.

I INTRODUCTION

‘We’re all in this together’ has been an often-used phrase during the COVID-19 pandemic. Certainly, the pandemic, and its consequences for health and economic well-being, has presented challenges for all members of the Australian community. However, the pandemic has also exposed the potential for diverse impacts upon different groups within the community, and the need for tailored responses to address these impacts.¹ COVID-19 has provided a crucible in which

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¹ Nigel Stobbs, Belinda Bennett and Ian Freckelton, ‘Compassion, Law and COVID-19’ (2020) 27(4) *Journal of Law and Medicine* 865.

Australian laws and policies on a range of issues have been tested. It has highlighted the tensions that can exist between protecting individuals and ensuring their ability to participate in the community, and between aspirational policies and the challenges of implementing them in practice.

In this article we focus on the interests of older Australians during the pandemic, analysing aspects of Australian law in the context of the particular ways that the pandemic has disrupted the lives of older members of the Australian community. As we argue below, a rights-based approach, which recognises that ageing occurs throughout the whole of life,² and that takes the differing abilities and needs of older persons as a starting point, can help to ensure that legal and policy responses to COVID-19 fully meet the needs of older members of the Australian community. This focus on the pandemic's impact on older persons is particularly important given that COVID-19 has been associated with an increased risk of serious outcomes and increased mortality for older persons.³ Social distancing measures have also had a significant impact on older people, through social isolation at home or through restrictions on visits to aged care facilities. Furthermore, for some older persons, the pandemic-related social isolation may be exacerbated by a lack of access to technologies such as the internet, a lack of digital literacy, or through a choice not to engage with those technologies.⁴ However, one consequence of the perceived vulnerability of older people to COVID-19 is a risk that they will be characterised as needing care, a view that risks ignoring their heterogeneous abilities and needs and instead perpetuates harmful ageist stereotypes.⁵ The World Health Organization has noted that '[a]geism refers to the stereotypes, prejudice and discrimination directed towards others or oneself based on age.'⁶

² Bridget Lewis, Kelly Purser and Kirsty Mackie, *The Human Rights of Older Persons: A Human Rights-Based Approach to Elder Law* (Springer, 2020) 9; World Health Organization, *Global Strategy and Action Plan on Ageing and Health* (Report, 2017) 21 <<https://www.who.int/publications/i/item/9789241513500>>; World Health Organization, *World Report on Ageing and Health* (Report, 2015) 14 <<https://www.who.int/publications/i/item/9789241565042>>. The World Health Organization has noted '[a]geing is a natural and lifelong process that, while universal, is not uniform': World Health Organization, *Global Report on Ageism* (Report, 2021) xix ('Ageism') <<https://www.who.int/publications/i/item/9789240016866>>.

³ Australian Government Department of Health and Aged Care, 'Coronavirus (COVID-19) Advice for Older People and Carers' (Web Page, 29 March 2022) <<https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/advice-for-people-at-risk-of-coronavirus-covid-19/coronavirus-covid-19-advice-for-older-people>> ('COVID-19 Advice for Older People and Carers').

⁴ For discussion, see Part V.

⁵ Hans-Joerg Ehni and Hans-Werner Wahl, 'Six Propositions against Ageism in the COVID-19 Pandemic' (2020) 32(4-5) *Journal of Aging & Social Policy* 515; Lewis, Purser and Mackie (n 2) chs 1, 4, esp 30. The United Nations has noted that '[e]fforts to protect older persons should not overlook the many variations within this category, their incredible resilience and positivity, and the multiple roles they have in society, including as caregivers, volunteers and community leaders. We must see the full diversity within the older persons category': United Nations, *The Impact of COVID-19 on Older Persons* (Policy Brief, May 2020) 2 <<https://unsdg.un.org/resources/policy-brief-impact-covid-19-older-persons>>.

⁶ World Health Organization, *Ageism* (n 2) xix.

By focussing on the impact of the pandemic on older Australians we aim to evaluate the adequacy of existing legal and regulatory frameworks and responses in meeting the needs of this section of the Australian community. However, a focus on older people also presents two main challenges. First is the challenge of defining the group of ‘older people.’ Unlike ‘adulthood’, which is achieved on reaching a specific age,⁷ ‘older age’ lacks this specificity, with the potential for a definition based on a fixed age failing to appreciate the range of experiences — from healthy and active to those needing more support — constituting older age.⁸ From a regulatory point of view, this lack of definitional clarity can present difficulties in defining the group to whom programs and support should be directed. As Mégret has noted, ‘the first challenge of conceptualising the rights of the old is the difficulty of defining them as a distinct population’.⁹ In Part II we analyse the challenges of defining ‘older’ while simultaneously recognising the importance of not homogenising the ageing experience.

A further aspect of the definitional challenge relates to whether the focus of analysis is on older people living in residential aged care, or whether it is on older people who live at home. In analysing the issues that may arise in responding to COVID-19, we focus our analysis in this article on the rights and interests of older Australians living in the community, rather than on the issues that may arise in relation to residential aged care. This is not to suggest that residential aged care is unimportant. Indeed, we recognise the challenges that COVID-19 has posed for residential aged care worldwide.¹⁰ However, in choosing to focus on community-based ageing we also recognise that the majority of older Australians continue to live in the community. According to figures from the Australian Institute of Health and Welfare, in 2017–18 aged care services were received by more than 1.2 million people, of whom 7 per cent were living in residential aged care.¹¹ Twenty-two per cent of Australians aged over 65 years were receiving some home-based support or care, and 71 per cent were living at home without government-

⁷ In Australia, the age of majority is 18 years, although decision-making capacity may be recognised at a younger age. For example, ‘mature minors’ may have capacity to make some medical decisions for themselves without parental consent: see *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112, adopted by the High Court in *Secretary, Department of Health and Community Services v JWB and SMB (Marion’s Case)* (1992) 175 CLR 218; *Consent to Medical Treatment and Palliative Care Act 1995* (SA) s 12.

⁸ For discussion, see Part II.

⁹ Frédéric Mégret, ‘The Human Rights of Older Persons: A Growing Challenge’ (2011) 11(1) *Human Rights Law Review* 37, 42.

¹⁰ See, eg, *Royal Commission into Aged Care Quality and Safety: Care, Dignity and Respect* (Final Report, March 2021) vol 1 (‘*Final Report Vol 1*’); *Royal Commission into Aged Care Quality and Safety: Aged Care and COVID-19* (Report, October 2021); William Gardner, David States and Nicholas Bagley, ‘The Coronavirus and the Risks to the Elderly in Long-Term Care’ (2020) 32(4–5) *Journal of Aging & Social Policy* 310; David C Grabowski and Vincent Mor, ‘Nursing Home Care in Crisis in the Wake of COVID-19’ (2020) 324(1) *JAMA* 23.

¹¹ Australian Institute of Health and Welfare, *Australia’s Welfare Snapshots* (Report, 2019) 175 <<https://www.aihw.gov.au/getmedia/82f724a3-c82a-412f-bb7b-5424fcfeta4e/Australias-welfare-snapshots-2019.pdf.aspx>>.

supported aged care services.¹² Given that most older Australians are still living in the community rather than in residential aged care, it is both timely and important to consider the impact of the pandemic on their rights and interests.

The second challenge that arises in analysing the legal and regulatory responses to COVID-19 in terms of their impact on older Australians is in choosing the lens for the analysis. In this article we have chosen to use a rights-based approach through which to analyse the issues related to COVID-19 and older Australians. In adopting this approach, we seek to position the rights and interests of older people at the centre of our analysis. We believe that such an approach is important in order to be able to assess the impact of the pandemic, and the adequacy of legal and regulatory responses to it. In adopting a rights-based approach we recognise that there is, to date, no international convention on the rights of older persons ('CROP') that clearly articulates those rights. Australian human rights law is also not uniform, and although there is federal antidiscrimination legislation, only Victoria, Queensland and the ACT have human rights legislation.¹³ In Part III, we analyse the literature around human rights law and older persons, and the growing recognition of the need to see older persons not only as passive beneficiaries of care, but as active holders of rights.¹⁴ We also analyse the current patchwork of Australian human rights law and consider its relevance and application to the public health emergency posed by the COVID-19 pandemic.

Having analysed the definitional challenges (Part II) and the growing recognition of the rights of older people (Part III), the remaining parts of the article focus on areas of law as examples through which to illustrate the impact of the pandemic on older Australians, and through which to analyse the adequacy of legal and regulatory responses to it. In Part IV, we analyse the relevance of discrimination law for older people's access to goods and services. Although domestic discrimination law largely reflects the values and principles of international human rights, as our discussion in this Part shows, there are some challenges relating to its practical application, particularly in the complex situation posed by a pandemic. Part V considers the challenges posed by social isolation for older people during the pandemic and some of the legal responses to it. We also consider the potential role for technology as a tool for overcoming social isolation and the challenges this may present for older members of the community. In this Part, we also consider the role of technology and changes to Australian laws that have been made during the pandemic to support members of the Australian community in managing their legal affairs during the pandemic,

¹² Ibid.

¹³ *Charter of Human Rights and Responsibilities Act 2006* (Vic); *Human Rights Act 2019* (Qld); *Human Rights Act 2004* (ACT).

¹⁴ For example, the *Royal Commission into Aged Care Quality and Safety* has recommended a rights-based approach form the basis of new aged care laws in Australia: see *Final Report Vol 1* (n 10) 14, 79. See also Australian Commission on Safety and Quality in Health Care, *National Safety and Quality Health Standards* (Australian Commission on Safety and Quality in Health Care, 2nd ed, 2017) 18.

using valid will-making and estate planning as an example to illustrate these issues.

As a society, developing knowledge of COVID-19 and of possible treatments will be important aspects of responding to the pandemic. In this context, and given the increased risk of severe disease for older people with COVID-19, it will be important to ensure that older persons are included in research. In Part VI, we analyse the current law in this area and the challenges that may arise where capacity is lost or is diminishing. By illustrating the impact of the pandemic and legal responses to it in quite separate areas (including discrimination law, will-making and estate planning, and medical research) we aim to show the range of ways in which older people have been affected by the pandemic, and to provide insights into the adequacy of Australian laws to meet their needs in these areas. We conclude, in Part VII, that there is an opportunity to reflect upon the challenges and tensions highlighted by COVID-19, to ensure that the future development of Australian law takes into account the needs of older Australians.

II AGEING: DEFINITIONS AND DATA

COVID-19 is especially dangerous for people over the age of 70 years or for those over the age of 65 years with chronic health conditions, as they have an increased risk of severe disease and mortality.¹⁵ Outside the context of COVID-19, the chronologically-based definition of 'older' adopted more generally can vary anywhere from 50 years and over (for Aboriginal and Torres Strait Islander peoples), to 60,¹⁶ or to 65 years and older.¹⁷ Defining what we mean by 'older' is therefore necessary. It enables accurate data collection in relation to an identified cohort, which can then be used to inform appropriate policy responses, including in the legal and health fields.¹⁸ Disaggregation of data, including by age, is an important aspect of data collection and analysis, and can help to monitor healthy ageing across the life course.¹⁹ However, the very fact that ageing is a process increasingly recognised as occurring throughout the whole of the life course, can make separating out a category of 'older' persons problematic. A person can be 90 and in better health than a chronologically much younger person, and thus

¹⁵ Australian Government Department of Health and Aged Care, 'COVID-19 Advice for Older People and Carers' (n 3).

¹⁶ United Nations Department of Economic and Social Affairs, Population Division, *World Population Ageing 2015: Highlights*, ST/ESA/SER.A/368 (2015) 4 ('*World Population Ageing 2015: Highlights*').

¹⁷ See, eg, Australian Institute of Health and Welfare, 'Older People: Overview' (Web Page, 30 September 2021) <<http://www.aihw.gov.au/ageing/>>.

¹⁸ In its policy brief, the United Nations noted that '[t]he unprecedented nature of the crisis has highlighted the invisibility of older persons in public data analysis. Innovative approaches, backed by evidence and data disaggregated by age, but also sex and relevant socio-economic characteristics, are essential to effective public policy making that is inclusive of older persons': United Nations (n 5) 4.

¹⁹ World Health Organization, *Global Strategy and Action Plan on Ageing and Health* (n 2) 21.

determining the notion of ‘older’ by number risks amplifying ageist stereotypes that accompany becoming ‘old’.²⁰ Recognising that there are differences between older people, the category of ‘old’ is sometimes divided into the ‘young old’, the ‘old old’ and the ‘oldest old’.²¹

The social discourses around ageing are complex. For example, as Fineman points out, older persons experience both positive and negative assumptions linked with age-related social security payments. On the negative side, older persons have often been seen as in ‘need’ of social security payments due to the unlikelihood of their employment and therefore probability of their poverty.²² On the positive side, older persons have been seen as deserving of welfare payments, often predicated upon the contributions they made while in paid employment.²³ These views have been challenged in more recent years by the growing number of older persons continuing to work in paid employment after traditional retirement age, and by concerns over the impact of the ageing of society on future welfare budgets.²⁴ Furthermore, in a society that values autonomy and self-sufficiency, the vulnerability and dependency assumed to exist when a person becomes ‘older’ can be stigmatising.²⁵ Fineman has argued, however, that there is an ‘inevitable’ dependence that is universal and that arises from being human.²⁶ Fineman proposes ‘[t]he idea of a universal “vulnerable subject” to replace the universal liberal subject’, arguing that ‘[e]very actual adult human being, no matter how strong and independent he or she may seem, is both presently and has been in the past reliant on others and on social institutions.’²⁷ The language used to describe older persons is also important, with some terms such as ‘elderly’ seen as ‘invariably pejorative: who wants to buy an elderly car or travel in an elderly aeroplane?’²⁸ However, there may be cultural dimensions to these understandings.

²⁰ See, eg, SunLife, *Ageist Britain?* (Report, 2019) <<https://www.sunlife.co.uk/siteassets/documents/ageist-report-2019.pdf>>; Amelia Hill, ‘Over A Third of Britons Admit Ageist Behaviour in New Study’, *The Guardian* (online, 19 August 2019) <<https://www.theguardian.com/society/2019/aug/19/over-a-third-of-britons-admit-ageist-behaviour-in-new-study>>; Lewis, Purser and Mackie (n 2) ch 1; Kelly Purser and Karen Sullivan, ‘Capacity Assessment and Estate Planning: The Therapeutic Importance of the Individual’ (2019) 64 *International Journal of Law and Psychiatry* 88, 92; Australian Law Reform Commission, *Elder Abuse: A National Legal Response* (Report No 131, May 2017) 32, 34; World Health Organization, *World Report on Ageing and Health* (n 2) 7–8, 10–11.

²¹ See, eg, Adam J Garfein and A Regula Herzog, ‘Robust Aging among the Young-Old, Old-Old, and Oldest-Old’ (1995) 50B(2) *Journals of Gerontology: Social Sciences* S77.

²² Martha Albertson Fineman, ‘“Elderly” as Vulnerable: Rethinking the Nature of Individual and Societal Responsibility’ (2012) 20 *Elder Law Journal* 71, 75–6.

²³ *Ibid.*

²⁴ *Ibid* 78–9. Fineman argues that ‘[t]he image of the elderly has devolved from those who have contributed, and thus are deserving, to those who are greedy and destructive’: at 79.

²⁵ *Ibid* 87.

²⁶ *Ibid* 86.

²⁷ *Ibid* 88.

²⁸ Marianne Falconer and Desmond O’Neill, ‘Out with “the Old,” Elderly, and Aged’ (2007) 334(7588) *British Medical Journal* 316, 316. We are grateful to Eliana Close and Tina Cockburn for bringing this article to our attention. See also World Health Organization, *Ageism* (n 2) xx: ‘[w]ords such as elderly, old or senior elicit stereotypes of older people as universally frail and dependent, and they are frequently used in a pejorative sense.’

In Aboriginal and Torres Strait Islander communities, Elders play an important role and are recognised and valued for their wisdom and experience.²⁹

These definitional issues and social discourses are particularly important given the impact of the COVID-19 pandemic on older members of the community. This includes the impact of social isolation on those members.³⁰ Commentators have expressed concern over ageist discourses during COVID-19.³¹ COVID-19 has been portrayed as a problem for older adults, with older adults characterised as ‘vulnerable’.³² However, ‘[y]ounger adults are not immune to this virus, and they share responsibility for its spread.’³³ Furthermore, although older people may have an increased physical risk of severe disease from COVID-19, it has been argued that their life experience may give them important psychosocial strength for coping with the uncertainties created by the pandemic.³⁴

The challenges of ageism have been effectively and relentlessly highlighted by COVID-19 as evidenced by, for example, the responses adopted in certain countries in relation to the rationing of care or finite resources — often a decision (largely) predicated upon the age of the person.³⁵ Gender and race are also indicators of COVID-19 related risk, as are pre-existing compromised immune systems.³⁶ It has been argued that it would be intolerable to use any of these factors as determinants for resource rationing, as decisions about treatment must be made on a case-by-case basis having regard to all relevant factors.³⁷ This again highlights the pervasiveness of ageism throughout modern society. It also serves to highlight the lack of dedicated international protection for the rights of older persons, which will be the focus of the next Part.

III AGEING AND HUMAN RIGHTS

The COVID-19 pandemic has presented a complex picture of risk for older people, comprising the physical risk of severe disease, the risks of social isolation, and the

²⁹ Lucy Busija et al, ‘The Role of Elders in the Wellbeing of a Contemporary Australian Indigenous Community’ (2020) 60(3) *Gerontologist* 513.

³⁰ Joanne Brooke and Debra Jackson, ‘Older People and COVID-19: Isolation, Risk and Ageism’ (2020) 29(13–14) *Journal of Clinical Nursing* 2044.

³¹ Ehni and Wahl (n 5); World Health Organization *Ageism* (n 2) 24–6; Sarah Fraser et al, ‘Ageism and COVID-19: What Does Our Society’s Reponse Say about Us?’ (2020) 49(5) *Age and Ageing* 692.

³² Fraser et al (n 31) 693. See also Ehni and Wahl (n 5) 517–8.

³³ Fraser et al (n 31) 693–4.

³⁴ Majse Lind, Susan Bluck, and Dan P McAdams, ‘More Vulnerable? The Life Story Approach Highlights Older People’s Potential for Strength during the Pandemic’ (2021) 76(2) *Journals of Gerontology: Psychological Sciences* e45.

³⁵ Diana Popescu and Alexandru Marcoci, ‘Coronavirus: Allocating ICU Beds and Ventilators Based on Age is Discriminatory’, *The Conversation* (online, 22 April 2020) <<https://theconversation.com/coronavirus-allocating-icu-beds-and-ventilators-based-on-age-is-discriminatory-136459>>. See also Ehni and Wahl (n 5) 516–17.

³⁶ Popescu and Marcoci (n 35); Australian Government Department of Health and Aged Care, ‘COVID-19 Advice for Older People and Carers’ (n 3).

³⁷ Popescu and Marcoci (n 35).

risks of ageism. While this complex picture raises important issues about the rights of older people in the context of the pandemic, there are significant gaps in the contemporary legal frameworks through which those rights might be recognised. As noted earlier, there is no dedicated CROP. This is despite considerable advocacy by non-government organisations and scholars, and ongoing thematic work within the United Nations human rights network,³⁸ although the COVID-19 pandemic may provide an impetus for such a convention.³⁹ It has been argued by some that existing human rights laws are comprehensive enough to protect the rights of older persons, and that enacting a dedicated treaty for older persons would have the effect of singling them out or casting them as somehow ‘other’ in the eyes of international human rights law.⁴⁰ However, an analysis of existing human rights law shows that there are gaps that could be addressed through the enactment of a CROP. For example, existing laws do not recognise the particular ways in which older persons experience human rights violations flowing from ageism and elder abuse,⁴¹ an issue spotlighted by responses to COVID-19 worldwide.

Rather than identifying older persons as having different entitlements from other people, a dedicated convention would instead emphasise that ‘older’ people are entitled to the very same rights as everyone else, while acknowledging the specific ways that human rights may need to be addressed as we age. Further, much as the *Convention on the Rights of Persons with Disabilities* (‘CRPD’)⁴² did for persons with disability, a CROP would give flesh to the bones of the generalised human rights treaties and articulate the nature of states’ obligations in relation to older persons.⁴³ However, as we argue below, in the absence of a dedicated CROP, there are still important human rights protections that are binding in Australia and which should inform our responses to COVID-19. While these protections will have general application, applying to all members of the community, it is this universality of rights that is important to addressing ageism in the context of the COVID-19 pandemic where older people are particularly at

³⁸ Mégret (n 9); Lewis, Purser and Mackie (n 2) 58–60; Israel Doron and Itai Apter, ‘The Debate around the Need for an International Convention on the Rights of Older Persons’ (2010) 50(5) *Gerontologist* 586; Marthe Fredvang and Simon Biggs, ‘The Rights of Older Persons: Protection and Gaps under Human Rights Law’ (Social Policy Working Paper No 16, Centre for Public Policy and the Brotherhood of St Laurence, August 2012); Benjamin Mason Meier, Victoria Matus and Maximilian Seunik, ‘COVID-19 Raises a Health and Human Rights Imperative to Advance a UN Convention on the Rights of Older Persons’ (2021) 6(11) *BMJ Global Health* e007710:1, 2–4; Rosa Kornfeld-Matte, *Report of the Independent Expert on the Enjoyment of All Human Rights by Older Persons*, 39th sess, Agenda Item 3, UN Doc A/HRC/39/50 (10 July 2018); *Report of the Open-Ended Working Group on Ageing on its Eighth Working Session*, UN Doc A/AC.278/2017/2 (28 July 2017).

³⁹ Meier, Matus and Seunik (n 38).

⁴⁰ Baroness Sally Greengross, ‘Human Rights and Ageing: Are We Doing What’s Right?’ (Speech, Queensland Parliament House, 15 November 2019); Lewis, Purser and Mackie (n 2) 60–1.

⁴¹ Mégret (n 9) 44, 60–2; Lewis, Purser and Mackie (n 2) 60–1.

⁴² *Convention on the Rights of Persons with Disabilities*, opened for signature 13 December 2006, 2515 UNTS 3 (entered into force 3 May 2008) (‘CRPD’).

⁴³ Mégret (n 9) 65–6 For a more detailed analysis of existing human rights law, see Lewis, Purser and Mackie (n 2) ch 2.

risk of severe disease and have been particularly impacted by the need for social distancing.

A *International Human Rights Law*

There is a substantial framework of international and regional treaties that protect human rights, and the fundamental notion that human rights are universal and inalienable means that these protections must be extended to older persons.⁴⁴ For example, the *Universal Declaration of Human Rights* states that '[a]ll human beings are born free and equal in dignity and rights',⁴⁵ and that '[e]veryone is entitled to all the rights and freedoms set forth in this Declaration'.⁴⁶ While older people are entitled to the full complement of interdependent and indivisible human rights, certain rights have a more obvious importance for the experiences of older persons during a global pandemic and are worth noting here. Human rights principles, such as those articulated in the *International Covenant on Civil and Political Rights* ('ICCPR')⁴⁷ and the *International Covenant on Economic, Social and Cultural Rights* ('ICESCR')⁴⁸ thus provide a framework for assessing what level of restrictions is appropriate in response to a pandemic such as COVID-19.

The ICCPR guarantees certain non-derogable rights, including: the rights to freedom from cruel, inhuman or degrading treatment; freedom from slavery and servitude; equal recognition before the law; and freedom of thought, conscience and religion.⁴⁹ These rights cannot be limited, even in a time of emergency. Another of these non-derogable rights is the right to life, which includes protection from circumstances that represent a threat to life,⁵⁰ such as a global pandemic on the scale of COVID-19. However, the ICCPR also provides that some rights can be restricted in an emergency through proportionate legal responses designed to give effect to a legitimate outcome.⁵¹ Importantly, however, any

⁴⁴ World Health Organization, *World Report on Ageing and Health* (n 2) 5.

⁴⁵ *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, UN Doc A/810 (10 December 1948) art 1 ('*Universal Declaration of Human Rights*').

⁴⁶ *Ibid* art 2.

⁴⁷ *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976) art 4(2) ('ICCPR'). For discussion, see Lawrence O Gostin, *Global Health Law* (Harvard University Press, 2014) 256.

⁴⁸ *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976) ('ICESCR').

⁴⁹ ICCPR (n 47) art 4(2).

⁵⁰ ICCPR (n 47) art 6; United Nations Human Rights Committee, *General Comment No 36: Article 6: Right to Life*, 124th sess, UN Doc CCPR/C/GC/36 (3 September 2019).

⁵¹ For example, ICCPR (n 47) art 4(1) states: '[i]n time of public emergency which threatens the life of the nation and the existence of which is officially proclaimed, the States Parties to the present Covenant may take measures derogating from their obligations under the present Covenant to the extent strictly required by the exigencies of the situation, provided that such measures are not

limitations placed on human rights must be the least restrictive option available in the circumstances, and are only lawful as long as the need remains justifiable.⁵² While restrictions on movement or interferences with privacy could therefore be justified in the name of curbing the spread of the pandemic, these measures must be lifted once the need for them is no longer apparent.

The *ICESCR* protects rights to an adequate standard of living and to the highest attainable standard of health (including access to health care services).⁵³ The *ICESCR* requires States Parties 'to take steps ... with a view to achieving progressively the full realization of the rights recognized in the [*ICESCR*]'.⁵⁴ Under the *ICESCR*, limitations are permitted 'as are determined by law only in so far as this may be compatible with the nature of these rights and solely for the purpose of promoting the general welfare in a democratic society'.⁵⁵ Again, the rights articulated in the *ICESCR* are critical to ensuring appropriate conditions of care within aged and health care contexts, and this extends both to specific medical responses to the pandemic and consequent impacts for healthcare services more broadly. In the early days of the COVID-19 pandemic, the United Nations special rapporteurs on human rights confirmed that:

Everyone, without exception, has the right to life-saving interventions and this responsibility lies with the government. The scarcity of resources or the use of public or private insurance schemes should never be a justification to discriminate against certain groups of patients ... Everybody has the right to health.⁵⁶

Also relevant to the COVID-19 pandemic is the recognition in international human rights law of the finite nature of resources, and that choices to allocate limited health care services to some patients over others may be necessary. However, these choices cannot be made on discriminatory grounds, and a person's age alone would not be sufficient reason to deny them access to an ICU bed or ventilator.⁵⁷ The *ICESCR* also protects rights to employment and social security,

inconsistent with their other obligations under international law and do not involve discrimination solely on the ground of race, colour, sex, language, religion or social origin.' For discussion, see Gostin (n 47) 256. For an analysis of these issues from a European perspective, see Audrey Lebre, 'COVID-19 Pandemic and Derogation to Human Rights' (2020) 7(1) *Journal of Law and the Biosciences* 1.

⁵² Office of the High Commissioner for Human Rights, *Emergency Measures and COVID-19: Guidance* (27 April 2020), 1-2.

⁵³ *ICESCR* (n 48) arts 11, 12; United Nations Committee on Economic, Social and Cultural Rights, *General Comment No 14: The Right to the Highest Attainable Standard of Health (Article 12 of the International Covenant on Economic, Social and Cultural Rights)*, UN ESCOR, 22nd sess, Agenda Item 3, UN Doc E/C.12/2000/4 (11 August 2000) ('*General Comment No 14*').

⁵⁴ *ICESCR* (n 48) art 2(1). See also Gostin (n 47) 251

⁵⁵ *Ibid* art 4. See also Gostin (n 47) 256.

⁵⁶ 'No Exceptions with COVID-19: "Everyone Has the Right to Life-Saving Interventions": UN Experts Say', (Press Release, United Nations Human Rights Office of the High Commissioner, 26 March 2020) <<https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25746&LangID=E>>.

⁵⁷ Sarah Joseph, 'International Human Rights Law and the Response to the COVID-19 Pandemic' (2020) 11(2) *Journal of International Humanitarian Legal Studies* 249, 266.

and the right to participate in social and cultural activities,⁵⁸ all of which can be impacted by shut-down measures and the associated economic downturn.

In addition to these two core covenants, there are also treaties that protect the rights of particular classes of people, including the *CRPD* and the *Convention on the Elimination of All Forms of Discrimination against Women* ('CEDAW')⁵⁹ and *International Convention on the Elimination of All Forms of Racial Discrimination* ('CERD').⁶⁰ These instruments point to the need to recognise the impacts of structural and systemic discrimination or disadvantage on different groups' experiences of the pandemic and responses to it. Australia is a party to all of these treaties and is therefore obliged under international law to respect, protect and fulfil these rights for all people within its jurisdiction.

Underpinning the treaties discussed above are a number of fundamental principles, which ought to guide responses to the COVID-19 pandemic and other emergency situations. They represent both the core values that human rights law promotes through the protection of specific rights, as well as norms that shape the implementation of those protections. They can be particularly useful in complex situations where competing priorities make it difficult to discern the most human rights-compatible approach. These core values include respect for the dignity, autonomy and liberty of each individual, which are understood as the foundations of modern human rights law.⁶¹

In the context of developing responses to global pandemics, these principles demand that, in dealing with the health risks facing older persons, we do not overlook their agency in assessing and responding to those risks or enact policies that disproportionately restrict their liberty.⁶² The fundamental principles underpinning human rights also include universality and non-discrimination, recognising that human rights belong to all people and must be guaranteed without discrimination.⁶³ Again, these principles have particular relevance for older persons, as they prevent the discounting of older persons' human rights simply on the basis of their age. This has a powerful resonance in relation to COVID-19, where there has been debate as to the degree to which social and economic activities should shut down in order to respond to the health crisis, which is frequently portrayed as being specifically intended to lower the risk to the older population. This then has the outcome of effectively pitting the health needs of older persons against the economic needs of younger generations who are less at risk from the health-related risks of COVID-19. Troubling arguments

⁵⁸ ICESCR (n 48) arts 6, 9, 15.

⁵⁹ *Convention on the Elimination of All Forms of Discrimination against Women*, opened for signature 18 December 1979, 1249 UNTS 13 (entered into force 3 September 1981) ('CEDAW').

⁶⁰ *International Convention on the Elimination of All Forms of Racial Discrimination*, opened for signature 21 December 1965, 660 UNTS 195 (entered into force 4 January 1969) ('CERD').

⁶¹ For more detail on the core values and principles underpinning a human rights-based approach, see the human rights framework developed by Lewis, Purser and Mackie (n 2) ch 3.

⁶² *Ibid.*

⁶³ See *Universal Declaration of Human Rights* (n 45); Lewis, Purser and Mackie (n 2) 73–4, 77.

then subsequently arise, which claim that protecting older persons' lives is not an adequate justification for the economic and social costs of lock-down measures. Such arguments, however, represent a form of age-discrimination that is inconsistent with these fundamental principles of human rights.⁶⁴ They also have the potential to perpetuate ageist attitudes in the community, which contribute to other, more widespread violations of human rights.⁶⁵ As the United Nations Department of Economic and Social Affairs Programme on Ageing has noted, '[p]ublic discourses that focus on fatalities more than on infections portray COVID-19 as a disease of older people, leading to social stigma, discrimination and exacerbating negative stereotypes about older persons'.⁶⁶

As we have argued above, the values and principles of international human rights law are directly relevant to the rights of older people in the context of the COVID-19 pandemic. However, these rights are generally articulated through treaties that have general application (such as the ICCPR and the ICESCR) or that have application to specific groups of which older people are a sub-group (such as CEDAW, which applies to women). To date, there is no international convention specifically addressing the rights of older people that could be used to guide the development of laws and policies that meet the needs of older people. In the next Part, we discuss the scope of domestic Australian human rights law.

B Australian Human Rights Law

In Australia, only Queensland, Victoria and the ACT have enacted human rights legislation⁶⁷ (although, as a matter of international law, Australia is responsible for ensuring that all internal jurisdictions comply with its treaty obligations).⁶⁸ There are a number of features of these state and territory laws that are worth noting in relation to pandemic responses in Australia.

⁶⁴ Joseph J Amon and Margaret Wurth, 'A Virtual Roundtable on COVID-19 and Human Rights with Human Rights Watch Researchers' (2020) 22(1) *Health and Human Rights Journal* 399, 408. See also Daniele Carrieri, Fedro Alessandro Peccatori and Giovanni Boniolo, 'COVID-19: A Plea to Protect the Older Population' (2020) 19(1) *International Journal for Equity in Health* 72 ('COVID-19'); Lisa Rosenbaum, 'Facing Covid-19 in Italy: Ethics, Logistics, and Therapeutics on the Epidemic's Front Line' (2020) 382(20) *New England Journal of Medicine* 1873.

⁶⁵ For a discussion on the links between ageism and human rights violations, see Lewis, Purser and Mackie (n 2) ch 5.

⁶⁶ United Nations Department of Economic and Social Affairs, 'COVID-19 and Older Persons: A Defining Moment for an Informed, Inclusive and Targeted Response', *Ageing* (Web Page, 8 May 2020) <<https://www.un.org/development/desa/ageing/news/2020/05/covid19/>>.

⁶⁷ *Human Rights Act 2019* (Qld); *Human Rights Act 2004* (ACT); *Charter of Human Rights and Responsibilities Act 2006* (Vic). For discussion, see Kylie Evans and Nicholas Petrie, 'COVID-19 and the Australian Human Rights Acts' (2020) 45(3) *Alternative Law Journal* 175; Michelle A Gunn and Fiona J McDonald, 'COVID-19, Rationing and the Right to Health: Can Patients Bring Legal Actions if They Are Denied Access to Care?' (2021) 214(5) *Medical Journal of Australia* 207.

⁶⁸ *Responsibility of States for Internationally Wrongful Acts*, GA Res 56/83, UN Doc A/RES/56/83 (28 January 2002, adopted 12 December 2001) annex art 4(1) ('*Responsibility of States for Internationally Wrongful Acts*').

First, the fact that only three jurisdictions have human rights law creates obvious gaps where human rights are not directly protected at the state or territory level. As discussed below in Part IV, all states and territories have anti-discrimination legislation that goes some way to protecting human rights, but this legislation is limited in terms of the protected attributes and contexts in which discrimination is prohibited.

Second, for the most part, these human rights laws only protect civil and political rights, not economic, social and cultural rights. Rights to health, housing, an adequate standard of living or social security are therefore not protected. The exception to this is the recently-enacted Queensland *Human Rights Act 2019*, which does protect the right to access health services, but which falls short of protecting the more comprehensive notion of the right to health found in international law.⁶⁹ By focussing on civil and political rights, domestic human rights law in Australia strongly focusses on ‘negative’ rather than ‘positive’ rights — it stresses governments’ obligations not to interfere with liberties and freedoms, but imposes few positive obligations to support and promote the full enjoyment of human rights.

Third, the rights contained in these laws only create obligations for public entities (Parliament, government departments and private actors performing public functions);⁷⁰ they do not apply to private actors. In relation to older persons, this creates a significant gap given that the majority of aged care facilities are privately owned and operated. While under general principles of international human rights law governments are obliged to protect human rights by regulating the acts of corporations or other private entities, this is difficult to enforce domestically and, as the *Royal Commission into Aged Care Quality and Safety* found, breaches of human rights have occurred in aged care settings (even outside the context of the pandemic).⁷¹ Furthermore, although significant government funding is dedicated to residential aged care facilities, most older Australians prefer to remain in their own homes and a large number (around one million people) receive aged-care services at home.⁷² These services are delivered by a wide range of private providers, raising questions of how to ensure human rights standards are adhered to generally with homecare services and specifically how the human rights impacts of isolation can be addressed in the pandemic-era. It also highlights the need to ensure that government funding of aged care properly

⁶⁹ *Human Rights Act 2019* (Qld) s 37: ‘(1) [e]very person has the right to access health services without discrimination. (2) A person must not be refused emergency medical treatment that is immediately necessary to save the person’s life or to prevent serious impairment to the person.’

⁷⁰ *Ibid* ss 9–10, 58; *Human Rights Act 2004* (ACT) ss 40–40B; *Charter of Human Rights and Responsibilities Act 2006* (Vic) ss 4, 38.

⁷¹ *Royal Commission into Aged Care Quality and Safety: Neglect* (Interim Report, 31 October 2019) vol 1 <<https://agedcare.royalcommission.gov.au/publications/interim-report>>; *Royal Commission into Aged Care Quality and Safety: Care, Dignity and Respect* (Final Report, 1 March 2021) vol 2, 91–99.

⁷² *Final Report Vol 1* (n 10) 24; Julie Power, ‘Ageing at Home: Too Little Choice for Older Australians’, *Sydney Morning Herald* (online, 16 August 2020) <<https://www.smh.com.au/national/ageing-at-home-too-little-choice-for-older-australians-20200816-p55m5d.html>>.

reflects the preference of most Australians to remain in their homes — a need that the Royal Commission has identified.⁷³

A fourth key point to note is that human rights legislation in Australia offers few opportunities for legal action to be pursued to enforce the rights afforded. In Queensland, a complaint can be brought to the Human Rights Commission, which can conduct a conciliation conference to try to resolve the matter. Otherwise, the key enforcement mechanism is to ‘piggy-back’ a human rights claim onto another legal cause of action — there is no independent pathway to bring a human rights claim before a court or tribunal.⁷⁴ Without providing fully justiciable human rights, Australia’s domestic legislative framework could be thought of as being more aspirational than legally enforceable. It should be noted, however, that these laws have had the effect of engaging legislatures with important questions of how to balance competing rights in responding to a complex pandemic situation.⁷⁵

The experience of older people during the COVID-19 pandemic has highlighted some of the shortcomings in Australia’s domestic protections of human rights. The layering of international and domestic human rights laws, along with the fundamental principles of human rights which underpin those laws, creates a detailed framework of obligations that can be used to assess the risks posed to individuals by pandemics and pandemic response measures, and to guide the implementation and revocation of those measures to ensure maximum enjoyment of human rights. We have seen legislatures give regard to these principles in devising and justifying many of their responses to the pandemic.

However, the lack of specific protections for older people’s human rights at either the international or domestic level creates a risk that their rights will be overlooked or discounted. The COVID-19 pandemic exposed the prevalence of ageist attitudes in relation to many issues, including the question of what level of economic limitation on businesses and travel could be justified on the grounds of protecting more vulnerable members of the community. Without a dedicated international human rights treaty for older people, or specific age-based protections within domestic human rights laws, there is a risk that general human rights protections will be applied in a way that does not give adequate regard to

⁷³ *Final Report Vol 1* (n 10) 8, 55.

⁷⁴ *Human Rights Act 2019* (Qld) s 59.

⁷⁵ For example, the Commonwealth Parliamentary Joint Committee on Human Rights has been meeting regularly to scrutinise federal legislation for its impact on human rights: ‘COVID-19 Legislative Scrutiny’, *Parliament of Australia* (Web Page) <https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Human_Rights/COVID19_Legislative_Scrutiny>. State and territory legislation also requires that scrutiny processes be followed: see, eg, Statement of Compatibility, COVID-19 Emergency Response Bill 2020 (Qld) <<https://www.parliament.qld.gov.au/documents/tableOffice/TabledPapers/2020/5620T638.pdf>>; Human Rights Certificate, *Public Health (COVID-19) and Other Legislation Amendment Regulation 2020* (Qld) <<https://www.parliament.qld.gov.au/Documents/TableOffice/TabledPapers/2020/5620T548.pdf>>. For discussion, see Evans and Petrie (n 67).

older people's particular experiences. Ageist attitudes may still be present in the way that generalist protections and principles are applied.

Further, the framework of human rights laws in Australia generally requires only that legislatures and other decision-makers have regard to human rights; there are limited consequences or enforcement options if a law or regulation interferes with human rights. Although older people are covered by general human rights protections outlined above, the absence of specific protections relating to ageing and meaningful enforcement processes represents a significant gap in current laws, which should be addressed. In the following three Parts, we analyse different aspects of Australian law and evaluate their adequacy in terms of addressing the needs of older Australians during the COVID-19 pandemic. In the following Part, we continue our rights-based analysis by considering the scope and relevance of Australian anti-discrimination legislation.

IV AGEING AND DISCRIMINATION LAW

Lockdowns and social distancing measures that aim to reduce the spread of disease within the community can affect the ability of individuals or groups to access goods and services. In this Part, we analyse the role of discrimination law in ensuring that access (or disruption of access) to goods and services is on a basis that is free of discrimination. As noted above, in Part III, as signatory to a range of international human rights instruments such as the *ICCPR* and *ICESR*, Australia is obliged to implement domestically its obligations under those instruments.⁷⁶ In Australia, anti-discrimination legislation has been deployed as a vehicle to implement those obligations;⁷⁷ it could be said that it puts human rights theory into practice. Analysis of how anti-discrimination law may apply in respect of COVID-19 related treatment of older Australians, however, is necessarily speculative in the absence of relevant case law guidance and will depend on the facts of the particular case. We begin in the next section by providing an overview of the legislative framework for anti-discrimination legislation in Australia.

A The Scheme of Australian Anti-Discrimination Legislation

Although there is no international convention on the rights of older persons as discussed in Part III, Australian anti-discrimination law does provide protection from age discrimination. Each Australian state and territory has generic anti-discrimination or equal opportunity legislation, which also prohibits

⁷⁶ See above n 68.

⁷⁷ See *Age Discrimination Act 2004* (Cth) s 10(7); *Disability Discrimination Act 1992* (Cth) s 12(8).

discrimination on the basis of age⁷⁸ and disability, or impairment.⁷⁹ Moreover, the Commonwealth has enacted a series of attribute-specific laws, relevantly the *Age Discrimination Act 2004* (Cth) ('ADA')⁸⁰ and the *Disability Discrimination Act 1992* (Cth) ('DDA').⁸¹ It is axiomatic, and a corollary of the ageing human body, that older people are disproportionately affected by disability when compared with the wider Australian community.⁸² While there is 'two-tiered' prohibition of discrimination at both Commonwealth and state or territory level, and choice as to jurisdiction for a complainant,⁸³ it is appropriate for this article to focus on the Commonwealth legislation as setting the benchmark for what is prohibited and what is authorised discriminatory conduct. The Commonwealth is, after all, the jurisdiction obliged by international law to protect human rights, and the ADA and DDA apply throughout Australia and bind even the Crown, including the Crown in right of a state.⁸⁴

The ADA expressly provides that discrimination on the ground of age does not include discrimination on the ground of disability⁸⁵ — they are separate actions. An older person experiencing COVID-19-related discrimination may bring an action under either or both the ADA or DDA, depending on their personal circumstances and the nature of the discrimination.⁸⁶ An aggrieved person for the purposes of the ADA and the DDA must prove a relevant 'protected attribute'; age for the ADA, or disability for the DDA. The ADA contemplates that a group 'above a particular age'⁸⁷ may experience discrimination. The DDA defines disability widely to cover physical, intellectual, psychiatric, behavioural and sensory impairment.⁸⁸ An aggrieved person must demonstrate that the conduct they complain of has occurred in a 'protected area' of public life including

⁷⁸ *Discrimination Act 1991* (ACT) s 7(1)(b); *Anti-Discrimination Act 1977* (NSW) s 49ZYA; *Anti-Discrimination Act 1992* (NT) s 19(1)(d); *Anti-Discrimination Act 1991* (Qld) s 7(f); *Equal Opportunity Act 1984* (SA) s 85K; *Anti-Discrimination Act 1998* (Tas) s 16(b); *Equal Opportunity Act 2010* (Vic) s 6(a); *Equal Opportunity Act 1984* (WA) s 66V.

⁷⁹ *Discrimination Act 1991* (ACT) s 7(1)(e); *Anti-Discrimination Act 1977* (NSW) s 49B; *Anti-Discrimination Act 1992* (NT) s 19(1)(j); *Anti-Discrimination Act 1991* (Qld) s 7(h); *Equal Opportunity Act 1984* (SA) s 76; *Anti-Discrimination Act 1998* (Tas) s 16(k); *Equal Opportunity Act 2010* (Vic) s 6(e); *Equal Opportunity Act 1984* (WA) s 66A.

⁸⁰ *Age Discrimination Act 2004* (Cth) ('ADA').

⁸¹ *Disability Discrimination Act 1992* (Cth) ('DDA').

⁸² According to the Australian Institute of Health and Welfare, '50% of people aged 65 years and over have disability'. By comparison, '13% of people aged 15–64 years have disability': see Australian Institute of Health and Welfare, 'People with Disability in Australia' (Web Page, 2 October 2020) <<https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/people-with-disability/prevalence-of-disability>>.

⁸³ Note that 'double dipping' in respect of anti-discrimination complaints is barred: see, eg, ADA (n 80) s 12(4); DDA (n 81) s 13(4).

⁸⁴ ADA (n 80) s 13(1); DDA (n 81) s 14(1).

⁸⁵ ADA (n 80) s 6.

⁸⁶ See *Australian Human Rights Commission Act 1986* (Cth) pt IIB for relevant procedural considerations.

⁸⁷ ADA (n 80) s 5 (definition of 'age' example).

⁸⁸ DDA (n 81) s 4 (definition of 'disability').

employment,⁸⁹ education,⁹⁰ goods, services and facilities,⁹¹ access to premises⁹² and the administration of Commonwealth laws and programs.⁹³ The conduct complained of must be discriminatory conduct within the meaning of the legislation. Both Acts prohibit direct discrimination,⁹⁴ that is, less favourable treatment on the ground of age or disability, and indirect discrimination,⁹⁵ that is, the imposition of a discriminatory requirement or condition that disproportionately disadvantages persons of a certain age or age group, or persons with a disability.

Even if a prima facie case of discrimination is proved, if the respondent can prove a relevant exemption contained in the *ADA* or *DDA*, or can prove, in the case of indirect discrimination, that the condition is reasonably imposed, then the complainant's case may nevertheless fail. Exemptions for prima facie unlawful discrimination differ for each Act. The High Court has held that what is 'reasonable' in respect of indirect discrimination is an objective test that takes into account all relevant circumstances.⁹⁶ It is a feature of the *DDA*, too, that it imposes a positive obligation to make reasonable adjustment for people with disability so as to avoid direct or indirect discrimination.⁹⁷ Similar considerations are relevant to proof of reasonableness here, as apply in respect of reasonableness for indirect discrimination.

B COVID-19 and Potentially Discriminatory Treatment of Older Australians

It should be noted that older Australians have been the beneficiaries of more favourable treatment than younger Australians in the roll out of the COVID-19 vaccination program.⁹⁸ This prioritisation of older Australians over younger Australians is likely lawful under both the *ADA*, as 'positive discrimination',⁹⁹ and

⁸⁹ *ADA* (n 80) s 18; *DDA* (n 81) s 15.

⁹⁰ *ADA* (n 80) s 26; *DDA* (n 81) s 22.

⁹¹ *ADA* (n 80) s 28; *DDA* (n 81) s 24.

⁹² *ADA* (n 80) s 27; *DDA* (n 81) s 23.

⁹³ *ADA* (n 80) s 31; *DDA* (n 81) s 29.

⁹⁴ *ADA* (n 80) s 14; *DDA* (n 81) s 5.

⁹⁵ *ADA* (n 80) s 15; *DDA* (n 81) s 6.

⁹⁶ *Waters v Public Transport Corporation* (1991) 173 CLR 349, 395–6 (Dawson and Toohey JJ), 383 (Deane J). While *Waters v Public Transport Corporation* interpreted the *Equal Opportunity Act 1984* (Vic), the test for reasonableness articulated in the case is applied in *DDA* (n 81) cases. For a recent example from the Full Federal Court, see *Sklavos v Australasian College of Dermatologists* (2017) 256 FCR 247, 267 [80] (Bromberg J, Griffiths J agreeing at 290 [179], Bromwich J agreeing at 303 [213]). As the indirect discrimination provision in the *ADA* (n 80) s 15 is drafted in substantially the same terms as the *DDA* (n 81), it is likely that should a relevant case proceed to trial, it, too, would be interpreted consistent with the approach in *Waters v Public Transport Corporation*.

⁹⁷ *DDA* (n 81) ss 5(2), 6(2).

⁹⁸ See Australian Government Department of Health and Aged Care, 'COVID-19 Vaccines' (Web Page) <<https://www.health.gov.au/initiatives-and-programs/covid-19-vaccines>>.

⁹⁹ See *ADA* (n 80) s 33.

under the DDA, as a ‘special measure’,¹⁰⁰ for their benefit. However, examples of ‘ageist’ treatment of older Australians in relation to COVID-19 have been identified by the Australian Human Rights Commission (‘AHRC’).¹⁰¹ For example, the AHRC has identified health care rationing proposals and the impact of COVID-19 responses by employers as problematic for older Australians.¹⁰² Below we consider the relevance of anti-discrimination legislation to these areas.

1 Health Care Rationing

As the pandemic unfolded, and health service providers contemplated what they feared would be an inevitable shortage of hospital beds and ventilators, concerns were raised that hospital treatment may need to be rationed,¹⁰³ and that younger people might be given access before older people. A medical facility refusing access to an ICU bed or ventilator to a person aged over 70, for example, may amount to a case of direct discrimination on the ground of age in the protected area of goods, services and facilities. Similarly, it may be direct discrimination on the ground of disability to refuse access to an ICU bed or ventilator because a person had an underlying health condition consistent with being of an older age, such as high blood pressure or Type 2 Diabetes.

It should be noted, however, that the ADA s 42(3) expressly contemplates as lawful ‘decision[s] relating to health goods or services or medical goods or services’ if ‘taking ... age into account in making the decision is reasonably based on evidence, and professional knowledge, about the ability of persons of the ... [relevant] age to benefit from the goods or services’.¹⁰⁴ The evidence that may be relied on for proof of this exemption is ‘evidence that was reasonably available at the time the decision was made’.¹⁰⁵ Despite commentary suggesting that rationing is illegitimate, immoral and ‘discriminatory’,¹⁰⁶ this exemption suggests a possible defence to any allegation of discriminatory service rationing by a medical facility, especially had it been necessary in the early ‘hurly burly’ of the pandemic when compelling evidence quickly emerged that COVID-19

¹⁰⁰ See DDA (n 81) s 45.

¹⁰¹ See Kay Patterson, ‘Ageism and COVID-19’, *Australian Human Rights Commission* (Web Page, 5 May 2020) <<https://humanrights.gov.au/about/news/ageism-and-covid-19>>.

¹⁰² *Ibid.*

¹⁰³ *Ibid.*; Xavier Symons, ‘Rationing Care to Cope with COVID-19 Should Never be Based on Age Alone’, *Sydney Morning Herald* (online, 13 March 2020) <<https://www.smh.com.au/national/an-icu-age-limit-rationing-lifesaving-care-to-cope-with-covid-19-is-an-ethical-minefield-20200313-p549qc.html>>.

¹⁰⁴ ADA (n 80) s 42(3). For further discussion of rationing, see Gunn and McDonald (n 70).

¹⁰⁵ ADA (n 80) s 42(4).

¹⁰⁶ See Popescu and Marcoci (n 35).

mortality rates increased with age.¹⁰⁷ We are fortunate in Australia that such tough decisions have not yet had to be made.¹⁰⁸

The *DDA* does not have an equivalent exemption to *ADA* s 42 but does provide that it is not unlawful to discriminate in the areas covered by Division 2 of the Act, which includes goods, services and facilities, if to avoid the discrimination would impose unjustifiable hardship on the service provider.¹⁰⁹ A shortage of beds and equipment may trigger a claim of unjustifiable hardship. Proof would entail a weighing of the detriment to the complainant of being excluded from necessary health care (death?), against the benefit to other COVID-19 patients who would be given preferential access to health care (life?), and the effect of the disability of the complainant in increasing the likelihood of death from COVID-19 even with access to care.

2 *Employment*

The potential for discrimination claims in the protected area of employment has also emerged as employers have taken steps to balance the need to minimise the risk of infection to staff against the need to maintain their business operations.

Circumstances surrounding individual workplaces and the variable nature of the work conducted at those workplaces makes it difficult to speculate on how any discrimination action may be decided. It should be noted, though, that where everyone is required to work from home, it may be difficult to prove direct discrimination — less favourable treatment. If only older workers or workers with disability are excluded, however, a direct discrimination claim may have better prospects of success. This is particularly the case where age is the ground for exclusion. Here age appears to be used as a proxy for objective vulnerability to infection and death. As noted above, an older person may be healthier than a much younger person, and objectively at lower risk of infection. A claim of direct disability discrimination may, of course, be countered by the ‘defence’ of unjustifiable hardship,¹¹⁰ which would require a weighing of pros and cons and costs of inclusion and exclusion in the relevant work context. Government mandating of social distancing may also be a relevant circumstance to be taken into account in the unjustifiable hardship enquiry.

A requirement that a person must attend the workplace may be reasonable or unreasonable depending on the circumstances. If it is demonstrably possible to

¹⁰⁷ See, eg, Amitava Banerjee et al, ‘Estimating Excess 1-Year Mortality Associated with the COVID-19 Pandemic According to Underlying Conditions and Age: A Population-Based Cohort Study’ (2020) 395(10238) *Lancet* 1715.

¹⁰⁸ See, for further information on health care rationing, Mohammed R Moosa and Valerie A Luyckx, ‘The Realities of Rationing in Health Care’ (2021) 17(7) *Nature Reviews Nephrology* 435.

¹⁰⁹ *DDA* (n 81) ss 24, 29A. Note that in respect of Commonwealth anti-discrimination legislation, the unjustifiable hardship exemption is a feature particular to the *DDA* (n 81) and is not available under other Commonwealth Acts, including the *ADA* (n 80), to exempt treatment on the basis of other protected attributes, including age.

¹¹⁰ *Ibid* s 21B.

perform regular work from home it may be difficult to prove that a requirement of attendance at work is reasonable. Some jobs, however, cannot be performed remotely and, in those instances, even though an older person or a person with disability may choose to resign in order to protect their health, a requirement of attendance at the workplace may be reasonable. Both the *ADA* and the *DDA* also provide a possible defence for employers where a complainant cannot fulfil the ‘inherent requirements’ of the job they were hired to perform.¹¹¹ In that situation, an employer may be able to legitimately terminate the employment.

C Impediments to a Discrimination Claim

While Australian law provides important protections from discrimination in access to goods and services, including protection from age-related discrimination, as we have argued above, it may provide limited protection in some situations in the context of a pandemic.

Even where there may be good prospects of a successful discrimination claim, it may be impractical or even impossible to proceed. A person who has been denied an ICU bed and a ventilator may have died and lost any opportunity to sue, or they may be too ill to bring a claim. Even though representative actions are available in such a situation,¹¹² and an interim injunction restraining a rationing decision may potentially be ordered,¹¹³ in such a traumatic set of circumstances, legal action may be too late or not contemplated as a priority. While those who have been the victim of discrimination at work may consider suing, evidence suggests that most will not. A survey conducted by the Australian Human Rights Commission in July and August 2018 found alarming levels of age discrimination against older workers¹¹⁴ — even without a pandemic — but low numbers of complaints of discrimination proceed to hearing. All in all, as a vehicle for protecting the rights and freedoms of older people, Australian anti-discrimination legislation is limited in its efficacy. Indeed, the relevant Commonwealth legislation promises to remove discrimination only ‘as far as possible’ and to ensure equal protection of rights only ‘as far as practicable’.¹¹⁵

The COVID-19 pandemic has also had a significant impact on older people in terms of their social interaction. In the following Part we analyse the implications of social isolation for older people — a challenge that existed before the pandemic but that has been exacerbated by it — and the role that technology can play in supporting social interaction and legal decision-making during a pandemic.

¹¹¹ *ADA* (n 80) s 18(4); *DDA* (n 81) s 21A.

¹¹² *Australian Human Rights Commission Act 1986* (Cth) s 46P(2)(c).

¹¹³ *Ibid* s 46PP.

¹¹⁴ ‘Employing Older Workers (2018)’, *Australian Human Rights Commission* (Web Page, 31 October 2018) <<https://humanrights.gov.au/our-work/age-discrimination/publications/employing-older-workers-2018>>.

¹¹⁵ See *ADA* (n 80) s 3(a),(b); *DDA* (n 81) s 3(a),(b).

V SOCIAL ISOLATION, TECHNOLOGY AND THE LAW

The concept of isolation (or ‘iso’) is unavoidable in the newly developed coronavirus lexicon, which has also seen the emergence of terms such as ‘boomer remover’ (used mainly by younger generations, again serving as an example of the inherent ageism, but also intergenerational tension, that is pervasive throughout society).¹¹⁶ Isolation is mandated for those showing symptoms for COVID-19. At times it has also been recommended for ‘older’ people,¹¹⁷ and in some jurisdictions aged-care facilities have gone into lockdown, with the associated social isolation for older people that accompanies such a measure.¹¹⁸

The effects of isolation are particularly important for older people given that ageing (and the amorphous concept of ‘healthy’ ageing) can be impacted by a person’s exposure to social change, including through isolation.¹¹⁹ Approximately one third of older Australians live alone.¹²⁰ Thus, the measures designed to protect from COVID-19 may actually have unintended negative consequences. The impact of isolation, and associated loneliness, on older people therefore has potentially substantial implications for their human rights.¹²¹

Even without a pandemic, older people can, and do, experience social exclusion, which can be for prolonged periods or more episodic in nature. Social exclusion is a complex process that generally involves the denial of goods and services as well as resources that are available to other cohorts within society more generally and which also endangers the human rights of older persons.¹²² This can occur for a number of reasons including, for instance, physical, health,

¹¹⁶ Kate Burridge and Howard Manns, “‘Iso”, “Boomer Remover” and “Quarantini”: How Coronavirus is Changing Our Language’, *The Conversation* (online, 12 May 2020) <<https://theconversation.com/iso-boomer-remover-and-quarantini-how-coronavirus-is-changing-our-language-136729>>. See also Brooke and Jackson (n 30).

¹¹⁷ See eg, Rob Harris and Fergus Hunter, ‘Elderly Australians Told to Self-Isolate at Home, Outdoor Gatherings Restricted to Two People’, *Sydney Morning Herald* (online, 29 March 2020) <<https://www.smh.com.au/politics/federal/elderly-australians-told-to-self-isolate-at-home-outdoor-gatherings-restricted-to-two-people-20200329-p54fig.html>>.

¹¹⁸ Claire Moodie, ‘Aged Care Operators Defend Coronavirus Lockdown as Premier, Prime Minister Urge Facilities to Relax Visit Bans’, *ABC News* (online, 23 April 2020) <<https://www.abc.net.au/news/2020-04-23/aged-care-providers-defend-coronavirus-lockdown-amid-criticism/12177096>>.

¹¹⁹ United Nations Department of Economic and Social Affairs, ‘Health Inequalities in Old Age’ (Briefing Paper, April 2018) 1 <<https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2018/04/Health-Inequalities-in-Old-Age.pdf>>; *World Population Ageing 2015: Report* (n 15) 90–1; Emilie Courtin and Martin Knapp, ‘Social Isolation, Loneliness and Health in Old Age: A Scoping Review’ (2017) 25(3) *Health and Social Care in the Community* 799.

¹²⁰ Senator Anne Ruston, ‘Supporting Isolated Senior Australians to Stay Connected’ (Media Release, Minister for Families and Social Services, 28 May 2020) <<https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22media%2Fpressrel%2F7363490%22>>.

¹²¹ World Health Organization, *World Report on Ageing and Health* (n 2) 74. See also Lewis, Purser and Mackie (n 2) 100.

¹²² Kieran Walsh, Thomas Scharf and Norah Keating, ‘Social Exclusion of Older Persons: A Scoping Review and Conceptual Framework’ (2017) 14(1) *European Journal of Ageing* 81, 83; Ruth A Levitas et al, *The Multi-Dimensional Analysis of Social Exclusion* (Report, Department for Communities and Local Government, January 2007) 9, cited in Lewis, Purser and Mackie (n 2) 99.

financial, social and structural considerations, and can result from, or be reinforced by, ageism. Social exclusion can have the effect of devaluing the contributions and potential contributions of older persons to their communities through limiting the ability to participate.¹²³ As Walsh et al have identified, social exclusion can negatively impact both the quality of life of the older person and the cohesiveness of the local community.¹²⁴

Significantly, social exclusion, or isolation, can be linked to depression, which can be a factor in the assessment of capacity.¹²⁵ It is also a key risk factor for elder abuse, including the exertion of any undue influence.¹²⁶ The ageism prevalent in society further reinforces the opportunities for elder abuse to occur given that older persons are frequently invisible and devalued, with the same attitudes being displayed and/or taken advantage of by abusers. This was the case pre-pandemic and thus the effects of social exclusion — or isolation — have only been heightened by the current pandemic.

Kornfeld-Matte, the former Independent Expert on the Human Rights of Older Persons, has highlighted the nexus between social exclusion (and isolation) and, significantly in the context of COVID-19, the right to the highest attainable standard of health, including mental health.¹²⁷ As Kornfeld-Matte articulates, inclusion requires equal access to all goods, services and resources, with support given where necessary to facilitate the full participation of older persons (where they choose to do so) in all aspects of social life, including in the receipt of healthcare as well as, for example, accessing public spaces and buildings, and shopping.¹²⁸ Advancing a person's ability to genuinely participate in the social and cultural activities of their local community is therefore fundamental to respecting an individual's autonomy and dignity.

Ensuring that facilities and services are available for the general population on an equal basis that responds to individual needs is especially significant in the COVID-19 era. This speaks, not only to the need to address social exclusion resulting from isolation for older persons, and the associated health and mental health effects, but also to the need to keep the discriminatory effects of ageism at the front of our minds, particularly in relation to any rationing of care debates, as discussed in Part IV.

¹²³ Kornfeld-Matte (n 38) [25], cited in Lewis, Purser and Mackie (n 2) 99.

¹²⁴ Walsh, Scharf and Keating (n 122) 83; Levitas et al (n 122) 9, cited in Lewis, Purser and Mackie (n 2) 99.

¹²⁵ Jennifer Moyer, Daniel C Marson and Barry Edelstein, 'Assessment of Capacity in an Aging Society' (2013) 68(3) *American Psychologist* 158, 162; Lewis, Purser and Mackie (n 2) 146.

¹²⁶ Briony Dow and Melanie Joosten, 'Understanding Elder Abuse: A Social Rights Perspective' (2012) 24(6) *International Psychogeriatrics* 853, 854; Lewis, Purser and Mackie (n 2) 99.

¹²⁷ Rosa Kornfeld-Matte, *Report of the Independent Expert on the Enjoyment of All Human Rights by Older Persons*, 27th sess, Agenda Item 3, UN Doc A/HRC/27/46 (24 July 2014); United Nations Committee on Economic Social and Cultural Rights, *General Comment No 4: The Right to Adequate Housing (Art. 11(1) of the Covenant)*, UN ESCOR, 6th sess, UN Doc E/1992/23 (13 December 1991); *General Comment No 14* (n 53); Lewis, Purser and Mackie (n 2) 100.

¹²⁸ Kornfeld-Matte (n 38) [70], cited in Lewis, Purser and Mackie (n 2) 100.

Connected to this is the need to provide for culturally and ethnically appropriate initiatives, which should ideally foster the participation of members of specific cultural or ethnic groups to ensure authentic co-design and ongoing evaluation. The Political Declaration and Madrid International Plan of Action on Ageing recognises the need for such approaches respecting different cultural and religious traditions.¹²⁹ This is especially significant when viewed in terms of COVID-19 and the impacts of mandated isolation on older people from culturally and linguistically diverse backgrounds. It is important to note here, for example, the call for multilingual COVID-19 resources to effectively communicate to non-English speaking older people who may be at greater risk of contracting COVID-19 through a lack of understanding.¹³⁰

The impact of isolation on older Australians, which has been so effectively highlighted by the pandemic, is so significant, in fact, that the Federal Government launched two new targeted initiatives in an attempt to combat loneliness (and its effects) arising from isolation.¹³¹ Almost \$5 million will be dedicated to expanding 'Friend Line', a national telephone support service. A further \$1 million has been awarded in grants to 215 community organisations to provide digital devices — for instance, mobile phones and laptops — to 'at-risk' older people.¹³² While any measure attempting to address the effects of isolation, both during and beyond the pandemic, is welcome, it is interesting that technology was seen as the 'solution' to addressing isolation and the resultant risk of social exclusion of older people. The objective to address isolation fulfils a human-rights-based approach in promoting participation and autonomy (to a degree). However, the use of any technological devices needs to be accessible and affordable. While the devices can incur a significant initial outlay, which these government initiatives are designed to address, there are ongoing and not insignificant associated costs in terms of other living expenses and, for example, the current rate of the aged pension. This is also assuming that reliable telephone and internet services are available, which may not be the case, especially in geographically remote areas or for those on lower-incomes.¹³³ Educational, social and cultural factors can also influence the uptake of such devices and thus need to be considered, including respecting an individual's wish to engage, or not to engage, with technology on an individual level representative of that person's

¹²⁹ United Nations, 'Political Declaration and Madrid International Plan of Action on Ageing' (Declaration and Plan of Action, Second World Assembly on Ageing, 8–12 April 2002) [115].

¹³⁰ Tasha Wibawa, 'Push for Multilingual COVID-19 Resources to Help Elderly People Who Don't Speak English', *ABC News* (online, 21 March 2020) <<https://www.abc.net.au/news/2020-03-21/coronavirus-information-limited-language-cald-australia/12063104>>.

¹³¹ Ruston (n 120).

¹³² *Ibid.*

¹³³ Bridget Lewis et al, Submission to Australian Human Rights Commission, *Human Rights and Technology Issues Paper* (2 October 2018) 12.

level of comfort.¹³⁴ Older people may thus experience a ‘double burden of social and digital exclusion’.¹³⁵

One example in a legal context where technology has been used in an attempt to address the effects of pandemic-related social isolation is in the area of wills and estate planning more broadly. The pandemic has produced an increased focus on mortality. The need for isolation, social distancing, remote working arrangements and restrictions on movement presented challenges for compliance with the traditional formalities required for valid will-making, notably the requirement for two adults to be ‘in the physical presence of the testator’ with respect to witnessing or attesting the testator’s signature.¹³⁶ Valid witnessing of other documents frequently employed in estate planning, such as enduring powers of attorney (‘EPAs’), has also been made more difficult in the light of social isolation and other restrictions imposed as a result of COVID-19. Given the significance of the impact on will-making and executing EPAs, emergency measures were introduced in many jurisdictions internationally, including in Australia, to enable electronic witnessing to facilitate the valid execution of testamentary and substitute decision-making documents during the pandemic.¹³⁷ Queensland, for instance, also restricted the witnessing role to specific categories of witness, such as a lawyer, and included a sunset clause for the emergency provisions.¹³⁸ The emergency measures in relation to will-making and executing enduring documents in Queensland expired on 1 July 2021.

¹³⁴ Jessica Francis et al, ‘Aging in the Digital Age: Conceptualizing Technology Adoption and Digital Inequalities’ in Barbara Barbosa Neves and Frank Vetere (eds), *Ageing and Digital Technology: Designing and Evaluating Emerging Technologies for Older Adults* (Springer, 2019) 35; ‘Australian Digital Inclusion Index’, *Digital Inclusion Index* (Web Page) <<https://digitalinclusionindex.org.au/>>; Lewis, Purser and Mackie (n 2) ch 4.

¹³⁵ Alexander Seifert, Shelia R Cotten and Bo Xie, ‘A Double Burden of Exclusion? Digital and Social Exclusion of Older Adults in Times of COVID-19’ (2021) 76(3) *Journals of Gerontology: Social Sciences* e99, e99.

¹³⁶ Bridget J Crawford, Kelly Purser and Tina Cockburn, ‘Wills Formalities in a Post-Pandemic World: A Research Agenda’ (2021) *University of Chicago Legal Forum* 93, 93, 111–121 (‘Wills Formalities in a Post-Pandemic World’); Kelly Purser, Tina Cockburn and Bridget J Crawford, ‘Wills Formalities Beyond COVID-19: An Australian–United States Perspective’ (2020) 5 *University of New South Wales Law Journal Forum* 1, 1–14 (‘Wills Formalities Beyond COVID-19’). On the traditional role of the formalities in will-making, see, eg, Kelly Purser and Tina Cockburn, ‘Wills Formalities in the Twenty-First Century: Promoting Testamentary Intention in the Face of Societal Change and Advancements in Technology: An Australian Response to Professor Crawford’ [2019] (4) *Wisconsin Law Review Forward* 46; Bridget J Crawford, ‘Wills Formalities in the Twenty-First Century’ [2019] (2) *Wisconsin Law Review* 269, 271; David Norton and Reid Kress Weisbord, ‘COVID-19 and Formal Wills’ [2020–2021] 73 *Stanford Law Review Online* 18, 18–27.

¹³⁷ *Electronic Transactions Amendment (COVID-19 Witnessing of Documents) Regulation 2020* under the *Electronic Transactions Act 2000* (NSW); *COVID-19 Emergency Response Act 2020* (Qld); *Justice Legislation (COVID-19 Emergency Response – Documents and Oaths) Regulation 2020* (Qld); Supreme Court of Queensland, *Amended Practice Direction No 10 of 2020: Informal Wills/COVID-19*, 3 November 21. See also Purser, Cockburn and Crawford, ‘Wills Formalities Beyond COVID-19’ (n 136); Crawford, Purser and Cockburn, ‘Wills Formalities in a Post-Pandemic World’ (n 136).

¹³⁸ *COVID-19 Emergency Response Act 2020* (Qld); *Justice Legislation (COVID-19 Emergency Response – Documents and Oaths) Regulation 2020* (Qld) s 5.

In relation to valid will-making, the Australian Council of Human Rights Authorities ('ACHRA') notes that there has been a reported increase in the number of requests by older people for legal assistance to make a will since the onset of the pandemic given the heightened 'family and financial pressure[s]'.¹³⁹ ACHRA further highlights the need to ensure that any testamentary instruments 'are truly reflective of the testator's wishes'.¹⁴⁰ Such a comment highlights the necessity not only of fulfilling the formal requirements to make a valid will, but also the mental requirements, particularly issues of capacity and its assessment, knowledge and approval, as well as the absence of suspicious circumstances and undue influence.¹⁴¹

The restriction of eligible witnesses to certain categories, such as lawyers, was designed, in part, to address some of these concerns, particularly in relation to attempting to ensure satisfactory capacity assessments and in identifying elder financial abuse.¹⁴² The effectiveness of such measures remains to be seen, however, especially considering the difficulties faced with satisfactorily assessing capacity under 'normal conditions', let alone during and post-pandemic.¹⁴³ The restriction of witnesses to eligible categories also raises issues of access to justice — that is, the ability to both access and afford appropriate advice.¹⁴⁴ Pre-pandemic, older persons in regional, and especially rural and remote, areas, may not have had 'easy' access to a solicitor. The restrictions arising as a result of the pandemic heighten these issues, although the use of virtual witnessing may be suggested as a solution, both during and post-pandemic. However, as discussed above, this is predicated upon having the means to access quality internet and the appropriate devices.¹⁴⁵ Furthermore, technology does not necessarily address broader challenges for wills and estate planning, particularly in relation to ensuring the mental elements necessary for, for example, executing a valid will.¹⁴⁶

As the discussion above indicates, technology can help to address social isolation during the pandemic. In addition, as the wills and estate planning example shows, measures such as virtual witnessing of documents may assist older people — and indeed people of all ages — to manage important aspects of their lives during periods of social isolation. However, technology is unlikely to provide a total solution to the issues discussed above and should not be blindly

¹³⁹ Australian Council of Human Rights Authorities, 'Statement: April 2020' (28 April 2020) <<https://antidiscrimination.nsw.gov.au/anti-discrimination-nsw/about-us/news/2020/australian-council-of-human-rights-authorities-statement---april.html>>.

¹⁴⁰ Ibid.

¹⁴¹ On these, see, eg, *Nicholson v Knaggs* [2009] VSC 64.

¹⁴² Purser, Cockburn and Crawford, 'Wills Formalities Beyond COVID-19' (n 136) 9.

¹⁴³ On capacity assessment in this context see, eg, Kelly Purser, *Capacity Assessment and the Law: Problems and Solutions* (Springer, 2017); Purser, Cockburn and Crawford 'Wills Formalities Beyond COVID-19' (n 136).

¹⁴⁴ Purser, Cockburn and Crawford, 'Wills Formalities Beyond COVID-19' (n 136) 1.

¹⁴⁵ Ibid 10.

¹⁴⁶ Ibid 13.

assumed to do so without first establishing a relevant evidence-base.¹⁴⁷ Following the pandemic, it will be important to critically assess all initiatives introduced during the pandemic in response to the effects of social isolation.

As is clear from the discussion above, the COVID-19 pandemic has had a significant impact on the lives of older Australians. Vaccines and treatments for COVID-19 will play an important role in enabling the easing of social distancing and other restrictions. Given the increased risk to older people of severe disease and mortality from COVID-19, including older people in medical research of vaccines and treatments will be important.¹⁴⁸ In the following Part we analyse the legal frameworks in Australian law for conducting research with older people.

VI CONDUCTING COVID-19 RESEARCH WITH OLDER PEOPLE

There has been a global race to research the origins, physiological trajectory, and the best forms of symptomatic management of COVID-19. As at July 2022, in addition to vaccines already in use, there were over 168 possible vaccines under clinical evaluation (and over 198 in preclinical evaluation)¹⁴⁹ and many other treatments now being investigated. Much of this biomedical research, all aimed at minimising the harms of the pandemic in the human population, requires people to act as research participants. In this Part, the law on capacity to consent and substitute decision-making is examined in the context of COVID-19 research. Given the disproportionate effects of COVID-19 on older people, it is likely that the research participants sought will include a number of older people, some of whom will have lost decision-making capacity. We examine the sometimes competing human rights issues that need to be considered when there is a request to include an older person in medical research related to COVID-19 — particularly participation in clinical trials and experimental health care to treat COVID-19.

A *Human Rights in Research*

In the medical research context, tensions exist between protecting against harm and providing potentially vulnerable participants with a 'voice' to allow altruistic participation.¹⁵⁰ This is unsurprising given the historical atrocities that have been carried out against the most vulnerable groups in society in the name of

¹⁴⁷ Ibid 11–13; Crawford, Purser and Cockburn, 'Wills Formalities in a Post-Pandemic World' (n 136).

¹⁴⁸ Sarah J Richardson et al, 'Research with Older People in a World with COVID-19: Identification of Current and Future Priorities, Challenges and Opportunities' (2020) 49(6) *Age and Ageing* 901.

¹⁴⁹ World Health Organization, *COVID-19 Vaccine Tracker and Landscape* (Report, 19 July 2022) <<https://www.who.int/publications/m/item/draft-landscape-of-covid-19-candidate-vaccines>>.

¹⁵⁰ See Adrian Treloar and Claudia Dunlop, 'Research on Patients with Dementia' in Charles Foster, Jonathan Herring and Israel Doron (eds), *The Law and Ethics of Dementia* (Hart Publishing, 2014) 169, 169–75 (in the context of people with dementia).

advancing science.¹⁵¹ While older people as a group should not simply be categorised as ‘vulnerable’,¹⁵² the older person with COVID-19 surely can. With no cure, and significant morbidity and mortality, older people with COVID-19 are likely to be scared, vulnerable and physically isolated from friends and family. In this context, the question of how to involve such a person in medical research and maintain their human rights is an important one. Here, the focus is on the legal position of an older Australian with COVID-19 who has diminishing or else lost decision-making capacity, but who had previously expressed a wish to participate in research. Can such a person participate in COVID-19 medical research and, if so, in what circumstances?

Legally, there are a variety of ways in which a person who has declining decision-making capacity, or who has lost that capacity entirely, can be authorised to take part in research. These may include advance consents (made prior to the loss of decision-making capacity) in the form of an advance care directive or, more commonly, substituted consent from a legally recognised substitute decision-maker. Differences arise in the law regarding substitute decision-making across Australia and the national ethical guidelines for research produced by the National Health and Medical Research Council (NHMRC) need to be adhered to by human research ethics committees (HRECs) approving research and researchers themselves.¹⁵³

Currently, as research is urgently needed and collaboration with large data sets is likely to yield the best results, there is a strong utilitarian argument to involve as many participants as possible in research. However, in Australia, differing laws may provide a significant barrier to this type of rapid research.

¹⁵¹ See, eg, James H Jones, ‘The Tuskegee Syphilis Experiment’ in Ezekiel J Emanuel et al (eds), *The Oxford Textbook of Clinical Research Ethics* (Oxford University Press, 2008) 86, 94; Thomas R Frieden and Francis S Collins, ‘Intentional Infection of Vulnerable Populations in 1946–1948: Another Tragic History Lesson’ (2010) 304(18) *JAMA* 2063.

¹⁵² See Part II above.

¹⁵³ National Health and Medical Research Council, *National Statement on Ethical Conduct in Human Research: 2007 (Updated 2018)* (Statement, 2018) <<https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018>> (‘*National Statement on Ethical Conduct*’). See also National Health and Medical Research Council, ‘COVID-19: Guidance on Clinical Trials for Institutions, HRECs, Researchers and Sponsors’, *Information for the Health and Medical Research Sector in Response to the COVID-19 Pandemic* (Statement) <<https://www.nhmrc.gov.au/research-policy/COVID-19-impacts#download>>. For discussion of these guidelines in the context of COVID-19 medical research, see Ian Freckelton, ‘Clinical Research without Consent: Challenges for COVID-19 Research’ (2020) 28(1) *Journal of Law and Medicine* 90.

B *Capacity to Consent: The Older Person with COVID-19*

1 *Direct Consent and Supported Decision-Making*

Some older people with COVID-19 will be capable of making their own decisions. Just because a person may have a particular condition, this does not automatically mean they lack decision-making capacity. This much is legally uncontroversial, although in practice, ingrained bias, ageism and other factors can lead people (including researchers) to make assumptions about an older person's decision-making capacity — particularly where they have a debilitating condition.¹⁵⁴ Any person with COVID-19 who retains decision-making capacity is able to decide whether they participate in medical research.

Some people with COVID-19 may have declining or fluctuating capacity due to their symptoms or pre-existing co-morbidities. In these circumstances, rather than assume an inability to make decisions, supported decision-making may help to extend that individual's decision-making capacity and autonomy. The CRPD imposes duties on States to change their law and practice to recognise supported decision-making.¹⁵⁵ This concept aims to support people with cognitive impairment to continue to make their own decisions. While it has no fixed definition, supported decision-making is part of a process undertaken prior to any permitted determination of incapacity and turning to a substitute decision-maker.¹⁵⁶ When practised, this process more fully respects the rights of adults who can be supported to make decisions. While the notion of supported decision-making is well known in the human rights literature, how that concept should operate in the research context is less well explored.¹⁵⁷

Victoria is the only jurisdiction that recognises a legally appointed supporter¹⁵⁸ (despite calls from most law reform commissions to implement this in other Australian jurisdictions).¹⁵⁹ Queensland has also incorporated principles that require attempts at supported decision-making before turning to a substitute decision-maker.¹⁶⁰ In theory, being able to appoint a medical support

¹⁵⁴ Megan S Wright, 'Dementia, Autonomy, and Supported Healthcare Decisionmaking' (2020) 79(2) *Maryland Law Review* 257, 273–7 (in the context of dementia).

¹⁵⁵ CRPD (n 42) art 12; Committee on the Rights of Persons with Disabilities, *General Comment No 1: Article 12: Equal Recognition Before the Law*, UN Doc CRPD/C/GC/1 (19 May 2014, adopted 11 April 2014).

¹⁵⁶ Shih-Ning Then et al, 'Supporting Decision-Making of Adults with Cognitive Disabilities: The Role of Law Reform Agencies' (2018) 61 *International Journal of Law and Psychiatry* 64, 64–75.

¹⁵⁷ Nola M Ries, Elise Mansfield and Rob Sanson-Fisher, 'Ethical and Legal Aspects of Research Involving Older People with Cognitive Impairment: A Survey of Dementia Researchers in Australia' (2020) 68 *International Journal of Law and Psychiatry* 101534 (who make this comment in relation to participation in dementia research).

¹⁵⁸ *Medical Treatment Planning and Decisions Act 2016* (Vic) pt 3 div 3; *Powers of Attorney Act 2014* (Vic) pt 7; *Guardianship and Administration Act 2019* (Vic) pt 4.

¹⁵⁹ Then et al, (n 156) 64–75; Tasmanian Law Reform Institute, *Review of the Guardianship and Administration Act 1995 (Tas)* (Final Report No 26, December 2018).

¹⁶⁰ *Guardianship and Administration Act 2000* (Qld) s 11B(3) (General Principle 10); *Powers of Attorney Act 1998* (Qld) s 6C (General Principle 10).

person — as in Victoria — may mean access to greater individualised assistance to understand and make decisions about participating in research. However, empirical evidence demonstrating this benefit is lacking.

2 *Substituted Consent — Making Decisions in Accordance with an Older Person's Preferences*

One mechanism whereby an older person with COVID-19 who lacks decision-making capacity may become a research participant is when authorisation is provided by a substitute decision-maker. The NHMRC *National Statement on Ethical Conduct in Human Research: 2007 (Updated 2018)* anticipates substitute decision-making occurring on behalf of some research participants.¹⁶¹ Here, the focus is on substitute decision-makers appointed by the person prior to a loss of decision-making capacity (eg enduring attorneys, enduring guardians) and default decisions-makers (eg statutory health attorneys, persons responsible, medical treatment decision makers, etc).

3 *Substitute Decision-Maker Appointed by the Person with COVID-19*

Most jurisdictions in Australia provide for a person with decision-making capacity to self-appoint a substitute decision-maker (eg enduring attorneys, enduring guardians), who is empowered to make decisions on that person's behalf during periods when they lack decision-making capacity. Relevantly in some jurisdictions, a substitute decision-maker may be appointed with authority to make medical decisions including participation in medical research.

In Victoria, Western Australia and the ACT, the appointment of substitute decision-makers is dealt with explicitly by legislation.¹⁶² Appointed substitute decision-makers with authority to make research decisions are required to consider a range of factors before making a decision.¹⁶³ Relevant to the COVID-19 pandemic, appointed decision-makers can make research decisions including participation in clinical trials or experimental health care.¹⁶⁴

In other Australian jurisdictions, the situation is more complex with different constraints on appointed substitute decision-makers and different pathways for authorising participation in medical research depending on whether

¹⁶¹ *National Statement on Ethical Conduct* (n 153) chs 4.4–4.5.

¹⁶² *Powers of Attorney Act 2006* (ACT) pt 4.3A; *Medical Treatment Planning and Decisions Act 2016* (Vic) s 75; *Guardianship and Administration Act 1990* (WA) pt 9E.

¹⁶³ *Powers of Attorney Act 2006* (ACT) s 41B–41D; *Medical Treatment Planning and Decisions Act 2016* (Vic) s 77; *Guardianship and Administration Act 1990* (WA) pt 9E div 2.

¹⁶⁴ This is sometimes referred to as 'health care that has not yet gained the support of a substantial number of practitioners in that field': *Guardianship and Administration Act 1990* (WA) s 3AA(2)(c). See also *Powers of Attorney Act 2006* (ACT) s 41A(2)(a)(i) (definition of 'experimental health care'). In Victoria, a medical research procedure includes 'procedure[s] carried out ... as part of a clinical trial': *Medical Treatment Planning and Decisions Act 2016* (Vic) s 3(1)(a) (definition of 'medical research procedure').

the research is classified as a clinical trial or experimental health care. Both may be relevant to COVID-19 research. Furthermore, in some jurisdictions, medical research is only able to be authorised if it comes within the ambit of general health care.

(a) Clinical Trials

In NSW and Queensland, if the research is a clinical trial with human research ethics approval, specific approval from the relevant Civil and Administrative Tribunal is required before participants who lack capacity can be recruited.¹⁶⁵ Once this approval is given, a substituted decision-maker appointed in relation to health care can generally provide consent on behalf of a proposed participant to participate in that clinical trial.¹⁶⁶ A similar situation exists in the Northern Territory but, unlike NSW and Queensland, there appears to be no need for tribunal approval. Instead, an ‘approved clinical research’ is carved out of the definition of restricted health care allowing an appointed decision-maker to authorise participation.¹⁶⁷

(b) Experimental Health Care

In these three jurisdictions, different authorisation pathways exist for health care that are experimental or ‘new health care of a kind that is not yet accepted as evidence-based, best practice health care by a substantial number of health care providers specialising in the relevant area of health care’. This type of research is also relevant to COVID-19 research where there is a limited and emerging, established evidence-base.

In NSW, this pathway is classified as ‘special treatment’ and can only initially be consented to by the NSW Tribunal, although the Tribunal can give authority for subsequent consent to a substitute decision-maker.¹⁶⁸ A similar situation exists in Queensland regarding ‘special medical research or experimental health care’.¹⁶⁹

¹⁶⁵ *Guardianship and Administration Act 2000* (Qld) s 74C; *Guardianship Act 1987* (NSW) pt 5 div 4A. For a recent case brought before the NSW Civil and Administrative Tribunal for authorisation to conduct a clinical trial related to COVID19 treatment see *Re STC3141* [2020] NSWCATGD 16, discussed in Freckelton (n 153) 103–106.

¹⁶⁶ However, the NSW Tribunal can choose to retain this function: *Guardianship Act 1987* (NSW) s 45AB.
¹⁶⁷ See *Advance Personal Planning Act 2013* (NT) s 25; *Advance Personal Planning Regulations 2014* (NT) reg 4. Note, guardians appointed by the tribunal in the Northern Territory are not authorised to consent to restricted health matters including health care provided for medical research purposes or new health care of a kind that is not yet accepted as evidence-based, best practice health care by a substantial number of health care providers specialising in the relevant area of health care: *Guardianship of Adults Act* (NT) ss 8(d)–(e), 23(2); *Guardianship of Adults Regulations 2016* (NT) reg 3(a).

¹⁶⁸ *Guardianship Act 1987* (NSW) ss 45(3), 45A.

¹⁶⁹ *Guardianship and Administration Act 2000* (Qld) ss 68, 72, 74.

In the Northern Territory, a substitute decision-maker cannot make these types of decisions and the Tribunal cannot empower them to provide subsequent consent in the same way.¹⁷⁰ The Tribunal's power to authorise research where it cannot be construed as a 'health care action' also seems limited.¹⁷¹

(c) *When Research is Not Mentioned in Legislation*

In South Australia and Tasmania, the legislation does not mention medical research. Therefore, for a substitute decision-maker to lawfully consent on behalf of an adult who lacks capacity to consent to participation in COVID-19 related research, that research must be categorised as a form of 'health care'.¹⁷² A substitute decision-maker in South Australia would need to try to make a decision that reflects what the person would have decided if they had capacity, whereas in Tasmania they would need to be satisfied that the research would be in the person's best interests.¹⁷³ Current Tasmanian legislation has led to uncertainty regarding who can authorise participation in research and in what circumstances.¹⁷⁴ For example, it could be argued that participation in a COVID-19 clinical trial or in experimental health care may fall within the broad ambit of making a medical decision on behalf of the person who lacks decision-making capacity. COVID-19 is a relatively new condition and treatment options are still developing, with much experimentation in management occurring globally. However, this claim may seem disingenuous — particularly in phase 0/1 clinical trials where benefit is not anticipated or very rare.

¹⁷⁰ *Advance Personal Planning Act 2013* (NT) s 25(2)(d); *Advance Personal Planning Regulations 2014* (NT) reg 4.

¹⁷¹ *Advance Personal Planning Act 2013* (NT) ss 3, 44. (Note, s 3 defines the following terms: "health care action" for an adult, means commencing, continuing, withholding or withdrawing health care for the adult"; "health care" means health care of any kind, including: (a) anything that is part of a health service, as defined in section 5 of the Health Practitioner Regulation National Law; and (b) the removal of tissue from a person's body in accordance with Part 2 of the *Transplantation and Anatomy Act 1979*).

¹⁷² *Consent to Medical Treatment and Palliative Care Act 1995* (SA) s 14(1): definition of 'health care' 'means any care, service, procedure or treatment provided by, or under the supervision of, a health practitioner for the purpose of diagnosing, maintaining or treating a physical or mental condition of a person'; *Guardianship and Administration Act 1995* (Tas) s 3: definition of 'medical or dental treatment' includes '(a) medical treatment (including any medical or surgical procedure, operation or examination and any prophylactic, palliative or rehabilitative care) normally carried out by, or under, the supervision of a medical practitioner; or (b) dental treatment (including any dental procedure, operation or examination) normally carried out by or under the supervision of a dentist'.

¹⁷³ *Consent to Medical Treatment and Palliative Care Act 1995* (SA) s 14C. Cf *Guardianship and Administration Act 1995* (Tas) s 43.

¹⁷⁴ See, eg, Tasmanian Law Reform Institute (n 159) 303–14 [13.7].

(d) Legislative Default Substitute Decision-Maker

In all jurisdictions (except the Northern Territory), legislation provides for someone to act as a substitute decision-maker for health decisions in the absence of a formal appointment (here referred to as the ‘default decision-maker’).¹⁷⁵ The relevant question is whether the legislative ‘default decision-maker’ for health care can make decisions regarding participation in medical research. In Western Australia and Victoria, the legislation authorises a person to act as a decision-maker for research decisions in the absence of an appointed substitute decision-maker or a tribunal/court appointed guardian.¹⁷⁶ The legislation differs in the specific factors that need to be considered by the default decision-maker prior to consenting. Western Australia, for example, has recently instituted a number of requirements including the need to obtain independent medical advice.¹⁷⁷ In contrast, the ACT’s equivalent default decision-maker is not able to authorise participation in ‘medical research’ (including experimental health care and clinical trials), and is instead only able to consent to the lesser and much smaller category of ‘low-risk research’ where the person would benefit from participating.¹⁷⁸

In Queensland, NSW, South Australia and Tasmania the same limitations appear to apply to the default decision-maker (known as the ‘statutory health attorney’ or ‘person responsible’) as to an appointed substitute decision-maker (discussed in the previous section). These inconsistencies and uncertainties present significant challenges for COVID-19 research participation by Australians.

(e) Decision-Making Principles

Where a person is authorised to make a substituted decision for participation in research, increasingly legislation requires a substitute decision-maker to take into account the human rights of the individual. Modern substitute decision-making legislation has been heavily influenced by the CRPD and this is reflected

¹⁷⁵ Ben White, Lindy Willmott and Shih-Ning Then, ‘Adults who Lack Capacity: Substitute Decision-Making’ in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 3rd ed, 2018) 208, 261–3.

¹⁷⁶ *Medical Treatment Planning and Decisions Act 2016* (Vic) ss 75, 77; *Guardianship and Administration Act 1990* (WA) ss 110ZP, 110ZQ, 110ZR.

¹⁷⁷ *Guardianship and Administration Act 1990* (WA) pt 9E div 2. See also, eg, *Medical Treatment Planning and Decisions Act 2016* (Vic) s 77.

¹⁷⁸ See *Guardianship and Management of Property Act 1991* (ACT) s 32D; *Powers of Attorney Act 2006* (ACT) s 41A(1): the definition of ‘low-risk research, in relation to a person — (a) means research carried out for medical or health purposes that — (i) poses no foreseeable risk of harm to the person, other than any harm usually associated with the person’s condition; and (ii) does not change the treatment appropriate for the person’s condition; but (b) does not include any activity that is part of a clinical trial’. Appointed substitute decision-makers are given wider powers to make decisions in relation to medical research: see *Powers of Attorney Act 2006* (ACT) pt 4.3A.

in the principles that must be followed by decision-makers, which prioritise the person's will and preferences.¹⁷⁹

The usual driver for participation in research is often an altruistic desire to contribute to a greater common good. While this altruistic motivation can be accommodated within the human rights principles of recognising a person's 'will and preferences', there can be difficulties for substitute decision-makers where a person's wishes appear to conflict with the person's other 'rights', for example, to avoid unnecessary medical intrusion or pain associated with administering treatment in a clinical trial. Acting as a substitute decision-maker is not an easy task and many may feel underprepared for the role.¹⁸⁰

C Participating in COVID-19 Research in Australia

In summary, in some Australian jurisdictions, confusion exists and/or barriers prevent older Australians with diminishing or no decision-making capacity from participating in research, even in circumstances where they may have wished to do so.

Current global research efforts have thrown into sharp relief the domestic regulatory barriers for older Australians to participate in medical research. Given the ongoing nature of urgent medical research both now and post-pandemic, state and territory governments should consider re-examining these regulatory barriers to participation in medical research by older Australians. Allowing Australians with diminished capacity or who lack capacity to participate in research when they wish to do so may be a significant way to respect that person's autonomy. Clarification of substitute decision-makers' legal authority to consent to such research — in circumstances where they know that a person would want to participate — is sorely needed in some Australian jurisdictions. In the absence of immediate legal reform, more practical guidance is needed to navigate the complexities of the legal framework for researchers, human research ethics committees and substitute decision-makers who are involved in deciding when older Australians can participate in COVID-19 related research. Until research provides solutions, older Australians are likely to continue bearing the brunt of this pandemic.

VII CONCLUSION

The challenges posed by COVID-19 have and will continue to test Australian law and policy in a wide range of areas impacting older persons. As we move towards living with COVID-19, it will be important to reflect upon the role of law in

¹⁷⁹ See, eg, *Medical Treatment Planning and Decisions Act 2016* (Vic) s 77.

¹⁸⁰ Freckelton (n 153) 106.

supporting the lives, health and social connectedness of ‘older’ Australians. It will be important to do so respecting both human rights and principles, while also remembering that ‘older persons’ are not a homogenous group. Whereas older people have been at increased risk of severe illness and mortality associated with COVID-19,¹⁸¹ automatically conceptualising them as vulnerable based on age alone risks perpetuating damaging and ageist stereotypes running counter to a human rights-based approach. Significantly, in this context, although international human rights law sees older people as active holders of rights, as discussed in Part III, there is, to date, no international convention that specifically addresses the rights of older people. Such a convention would help to guide the development of Australian laws and policies in this area. With or without an international convention, human rights laws should be enacted in all Australian jurisdictions to provide greater guidance for balancing competing rights-based claims in the context of public health responses. Further, these laws should clarify the obligations of private actors, such as aged-care service providers, and ensure adequate enforcement processes are available in the event that a breach of human rights occurs.

Even in the area of discrimination law, which does provide protection from age discrimination, as our discussion in Part IV illustrated, the definitions and scope of the relevant Acts may present practical challenges in addressing the issues raised in the context of COVID-19. It is a particular deficiency of the *DDA* and *ADA* that, even when there is clear evidence of discrimination, a remedy may be difficult to pursue.

As our analysis in this article also shows, in some areas, such as wills and estate planning, discussed in Part V, Australian law has proved adaptable, utilising technology to respond to the challenges posed by, for example, social distancing and isolation requirements, although, as discussed, it must be recognised that technology is unlikely to be a total solution to these challenges. In other areas, such as the regulation of medical research, discussed in Part VI, the pandemic has highlighted the complexity of existing regulatory frameworks, which may potentially be a barrier to participation in research by those who have expressed a wish to participate but now have diminished capacity or lack capacity. It will be important to ensure that our laws provide appropriate legal mechanisms for decision-making, consistent with the wishes of individuals, regarding participation in research.

Understanding that the experience of ageing ‘while universal, is not uniform’,¹⁸² can help to inform analysis of the rights and needs of older Australians. While COVID-19 has so effectively highlighted the importance of these issues, their recognition should remain an on-going priority for Australian law and any potential future law reform agendas.

¹⁸¹ See (n 15).

¹⁸² See World Health Organization, *Ageism* (n 2) xix. See also Part II.