A HUMAN RIGHTS ANALYSIS OF THE IMPACTS OF COVID-19 ON PERSONS IN AUSTRALIAN RESIDENTIAL AGED CARE FACILITIES

Submission to the Independent Expert on the enjoyment of all human rights by older persons

by

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1. INTRODUCTION

'She didn't have to die that way. None of them did...I get really angry when people say we're doing very well in Australia.'

Daughter describing the loss of her mother during a COVID-19 outbreak at an aged care facility in Victoria, July 2020.¹

1.1. About the authors

The Castan Centre for Human Rights Law ('Castan Centre') is an academic research centre within the Faculty of Law at Monash University which promotes human rights through research, policy submissions, education, and public engagement.² The Prof Joe Aged Care Advocacy Group led by Professor Joseph E Ibrahim conducts advocacy and provides education to raise awareness of the situation of persons in aged care.³

The authors, with support from students at the Castan Centre Human Rights Clinic, are collaborating on a project to analyse Australian residential aged care facilities ('RACFs') from a human rights perspective and demonstrating the need for Australia to adopt a rights-based approach to aged care that upholds the dignity, wellbeing and rights of older persons. Witnessing the disproportionate impact of the COVID-19 pandemic on older persons across the world, including Australia, our project has in the first instance been focused on Australia's response to the pandemic and its impacts on human rights of persons in RACFs and their family members.

1.2 Background to this submission

The authors welcome the mandate of the Independent Expert to ensure the enjoyment of all human rights by older persons, the importance of which has been particularly highlighted by the COVID-19 pandemic. Our submission presents information which raises serious concerns about the dignity, wellbeing, and rights of persons in Australian RACFs during the pandemic. We agree with the Independent Expert that these types of concerns are not new but are reflective of 'existing protection gaps' that stem from long-standing and systemic exclusion of older persons in society.⁴

¹ Interview 1 with family member (online, 12 November 2020).

² 'Castan Centre for Human Rights Law', *Monash University* at https://www.monash.edu/law/research/centres/castancentre/castancentre.

³ 'Prof Joe Aged Care Advocacy Group', *Prof Joe* at https://www.profjoe.com.au.

Claudia Mahler, Special Rapporteur, Report on the Impact of the coronavirus disease (COVID-19) on the enjoyment of all human rights by older persons, UN Doc A/75/205 (21 July 2020) [22].

The submission shares many of the Independent Expert's findings in her July 2020 report to the United Nations General Assembly on the impacts of COVID-19 on the rights of older persons. The aim of our submission is to bring concerns from Australia to the attention of the Independent Expert and other Special Procedure mandates for which the information is relevant. The submission is supported by desk-based research and testimonies of family members of persons in RACFs who lost their lives during the pandemic.

While not intended as an exhaustive account of what has taken place in Australian RACFs, the submission presents concerning information of past incidents and ongoing concerns regarding the dignity, wellbeing, and rights of persons in the Australian aged care system. Importantly, the submission provides a voice at the international level for persons directly affected by the lack of a rights-based approach to aged care in Australia. This is especially necessary in light of the lack of a national Bill of Rights or similar in Australia and the absence of a regional human rights mechanism through which persons in RACFs and their families can voice claims of human rights violations and seek effective remedy.

We hope that the submission will inform future reports and actions by the Independent Expert to address the gaps in protection of the rights of older persons, including persons living in RACFs and other institutions, and ensure that older persons are no longer left behind.

2. AGED CARE IN AUSTRALIA

2.1 Existing regulation and barriers to effective protection

2.1.1 Overview

RACFs in Australia include 'accommodation and personal care 24 hours a day, as well as access to nursing and general health services'. Persons aged 65 years or over (50 years for persons identifying as Indigenous) and who need support to carry out day-to-day life may be eligible for a place at a government-funded RACFs. 7

A government-funded RACF is subsidised and regulated by the federal government primarily through the *Aged Care Act* 1997 (Cth) and the *Quality of Care Principles* 2014 (Cth) ('Quality Principles'). It is run by an approved provider which may be a public, not-for-profit community, faith-based or charitable entity or a private entity.

Care for persons in need of support may also be provided through so-called "supported residential services (not classified as RACFs). These may be private and in the State of

6 'COVID-19 cases in aged care services – residential care', Australian Government Department of Health (30 September 2020) at https://www.health.gov.au/resources/covid-19-cases-in-aged-care-services-residential-care.

⁵ Ibid.

⁷ 'What is aged care?', *Australian Government Department of Health* at https://www.health.gov.au/health-topics/aged-care/about-aged-care/what-is-aged-care.

Victoria, for example, are regulated by the State Government.⁸ Such services may include retirement villages which are not RACFs but private-based operations.⁹ Analysis of non-RACFs however is beyond the scope of this submission.

To operate a RACF within the federal aged care system, providers must first be accredited by the regulator for aged care services, the Aged Care Quality and Safety Commission ('ACQSC') established through the *Aged Care Quality and Safety Commission Act 2018* (Cth).¹⁰ The ACQSC has various categories of functions in addition to accreditation, including the handling of complaints, provision of education, and 'consumer' engagement.¹¹ From 1 July 2019, approved providers which provide government-funded aged care services must comply with the *Aged Care Quality Standards* ('Quality Standards') against which the ACQSC monitors compliance.¹²

2.1.2 Complaints processes

In respect of complaints, the ACQSC has powers to 'enter and search' premises of an approved provider in response to a complaint relating to, for example, responsibilities under the Quality Principles such as upholding the dignity of the persons living in the RACF.¹³ While an approved provider has a responsibility to cooperate with the ACQSC under the *Aged Care Act 1997*, the ACQSC must still obtain consent of the occupier of the premises in question before conducting the search, which could conceivably pose a barrier to effective investigation of complaints.¹⁴

2.1.3 Lack of a human rights-based approach

An underlying problem to the effective protection of the rights of persons in Australian RACFs is the treatment of aged care as a consumer rights issue. As a starting point, the Quality Standards include Quality Standard 1 which focuses on '[c]onsumer dignity and choice'. 15

In addition, so-called 'consumer rights' are set out in the *Charter of Aged Care Rights* produced under the *Aged Care Act 1997* (Cth) which lists 14 rights that approved providers of all forms of government-funded aged care services, including RACFs, must respect.¹⁶ Persons receiving eligible aged care services must be given the option of signing the Charter and the

Aged Care Quality and Safety Commission Act 2018 (Cth) pt 2.

⁸ 'Non-government-funded providers', *Australian Government MyAgedCare* at https://www.myagedcare.gov.au/non-government-funded-providers; See e.g. *Supported Residential Services (Private Proprietors) Act 2010* (Vic).

⁹ Ibid.

¹¹ Ibid pt 3.

^{&#}x27;Guidance and Resources for Providers to support the Aged Care Quality Standards', Aged Care Quality and Safety Commission (Guidance Document, December 2019) at https://www.agedcarequality.gov.au/sites/default/files/media/Guidance %26 Resource V11.pdf.

¹³ Aged Care Quality and Safety Commission Act 2018 (Cth) s 65.

¹⁴ Ibid ss 66(1)(b), 65(3), 66.

¹⁵ Ibid p 15.

¹⁶ Charter of Aged Care Rights.

provider must provide an explanation of the rights therein.¹⁷ The consumer rights reflect various human rights recognised under international law, such as the right to 'be treated with dignity and respect' and to be informed about care and services in a way which the person receiving the services understands.¹⁸ While providers have an obligation to give the Charter to new residents and explain its content, this appears to mainly be a procedural obligation on part of providers to the funder.¹⁹ Persons in RACFs may also receive services without signing the Charter, which is voluntary.²⁰ The Charter regime also renders persons in RACFs dependent upon whether or not the provider does in fact provide them with the Charter and explains the meaning of the rights. For these reasons, the Charter does not present an alternative to a human rights-based approach to aged care whereby persons in receipt of aged care have recourse to an effective remedy following human rights breaches by the government and/or third parties.

In addition to the above, framing aged care as a consumer rights issue is problematic on several other counts. In particular, it fails to: (a) recognise the universal nature of human rights; and (b) adequately reflect the primary responsibility of the Australian governments (at the federal, state and territory levels) themselves to respect, protect and fulfil these rights. This includes taking steps, for example through regulation, to ensure that third parties do not violate rights.²¹ We underline the UN Human Rights Committee's observation that:

'[t]here may be circumstances in which the failure to ensure Covenant rights...would give rise to violations by States parties of those rights, as a result of States Parties' permitting or failing to take appropriate measures or to exercise due diligence to prevent, punish, investigate or redress the harm caused by such acts by private persons or entities.'²²

This observation underlines the various human rights principles upon which such regulation must be based, for example transparency, accountability and redress. A system of monitoring and complaints which depends in part on the consent of the provider or whether or not the provider provided the requisite information about rights to the person in RACFs (such as the system described in the preceding paragraphs) would not appear to bring about accountability and redress.

¹⁷ Ibid.

¹⁸ Ibid rights 2 and 5.

¹⁹ User Rights Principles 2014 (Cth) principle 11(1)-(2).

²⁰ Ibid principle 11(3).

See e.g. UN Human Rights Committee ('HRC'), General Comment No 31: The nature of the general legal obligation imposed on States Parties to the Covenant, 80th sess, UN Doc CCPR/C/21/Rev.1/Add.13 (29 March 2004) [8]. The UN Guiding Principles on Business and Human Rights also provide important guidance as to the positive obligations on part of States Parties to protect against third party violations - John Ruggie, Special Representative of the Secretary-General, Report on the Issue of Human Rights and Transnational Corporations and Other Business Enterprises, UN Doc A/HRC/17/31 (21 March 2011) annex 'Guiding Principles on Business and Human Rights: Implementing the United Nations 'Protect, Respect and Remedy' Framework'.

²² Ruggie (n 21).

A human rights-based framework may be inspired by instruments such as the *UN Guiding Principles on Business and Human Rights*.²³ While not legally binding, it provides an important normative framework to guide States Parties and private entities on how to uphold human rights obligations. As suggested by the Independent Expert, the *Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons* may provide another useful framework specifically focused on the rights of older persons to ensure a rights-based approach to aged care.²⁴

The absence of a human rights approach to aged care is particularly problematic in the context of Australia where there is currently no national level Charter or Bill of Rights which could alternatively be used to hold Australian governments to account for failure to respect, protect and fulfil rights, including that of persons in RACFs. Further, specific human rights legislation has only been enacted at the state and territory level in three jurisdictions, the Australian Capital Territory, Victoria and Queensland, which have incorporated some international human rights (mostly civil and political rights) into domestic law²⁵ As such, there are limited opportunities to bring complaints against governments for human rights breaches.

As evident from the date of most of the aged care instruments discussed above, most tools to measure, evaluate and improve quality and safety of the aged care sector are recent. In March 2019, the then Minister for Senior Australians and Aged Care, Mr Ken Wyatt AM, described the *Aged Care Charter of Rights* as a 'New Era of Aged Care Rights'. ²⁶ However, these recent reforms did not represent a human rights-turn in aged care. In fact, the extent to which the aged care is regulated remains more limited than in other sectors. For example, the aged care sector does not contain the same level of safeguards as the disability care sector to protect older persons from the use of restrictive practices, ²⁷ despite evidence of the detrimental impact which such practices have on the dignity, wellbeing and rights of older persons. ²⁸

In summary, treating aged care as a 'consumer rights' issue rather than a human rights issue in Australia demonstrates a failure to recognise the fundamental nature of these rights and the primary responsibility of Australian governments to ensure the enjoyment of all human rights of older persons on an equal basis with others. This is further evidenced by the limited regulation of aged care in contrast with other comparable sectors.

2.2 Royal Commission into Aged Care Quality and Safety

Mahler (n 4) [20] citing Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons (11 July 2003).

²³ Ibid.

²⁵ Human Rights Act 2004 (ACT); Charter of Human Rights and Responsibilities Act 2006 (Vic); Human Rights Act 2019 (Qld).

Wyatt AM, Ken, 'Ministerial media release: Australia Signs Up for New Era of Aged Care Rights', Aged Care Quality and Safety Commission (Media Release, 23 March 2019) at https://www.agedcarequality.gov.au/news/media-centre/ministerial-media-release-australia-signs-new-era-aged-care-rights.

²⁷ Castan Centre for Human Rights Law, *Use of Force in Detention and Other Closed Environments* (Report, November 2020) ch 3.

See e.g. Human Rights Watch, "Fading Away": How Aged Care Facilities in Australia Chemically Restrain Older People with Dementia (Report, 2019).

2.2.1 Previous investigations leading to the Royal Commission

COVID-19 impacted Australia at a time when the aged care sector was already undergoing significant review due to serious concerns about weaknesses in existing regulation as concluded in the previous section. This effort, resulted in numerous reports of, and investigations into, poor quality and safety of aged care services.²⁹ Among the concerns raised in these previous investigations were issues including poor access to and quality of care, excessive use of restraints (both chemical and physical), staff shortages and lack of appropriate training of staff, lack of regulatory oversight, difficulty in accessing complaints procedures, and the difficulty for people to navigate and understand the aged care system.³⁰

These revelations led to the establishment of a Royal Commission into Aged Care Quality and Safety ('Aged Care Royal Commission') on 8 October 2018 to analyse whether the quality and safety of aged care services meets the needs of the Australian community.³¹

2.2.2 The Interim Report

In its 2019 Interim Report, titled 'Neglect', the Aged Care Royal Commission found that the Australian aged care system:

'fails to meet the needs of our older, often very vulnerable, citizens. It does not deliver uniformly safe and quality care for older people. It is unkind and uncaring towards them. In too many instances, it simply neglects them.'32

With regret, the Commissioners declared that much of the concerns expressed in the previous investigations remained. In response to these and other findings, the Royal Commission has therefore called for 'a fundamental overhaul' of the way in which the aged care system is designed, regulated, and funded in Australia.³³

Senior Counsel Assisting the Royal Commission, Peter Gray QC and Peter Rozen QC, submitted their recommendations to the Royal Commission at the final Commission hearing in October 2020.³⁴ Among the recommendations featured is the call for a rights-based approach to aged care which, as noted above, is missing in the existing system.³⁵ The authors hope that the Aged Care Royal Commission strongly advocates these recommendations in its final report due to be published at the end of February 2021.

See e.g., Australian Law Reform Commission, Elder Abuse – A National Legal Response (Report No 131, May 2017); Kate Carnell AO and Prof Ron Paterson ONZM, Review of National Aged Care Quality Regulatory Processes (Report, October 2017). A collection of the findings of these and other reviews of the aged care system in Australia was produced by the Royal Commission into Aged Care Quality and Safety (Background Paper 8 - A history of aged care reviews, 28 October 2019).

Royal Commission into Aged Care Quality and Safety, Background Paper 8 (n 29) 1.

³¹ Royal Commission into Aged Care Quality and Safety (Interim Report: Neglect, 31 October 2019) vol 1.

³² Ibid 1.

³³ Ibid 10.

Peter Gray QC and Peter Rozen QC, Counsel Assisting's Submissions to the Royal Commission into Aged Care Quality and Safety (22 October 2020).

³⁵ Ibid [18], [149], [151].

In light of the existing challenges to the wellbeing, dignity and rights of persons in Australian aged care, COVID-19 has added unprecedented pressure to an already weak system in Australia, which is operating without a rights-based focus and is regulated by a newly established regulator with no experience of handling public health emergencies and without relationships with the sector.³⁶ The following section of the submission considers the impacts of COVID-19 on Australian RACFs and analyses these in light of the human rights of persons who had entrusted their wellbeing, dignity and rights (or that of their loved ones) to the Australian aged care system.

2.3 COVID-19 and Aged Care

2.3.1 Background

As the Independent Expert has noted, COVID-19 presents a particular risk for older persons as it disproportionately impacts older persons and magnifies violations of their rights.³⁷ The Independent Expert has also made clear that in addition to the impacts on the rights to life and health caused by contracting the virus, governments across the world have acknowledged instances of neglect of persons in aged care facilities.³⁸ In a statement signed by 146 governments, the signatories (including Australia) underlined that they were:

'deeply concerned about distressing reports indicating instances of neglect and mistreatment as well as high rates of mortality due to COVID-19, which are affecting older people living in nursing homes and care institutions.'39

The Aged Care Royal Commission has continued its work during the pandemic and in a special report on COVID-19 and aged care similarly observed that the pandemic poses an unprecedented challenge for the Australian aged care sector.⁴⁰

2.3.2 Statistics⁴¹

As the Aged Care Royal Commission noted in its special report, Australia's overall COVID-19 fatality rate of 2.6% (in September 2020) is low by international comparison while the rate of

Prof Joseph E Ibrahim, 'Precis of Evidence to the Royal Commission into Aged Care Quality and Safety' (Exhibit, 5 August 2020) [29]-[30] at https://agedcare.royalcommission.gov.au/system/files/2020-08/RCD.9999.0411.0001.pdf.

Claudia Mahler, Special Rapporteur, 'Older Persons Remain Chronically Invisible Despite Pandemic Spotlight, Says UN Expert' (2020) at https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx? NewsID=26319&LangID=E.

Mahler (n 4) [28] citing UN Department of Economic and Social Affairs ('UNDESA'), '146 Member States support the Secretary-General's policy brief on COVID-19 and older persons' (12 May 2020) at https://www.un.org/development/desa/ageing/uncategorized/2020/05/140-member-states-support-the-sg-policy-brief-on-covid19-and-older-persons/.

³⁹ Ibid

⁴⁰ Royal Commission into Aged Care Quality and Safety (Special Report, 1 October 2020) 2.

⁴¹ Continuously up-to-date statistics are available here at https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/coronavirus-covid-19-current-situation-and-case-numbers.

persons dying from COVID-19 and living in RACF, 74% (in September 2020), is 'a high figure by international standards'. ⁴² As reported by the Australian Department of Health (as of 8 January 2021), the *total number of RACFs* that have had outbreaks is 218 with a total number of *outbreaks that have taken place in RACFs* at 224 (as there were instances of more than one outbreak in some RACFs). ⁴³ The great majority of these outbreaks have been in the State of Victoria, with outbreaks of two or more cases also reported at four homes in New South Wales, one in South Australia and one in Tasmania. ⁴⁴ No active cases in Australian RACFs were reported as of 8 January 2021, with the last case being identified on 26 September 2020. ⁴⁵

2.3.3 Timeline of events⁴⁶

Australia's first case of COVID-19 was confirmed by the Minister for Health on **25 January 2020**, and a COVID-19 'Emergency Response Plan' was activated on 27 February 2020.⁴⁷ This was not a specific plan for the aged care sector but a national health sector plan which would be adapted and applied to specific sectors, including aged care.⁴⁸ The first RACF outbreak was confirmed in New South Wales on **3 March 2020**.⁴⁹ The first outbreak lasted approximately two months (until 7 May 2020) during which six persons in aged care with COVID-19 died.⁵⁰

An Aged Care COVID-19 Preparedness Forum was held by the Government on **6 March 2020**, just after the first outbreak was confirmed.⁵¹ Various commitments for specific preparedness in the aged care sector were made, such as for the Government to clarify roles of governments and providers in the COVID-19 response; develop strategies to ensure sufficient workforce; and communicate with aged care workers to provide guidance on how to stay protected and prepared.⁵² Issues of importance in respect of providers included the need

⁴² Royal Commission into Aged Care Quality and Safety, Special Report (n 40) 2.

^{43 &#}x27;COVID-19 outbreaks in Australian residential aged care facilities: National snapshot', *Australian Government Department of Health* (8 January 2021) at https://www.health.gov.au/sites/default/files/documents/2021/01/covid-19-outbreaks-in-australian-residential-aged-care-facilities-8-january-2021.pdf.

⁴⁴ Ibid.

⁴⁵ Ibid.

This timeline is drawn in part from the evidence provided by Prof Joseph E Ibrahim, co-author of this submission, to the Aged Care Royal Commission in August 2020. The full account of this timeline with more details is available at Ibrahim (n 36) [28].

⁴⁷ Greg Hunt, Minister for Health, and Prof Brendan Murphy, Chief Medical Officer, 'First confirmed case of novel coronavirus in Australia' (Media Release, 25 January 2020) at https://parlinfo.aph.gov.au/parlInfo/download/media/pressrel/7158085/upload_binary/7158085.pdf; Prime Minister of Australia, 'Transcript' (Press Conference, 27 February 2020) at https://www.pm.gov.au/media/press-conference-australian-parliament-house-4.

⁴⁸ Royal Commission into Aged Care Quality and Safety, Special Report (n 40) 4.

⁴⁹ 'Nurse and resident diagnosed with COVID-19' *NSW Government Health* (Media Release, 4 March 2020) at https://www.health.nsw.gov.au/news/Pages/20200304 03.aspx.

⁵⁰ Royal Commission into Aged Care Quality and Safety, Special Report (n 40) 4-5.

^{51 &#}x27;Statement from the Aged Care COVID-19 Preparedness Forum' *Ministers Department of Health* (Joint Statement, 9 March 2020) at https://www.health.gov.au/ministers/senator-the-hon-richardcolbeck/media /statement-from-the-aged-care-covid-19-preparedness-forum.

⁵² Ibid.

for each provider to activate COVID-19 response plans that include testing, maintaining infection control protocols, and communicating with persons in RACFs and their families on a regular basis regarding developments.⁵³ Commenting on the Government's COVID-19 response in aged care in evidence before the Aged Care Royal Commission in August 2020, Professor Joseph E Ibrahim, one of the authors of this submission, observed that Australia would have been 'far better prepared' if these concerns identified by the Government in early March 2020 had been effectively addressed.⁵⁴

On **13 March 2020**, the *National Guidelines for the Prevention, Control and Public Health Management of COVID-19 Outbreaks in Residential Care Facilities in Australia* were published by the Communicable Diseases Network Australia ('CDNA Guidelines').⁵⁵ With regards to RACFs specifically, the ACQSC also conducted an audit of preparedness of facilities, which was fraught with issues.

The audit was conducted through a self-assessment survey with approved providers. which Professor Ibrahim has highlighted was unlikely to generate 'full and frank response[s]' due to fear of sanctions from the regulator. A clear example of this is evidenced in the self-assessment surveys of two Victorian RACFs which responded that their homes were adequately prepared to handle an outbreak, and yet went on to experience the worst outbreaks seen in RACFs around the country (discussed in further detail below). The overestimation of capacity in the self-assessment forms was also recognised in the Aged Care Royal Commission's special report, which indicated that 99.5% of RACF survey respondents considered their preparedness as best practice or satisfactory. Further, the questions asked in the survey were arguably broad and do not appear to have provided a straightforward way for the ACQSC to provide tangible guidance to providers on any issues raised. A review of the two Victorian homes above underlined that 'self-assessment of any kind is no substitute for practicing or exercising a plan'.

There has also been indication that CDNA Guidelines themselves were inadequate. For example, the manager of one of the RACFs with an outbreak in Sydney which had a 46% mortality rate, Newmarch House, gave evidence before the Aged Care Royal Commission that the facility had followed the CDNA Guidelines when developing a COVID-19 response plan

⁵³ Ibid.

⁵⁴ Ibrahim (n 36) [28].

CDNA National Guidelines for the Prevention, Control and Public Health Management of COVID-19 Outbreaks in Residential Care Facilities in Australia, Communicable Diseases Network Australia (Guidelines, 13 March 2020) (updated on 30 April and 14 July 2020 respectively) at https://www.health.gov.au/sites/default/files/documents/2020/07/cdna-national-guidelines-for-the-prevention-control-and-public-health-management-of-covid-19-outbreaks-in-residential-care-facilities-in-australia.pdf.

⁵⁶ Ibrahim (n 36) [36].

Prof Lyn Gilbert AO and Adjunct Prof Alan Lilly, Independent Review of COVID-19 outbreaks at St Basil's Home for the Aged in Fawkner Victoria and Heritage Care Epping Gardens in Epping Victoria (Report, 30 November 2020) 18 at https://www.health.gov.au/sites/default/files/documents/2020/12/coronavirus-covid-19-independent-review-of-covid-19-outbreaks-at-st-basil-s-and-epping-gardens-aged-care-facilities.pdf.

⁵⁸ Royal Commission into Aged Care Quality and Safety, Special Report (n 40) 5.

⁵⁹ Ibrahim (n 36) [36].

⁶⁰ Gilbert and Lilly, *Independent Review of St Basil's and Epping Gardens* (n 57) 7.

and when conducting its ACQSC self-assessment had noted steps taken as 'best practice'.⁶¹ In the same hearing, the manager noted 'with the benefit of hindsight' that steps had not been 'best practice' partly due to the use of the CNDA Guidelines which the manager noted did not reflect the significant impact of COVID-19 as compared to other flu-like diseases.⁶² Further, she noted that having an infection specialist present at the facility would have been 'best practice in my eyes now.'⁶³

In March, there was no specific national body coordinating preparedness, response and prevention in RACFs or ways to synthesise evidence and lessons learned in the New South Wales outbreaks.⁶⁴ To assist with distribution of information, a hotline for older persons was launched in **April 2020**.

On 1 May 2020, the Government released a draft voluntary code of practice⁶⁵ for providers on visitations to RACFs instead of a streamlined approach at the national level. This meant that providers could, and did, take different approaches to whether and how visitors were allowed in RACFs. A separate Industry Code for Visiting Residential Aged Care Homes during COVID-19' was produced by one of the peak bodies, Council on the Ageing ('COTA') Australia, on 11 May 2020.

As Professor Ibrahim pointed out to the Aged Care Royal Commission, in May the growing number of cases in RACFs clearly illustrated that 'personal care workers were going to need more support and RACFs were not able to manage the outbreaks without substantial support.' Instead, reliance appeared to be placed on providers to execute response plans and gather the necessary resources, e.g. a sufficiently large and qualified workforce to accommodate isolation and quarantine of staff identified as COVID-19 positive or close contacts and still maintain quality and safety of care of persons in RACFs.

Community transmission in Victoria began to climb in **June 2020** and as the Aged Care Royal Commission notes in its special report:

'[i]t is unclear whether the lessons learnt from those outbreaks [in New South Wales RACFs] were shared widely before community transmission put people living and working in aged care in Victoria at risk'.⁶⁸

⁶¹ Royal Commission into Aged Care Quality and Safety, Special Report (n 40) 5.

⁶² Ibid 5-6.

⁶³ Ibid 6.

⁶⁴ Ibrahim (n 36) [38].

Voluntary Industry Code of Practice for Aged Care, Aged Care Workforce Industry Council (2020) at https://acwic.com.au/wp-content/uploads/The-Aged-Care-Voluntary-Industry-Code-of-Practice-2.pdf.

See Industry Code for Visiting Residential Aged Care Homes during COVID-19, Council on the Ageing Australia (Industry Code, 24 May 2020) at https://www.cota.org.au/policy/aged-care-reform/agedcare visitors/.

⁶⁷ Ibrahim (n 36) [43].

Royal Commission into Aged Care Quality and Safety, Special Report (n 40) 15.

No statements were made to the aged care sector by the principal national Government decision-making body between 20 June and 3 August 2020 when infections in Victorian RACFs increased exponentially to more than 500, and subsequently by 9 August to more than 1.000.⁶⁹

Despite the growing numbers and WHO advice that healthcare workers wear face masks, this was not advised to Victorian healthcare workers until **13 July 2020**, two days after the first COVID-19 related death in a Victorian RACF and five weeks after the WHO advice.⁷⁰ In July, a new Victorian Aged Care Response Centre (VACRC) was established to coordinate Commonwealth and Victorian efforts to combat COVID-19 in Victorian aged care facilities.⁷¹

As noted above, the total number of deaths of persons in RACFs in Australia amounts to 74% of the total number of deaths, 678 of 909 (as of 8 January 2021).⁷²

2.3.4 Independent reviews

Upon requests by the Commonwealth Government, independent reviews have been undertaken into the outbreaks at selected homes in New South Wales and Victoria:

- Newmarch House (NSW): 19 fatalities;⁷³
- Dorothy Henderson Lodge (NSW): 6 fatalities;⁷⁴
- St Basil's Home for the Aged (St Basil's) (Vic): 45 fatalities; 75 and
- Heritage Care Epping Gardens (Epping Gardens) (Vic): 38 fatalities.

Newmarch House and Dorothy Henderson Lodge

The Newmarch House independent review was produced between June and August 2020, during which time outbreaks in Victoria were taking place. Numerous deficiencies were identified, including communication problems, staffing shortages, and lack of training and guidance for new staff.

⁷⁰ Ibid 16.

⁶⁹ Ibid.

⁷¹ 'About the Victorian Aged Care Response Centre', *Australian Government Department of Health* at https://www.health.gov.au/initiatives-and-programs/victorian-aged-care-response-centre/about-the-victorian-aged-care-response-centre.

^{&#}x27;COVID-19 outbreaks in Australian residential aged care facilities: National snapshot', Australian Government Department of Health (8 January 2021) at https://www.health.gov.au/sites/default/files/documents/2021/01/covid-19-outbreaks-in-australian-residential-aged-care-facilities-8-january-2021.pdf.

Prof Lyn Gilbert AO and Adjunct Prof Alan Lilly, *Newmarch House COVID-19 Outbreak [April – June 2020]: Independent Review* (Final Report, 20 August 2020) at https://www.health.gov.au/sites/default/files/documents/2020/08/coronavirus-covid-19-newmarch-house-covid-19-outbreak-independent-review-newmarch-house-covid-19-outbreak-independent-review-final-report.pdf.

Prof Lyn Gilbert AO, Review of Dorothy Henderson Lodge (DHL) COVID-19 Outbreak (Report, 25 August 2020) at https://www.health.gov.au/sites/default/files/documents/2020/08/coronavirus-covid-19-review-of-dorothy-henderson-lodge-covid-19-outbreak-review-of-dorothy-henderson-lodge-covid-19-outbreak.pdf.

⁷⁵ Gilbert and Lilly, *Independent Review of St Basil's and Epping Gardens* (n 57).

⁷⁶ Ibid.

For example, the reviewers found a lack of clarity in the respective roles on part of external actors, including government agencies and the ACQSC, which created confusion on part of the provider. Another issue raised was the lack of communication with families concerned for their relatives in the RACF and difficulties in ensuring meaningful contact. The reviewers found a key lesson from the Newmarch House outbreak to be that:

'communication is a key priority and yet it is often underestimated. A communication protocol should be developed and highlight stakeholders, type of communication to be employed and frequency.'⁷⁹

Connected to challenges of communication was significant issues with staffing which was found to be 'severely depleted' due to isolation or quarantine of staff exceeding the anticipated surge workforce capacity.⁸⁰ While the review recognised that 'requirements for staff replacements could not have been reasonably anticipated', the loss of staff capacity was found to have increased due to either the quality or incorrect application of personal protective equipment (PPE).⁸¹ The reviewers called for an increase to at least 50% of staff to be furloughed and for the Australian Government to 'consider expanding its surge workforce capacity providers' to ensure support at scale to providers.⁸²

This issue was compounded by the fact that the main form of medical and clinical care was delivered at the facility, rather than a hospital, which the reviewers noted 'has many advantages' but which was in practice found to be 'compromised by inadequate staffing and support'. As a result, families reported care not achieving levels equivalent to care provided at hospitals. The reviewers confirmed that lack of additional medical and nursing support 'led to shortfalls in hospital-standard care for some residents with COVID-19 and neglect of or delays in, routine care of many others'.

In addition, training of new staff including training in infection prevention and control was a key lesson noted in the review. ⁸⁶ Presence of an infection prevention and control expert onsite at the start of the outbreak 'would, almost certainly, have resulted in more efficient and consistent use of limited resources (staff and PPE) and possibly, fewer COVID-19 cases'. ⁸⁷

⁷⁷ Gilbert and Lilly, *Independent Review of Newmarch House* (n 73) 4.

⁷⁸ Ibid 5, 27.

⁷⁹ Ibid 16.

⁸⁰ Ibid 5, 16.

⁸¹ Ibid.

⁸² Ibid 18.

⁸³ Ibid 5.

⁸⁴ Ibid.

⁸⁵ Ibid 20.

⁸⁶ Ibid 18.

⁸⁷ Ibid 26.

Concerns regarding the general quality of care were also reported by family members. This included the quality of food provided to their relatives in the RACF, which included 'frozen sandwiches, cold or inedible meals and delays in meal service delivery'. Families also reported observations of 'weight loss, dehydration and pressure sores' among other conditions during the outbreak and there was a shower ban in the facility during the first part of the outbreak raising concerns for hygiene. ⁸⁹

The independent review of Dorothy Henderson Lodge, also published in August 2020, revealed that the first identified outbreak in an Australian RACF did not result in an outbreak to the same extent as the other New South Wales home. The review notes that advice from an infection prevention specialist and medical review of persons in the home 'were essential components of successful management' of the outbreak.

One issue raised in the Dorothy Henderson Lodge review which was not dealt with specifically in the Newmarch review was prolonged isolation/quarantine of persons in the RACF as a result of infection prevention measures. 90 This was listed as a major challenge during the outbreak as persons were confined to their own rooms without any visitors for over three weeks. 91 This, the review notes, resulted in 'serious adverse effects' on both physical and mental well-being of the persons living in the RACF regardless of efforts to reduce such impacts. 92 One of the key lessons listed was the need for balance between protection from the virus and adverse impacts from prolonged confinement. 93

St Basil's and Epping Gardens

In Victoria, two large outbreaks took place at Epping Gardens and St Basil's RACFs during the second wave of community transmission, resulting in the death of 83 persons receiving care in the homes. Similarities with many issues identified in relation to Newmarch House, such as staffing and lack of communication, led a family member in Victoria to ask whether any lessons had in fact been learnt from Newmarch House.⁹⁴

A review of Epping Gardens and St Basil's was published in December 2020.⁹⁵ The reviewers found preparedness and planning for the emergency inadequate on part of both homes.⁹⁶ The RACFs it found was too reliant upon external support in handling the outbreaks, such as organisation of additional workforce.⁹⁷ Similarly, infection prevention and control was found to be 'suboptimal' in the two homes, which had both met the requirements as approved providers

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88 Ibid 27.
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⁸⁹ Ibid.

⁹⁰ Gilbert, *Independent Review of Dorothy Henderson Lodge* (n 74) 1.

⁹¹ Ibid.

⁹² Ibid.

⁹³ Ibid 2.

⁹⁴ Ibid 34.

⁹⁵ Gilbert and Lilly, *Independent Review of St Basil's and Epping Gardens* (n 57).

⁹⁶ Ibid 7.

⁹⁷ Ibid.

under aged care regulatory scheme,⁹⁸ pointing back to an already weak system prior to the pandemic and the grave impacts caused by the virus.

As noted in section 2.3.3 above, visitations to RACFs were regulated through a voluntary code of practice. ⁹⁹ Prior to the outbreak at St Basil's, the facility had restricted and then excluded visitors during Victoria's first wave in March, and families reported that it continued longer than at other facilities. ¹⁰⁰ Visitation was eventually arranged again in mid-May on an appointment-basis in a specific room separated by a window. ¹⁰¹ The RACF went into lockdown again in July when the outbreak started. A 'pressing need' for visitation with appropriate infection control arrangements was identified by the reviewers. ¹⁰²

Communication was another issue reported as inadequate by family members in Victoria, reminiscent of the experience in New South Wales. At St Basil's, all family members consulted by the reviewers noted inability to contact the RACF for information about their relatives, including test results (including being given incorrect advice about whether or not their relative had tested positive). A specific hotline and support with communication from social workers was only arranged three weeks into the outbreak by which time it was too difficult for social workers to obtain timely information from the overstretched workforce.

The reviewers also found staffing to be a significant concern in managing the outbreaks, with planning of surge workforce being insufficient to manage the sheer scale of the outbreak at these two homes. Due to the growing number of cases at St Basil's, the Victorian Department of Health and Human Services ('DHHS') decided a stand down of all staff was necessary. The reviewers note 'minor errors' that together resulted in the decision to stand down staff. This included a failure on part of the provider to notify the Department of Health in addition to the Victorian DHHS, delaying testing. Further, the DHHS and the ACQSC who were alerted to the first case did not notify the Commonwealth Department of Health.

The facility Chairman raised concerns about care that would be delivered if all staff were stood down, these concerns were also supported by geriatricians. According to the reviewers, the Commissioner of the ACQSC also suggested 'a more nuanced response'. A public health order was made by the Victorian Chief Health Officer on 21 July 2020 to St Basil's requiring all staff falling within the definition of close contact to leave the facility by 22 July. The

⁹⁸ Ibid.

⁹⁹ Voluntary Industry Code of Practice on Aged Care (n 65).

¹⁰⁰ Gilbert and Lilly, *Independent Review of St Basil's and Epping Gardens* (n 57) 32.

¹⁰¹ Ibid.

¹⁰² Ibid 9.

¹⁰³ Ibid 34.

¹⁰⁴ Ibid 37.

¹⁰⁵ Ibid 8.

¹⁰⁶ Ibid 22.

¹⁰⁷ Ibid.

¹⁰⁸ Ibid 21.

¹⁰⁹ Ibid.

reviewers noted that this order was in line with public health requirements in place due to the risk of COVID-19 to the residents. However, the review underlines that the 'success' of such a measure depended on the handover. However, the review underlines that the 'success' of such a measure depended on the handover.

The reviewers found the cross-over from old to new staff provided 'very little time for adequate handover of information' on how to care for the persons in the RACF and the operation of the home. There was confusion regarding the role of the replacement management which expected to assist rather than completely replace the St Basil's management. Further the surge workforce was inexperienced, many of whom had never worked in aged care. Most persons receiving care in the RACF were of Greek or Serbian origin and spoke little to no English, and many staff who did not speak Greek or Serbian also had English as their second language. This added to the challenges in caring for basic and clinical needs of the persons in the RACF.

Other reports included, for example, failure of staff to use PPE and adhere to physical distancing, lack of administrative staff to collect data, repeated requests for the same information from different agencies, who made unclear requests as teleconference participants and often did not adequately identify their respective departments.¹¹⁶

Of great concern was also the failure of staff to identify persons receiving care from photographs in their files, the mix-up of belongings, and the inappropriate or no administration of medication and dietary requirements. Conditions continued to deteriorate quickly following the staff stand down and external providers raised concerns with provision basic needs such as lack of showers and other basic hygienic, failure to deliver meals or leaving meal trays unattended for hours. Clinical care needs were also raised, including failure to conduct regular blood glucose checks, failure or inappropriate administration of medication (including one instance of a person given insulin without food resulting in hypoglycaemia and urgent hospital admission).

Upon arrival at the facility to assist with hospital transfers on 24 July, the chief medical officer from one of the hospitals told the reviewers: 'I've never seen anything as appalling as this in Australia...in terms of health care provided to Australians'. ¹²⁰ The transfers were delayed due to difficulty of identifying residents, belongings and records and added to existing distress and

¹¹⁰ Ibid 28.

¹¹¹ Ibid.

¹¹² Ibid 23.

¹¹³ Ibid 23-24.

¹¹⁴ Ibid.

¹¹⁵ Ibid 25, 26.

¹¹⁶ Ibid 26-27.

¹¹⁷ Ibid 26.

¹¹⁸ Ibid 27-28.

¹¹⁹ Ibid.

¹²⁰ Ibid 29.

exposure risk.¹²¹ Families reported their relatives arriving at the hospitals with pressure sores, weight loss and dehydration.¹²²

The ACQSC issued a 'Notice to Agree' to the RACF on 26 July requiring St Basil's to 'appoint an independent adviser to ensure the health and well-being of residents'. ¹²³ In Victoria, public health directions were also updated following St Basil's experience to allow an exemption from the Chief Health Officer for a close contact to continue work in some instances to 'maintain quality of care' which clearly had not been the case at St Basil's. ¹²⁴ By 31 July 2020, concerns remained unresolved and it was decided by the new management and the Department of Health that all remaining residents be transferred to hospital. ¹²⁵ Return of persons to the RACF after the outbreak took place in September and October but the facility remained closed for visitors until 25 November. ¹²⁶

The same reviewers also undertook a similar review with respect of Epping Gardens. The main findings of inadequate infection prevention preparedness and a lack of sufficient and qualified staff were noted above and shared with that of St Basil's. For example, at one shift on 27 July, there were only four staff members to care for more than 100 persons in the home. Other similar concerns which unfolded included observations that persons in the RACF were dehydrated, had untouched meal trays in their rooms and lacked support with personal hygiene. Visiting restrictions were also in place and the reviewers noted the impact it had on families and their relatives in the RACF. This was exacerbated in instances where families were incorrectly advised on the whereabouts of their relatives, many of whom had been transferred to different hospitals. Some persons receiving care at Epping Garden did not speak English and the inability of relatives to facilitate communication also added to the distress.

As was the case at St Basil's, a 'Notice to Agree' was issued by the ACQSC to Epping Gardens on 28 July and a specific onsite adviser was deployed to the RACF. 132

Legal action is currently underway in respect of St Basil's (coronial inquests and a class action) and Epping Gardens (class action).

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121
     Ibid.
122
     Ibid 35.
123
     Ibid 29.
     Ibid 28.
125
     Ibid 31.
126
     Ibid 37.
127
     Ibid 50.
128
     Ibid 51, 56.
129
     Ibid 58.
130
     Ibid.
     Ibid.
132
     Ibid 53.
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3. RIGHTS ANALYSIS

3.1 Australia's human rights obligations

While Australia does not have a national Bill of Rights or similar, it is a State Party to seven of the nine core human rights conventions:

- International Covenant on Civil and Political Rights ('ICCPR');¹³³
- International Covenant on Economic, Social and Cultural Rights ('ICESCR');¹³⁴
- Convention on the Rights of Persons with Disabilities ('CRPD');¹³⁵
- Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment ('CAT');¹³⁶
- Convention on the Elimination of All Forms of Discrimination Against Women ('CEDAW');¹³⁷ and
- International Convention on the Elimination of All Forms of Racial Discrimination ('ICERD'). 138

These instruments impose obligations on Australia to respect, protect and fulfil numerous rights at risk in the context of aged care and COVID-19 (as well as aged care more broadly).

This includes, for example, the rights to health and life, which impose positive obligations on States Parties to take steps to protect against threats to health and life.¹³⁹ Article 12(2)(c) of the ICESCR specifically notes the need for 'prevention, treatment and control of epidemic, endemic, occupational and other diseases.'¹⁴⁰ As the Committee on Economic, Social and Cultural Rights ('CESCR') has clarified, this includes the establishment of systems for urgent

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International Covenant on Civil and Political Rights, opened for signature 19 December 1966, 999 UNTS
 171 (entered into force 23 March 1976) (ratified by Australia 13 August 1980) ('ICCPR').

International Covenant on Economic, Social and Cultural Rights, opened for signature 19 December 1966, 993 UNTS 3 (entered into force 3 January 1976) (ratified by Australia 10 December 1975) ('ICESCR').

Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) (ratified by Australia 17 July 2008).

Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, opened for signature 4 February 1985, 1465 UNTS 85 (entered into force 26 June 1987) (ratified by Australia 8 August 1989).

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) (ratified by Australia 28 July 1983).

¹³⁸ 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) (ratified by Australia 30 September 1975).

See, eg, HRC, General comment No 36, Article 6 (Right to Life) UN Doc CCPR/C/GC/36 (3 September 2019) [26] ('General Comment No 36').

¹⁴⁰ ICESCR (n 134) art 12(2)(c).

treatment and care.¹⁴¹ It also requires Australia to use and improve data collection and other strategies to control infectious diseases.¹⁴²

In addition to meeting its obligations to uphold the rights to life and health, Australia must also meet its continuing obligations to respect, protect and fulfil other human rights to the extent they cannot be limited. As is well-established, human rights are interdependent, indivisible and interrelated and the violation of one right is often connected to or intersecting with the lack of the enjoyment of other rights.

Under international human rights law, duties to protect and fulfil human rights require the Australian Government not just to refrain from violations but to also take steps to establish a system which protects human rights from violation by private actors, for example, by ensuring effective regulation of approved providers, adequate training and education of sufficient healthcare staff and ensuring accessible channels to health-related information and services.¹⁴³

These duties remain during emergencies and as the CESCR has confirmed in the context of the right to health, even in situations of 'severe resources constraints...the vulnerable members of society can and indeed must be protected by the adoption of relatively low-cost targeted programmes.' The UN has specifically emphasised that states must promote and protect the rights of aged persons during the COVID-19 pandemic. The UN Office of the High Commissioner ('OHCHR') in the **COVID-19 Guidance Note** of April 2020 recommended that 'special attention... be paid to the risks faced by older persons' including isolation, neglect and aged-based discrimination in access to medical treatment. The OHCHR in that guidance highlighted that the situation of older persons living in institutions was 'particularly grave' and warned against further exposure of older persons to neglect and abuse.

That same month, the UN Department of Economic and Social Affairs ('UNDESA') specifically addressed the issue of older persons residing in long-term care facilities in their **COVID-19 Issue Brief**. In it, UNDESA acknowledged that 'older people, especially in isolation and those with cognitive decline, dementia and those who are highly care-dependent, may become more anxious, angry, stressed, agitated and withdrawn during the outbreak or while in isolation' and recommended that visitor policies balance protection of residents with their 'need for family connection' and other needs.¹⁴⁷

Committee on Economic, Social and Cultural Rights ('CESCR'), General Comment No 14: The Right to the Highest Attainable Standard of Health (Art 12) UN Doc E/C.12/2000/4 (11 August 2000) [16] ('General Comment No 14').

¹⁴² Ibid.

¹⁴³ Ibid [35], [48], [51].

CESCR, General Comment No 3: The Nature of States Parties' Obligations (Art 2 Para 1 of the Covenant), UN Doc E/1991/23 [12].

Office of the High Commissioner for Human Rights (OHCHR), COVID-19 Guidance (Report, 14 April 2020) 3; Also reiterated in OHCHR, COVID-19 Guidance (Report, 13 May 2020) 3.

¹⁴⁶ Ibid

UNDESA, Issue Brief: Older Persons and COVID-19 - A Defining Moment for Informed, inclusive and Targeted Response (Report, April 2020) 2.

The authors agree with the **Independent Expert's** recognition that '[p]hysical distance is crucial but creative and safe ways must be found to increase social connections' including through the use of remote technologies.¹⁴⁸

The UN has also released its **Policy Brief: The Impact of COVID-19 on Older Persons** in May 2020. The brief highlights that lockdowns, concentration of health resources on COVID-19, and workforce shortages can disrupt the provision of care to older persons and create barriers to obtaining effective health services. The UN recommended that states 'ensure continuity of adequate care services for older persons such as mental health services, palliative and geriatric care' including by way of supporting paid workers in institutional settings. In institutional settings.

The brief also reiterated the message of other UN bodies regarding prolonged isolation of aged persons, stating that "[p]hysical distancing" is crucial, but needs to be accompanied by social support measures and targeted care for older persons, including by increasing their access to digital technologies'. The UN further urged states to ensure that 'visitor policies in residential care facilities...balance the protection of others with the need for family and connection'. The unit of the protection of others with the need for family and connection'.

3.2 Impacts on the rights of persons in RACFs

Australia's COVID-19 response in the context of aged care has resulted in concerns for the human rights of persons in RACFs and issues raised in this submission have been selected based on desk-based research and interviews with family members of persons in RACFs in the State of Victoria. Our analysis primarily examines the impact of Australia's COVID-19 response on the right to health. Where relevant, we also consider the impact on other rights in connection with, or in addition to, the right to health, such as the rights to equality and non-discrimination, life, access to information and private and family life.

While not dealt with specifically, the right to a full and effective remedy permeates this submission. Non-repetition measures to prevent similar violations from occurring in Australian RACFs again form a crucial part of this right. Preventing future outbreaks through the 'benefit of hindsight' has been a key focus in the independent reviews of selected RACFs, as well as in the work of the Aged Care Royal Commission. The Commissioners underlined the forward-looking nature of their inquiry by noting that:

Rosa Kornfeld Matte, ""Unacceptable" – UN expert urges better protection of older persons facing the highest risk of the COVID-19 pandemic', *OHCHR* (Media Release, 27 March 2020) at https://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=25748&LangID=E.

See UN, Policy Brief: The Impact of COVID-19 on Older Persons (Report, May 2020).

¹⁵⁰ Ibid 5.

¹⁵¹ Ibid 8.

¹⁵² Ibid 3, 10-11.

¹⁵³ Ibid 8.

¹⁵⁴ See, eg, CESCR, General Comment No 14 (n 141) [59].

See, eg, Gilbert and Lilly, *Independent Review of St Basil's and Epping Gardens* (n 57) 69.

'[T]he nation needs to know what lessons have been and can still be learnt. The nation needs to know what is being done, and what will be done, to protect those people receiving aged care services [...]'156

The right to an effective remedy also requires accountability for past violations, beginning with the recognition and acknowledgement of some incidents that have taken place not only as events causing immense distress to residents and family members but also as violations of fundamental rights stemming from systemic and long-standing issues in an aged care sector which does not take a rights-based approach.

In its General Comment discussing the right to health, the CESCR has underlined that domestic incorporation of the right may 'significantly enhance the scope and effectiveness of remedial measures...'. ¹⁵⁷ As noted in the introduction, Australia does not have a national Bill of Rights or similar and there is no regional mechanism to which persons living in RACFs and their family members may turn to voice concerns of human rights violations.

The ability to raise human rights concerns at the international level through mechanisms such as special procedures therefore form an important part of the right of persons in RACFs and their family members to an effective remedy in addition to any domestic legal actions which may provide compensation but not necessarily acknowledgment of violations which have occurred. Both the remedy of past violations, as well as prevention of future violations, are crucial to fully respect, protect and fulfil the rights of older persons.

Issue 1: Communication and access to information

Access to health-related information is an essential element of the right to health.¹⁵⁸ Australia also has an obligation to respect, protect and fulfil access to information as part of the broader right of freedom of expression.¹⁵⁹ This includes taking steps to ensure that private actors, such as aged care providers, do not limit access to information.¹⁶⁰

In the independent reviews of the outbreaks in homes in New South Wales and Victoria summarised in section 2.3.4 above, key stakeholders, including family members of persons in RACFs, noted communication as a significant challenge during the RACF outbreaks. ¹⁶¹ Inadequate and sometimes inaccurate information as to matters such as the health status, whereabouts, and general wellbeing of their relatives were repeatedly raised as concerns by key stakeholders, including family members, adding to their own distress and anxiety over their relatives in the RACF. ¹⁶²

159 ICCPR (n 126) art 19(2).

¹⁵⁶ Royal Commission into Aged Care Quality and Safety, Special Report (n 40) 3.

¹⁵⁷ CESCR, General Comment No 14 (n 141) [60].

¹⁵⁸ Ibid [12].

¹⁶⁰ CESCR, General Comment No 14 (n 141) [35].

See i.e. Gilbert and Lilly, *Independent Review of Newmarch House* (n 73) 5, 27; See also Gilbert and Lilly, *Independent Review of St Basil's and Epping Gardens* (n 57) 34, 37,58.

Gilbert and Lilly, *Independent Review of Newmarch House* (n 73) 5, 27; Gilbert and Lilly, *Independent Review of St Basil's and Epping Gardens* (n 57) 34.

A family member who lost her parents-in-law at a Victorian RACF told the authors that she was informed that her father-in-law's test result was positive, only to receive notification later in the day that this was in fact incorrect.¹⁶³ When the father-in-law did eventually get infected with COVID-19, it took days to find out the result and this was only notified once he had been transferred to a hospital, not by the provider.¹⁶⁴

A call centre was set up in connection with the larger outbreaks in Victoria, but as the independent reviewers noted, this was a late development and took time to set up.¹⁶⁵ By the time it was in place, the pressure on the onsite staff was high already and social workers could not obtain information in time with demand.¹⁶⁶ This was confirmed in an interview with one family member who told the authors that her assigned social worker had not been able to obtain the relevant information from the care staff onsite.¹⁶⁷

The Government's decision to stand down all regular staff at Victorian care home St Basil's contributed to the lack of regular updates and communication due to the very limited handover discussed in the summary of the independent review above. New staff, many with limited to no experience of work in the aged care sector, did not recognise the persons receiving care at the RACF and were not familiar with their care needs. This was noted by one family member who told the authors that her mother was eventually referred to, not by name, but by her room number. Another family member reported that she had to take steps to have her mother's death certificate amended as it wrongfully stated that her mother died of COVID-19 despite never having a positive test. The error could have prevented particular religious funeral rituals had it not been changed in time.

As also noted in the case of St Basil's, both the approved provider and the Victorian health authorities failed to notify the Department of Health of the outbreak in the RACF and there were continuous questions regarding leadership and responsibility during the outbreak which added to confusion on the ground. While reporting procedures were set out in government guidance, what transpired at the homes in the independent reviews suggest an overall lack of clarity regarding the roles and responsibilities on part of each actor in the Australian aged care system, which in a crisis appears to have resulted in chaos and lack of clear leadership and cooperation between Government and approved provider. 174

¹⁶³ Interview 3 with family member (online, 19 November 2020).

¹⁶⁴ Ibid

¹⁶⁵ Gilbert and Lilly, *Independent Review of St Basil's and Epping Gardens* (n 57) 37.

¹⁶⁶ Ibid.

¹⁶⁷ Interview 2 with family member (online, 12 November 2020).

¹⁶⁸ Gilbert and Lilly, *Independent Review of St Basil's and Epping Gardens* (n 57) 27, 28.

¹⁶⁹ Ibid 23, 24.

¹⁷⁰ Interview 4 with family member (online, 19 November 2020).

¹⁷¹ Interview 2 (n 167).

¹⁷² Ibid.

Gilbert and Lilly, *Independent Review of St Basil's and Epping Gardens* (n 57) 22.

Gilbert and Lilly, *Independent Review of Newmarch House* (n 73) 4.

As noted above, the Government's decision to stand down regular staff at the St Basil's facility resulted in a lack of communication with family members as to the wellbeing of their loved ones, including whether or not they were still alive. ¹⁷⁵ One family member in Victoria observed:

'I couldn't talk to my mother for three days, I didn't know how she is, alive or dead'. 176

Another family member noted that her mother had several falls during the outbreak at a Victorian facility, which resulted in hospital transfers.¹⁷⁷ However, the daughter never found out what caused these falls, and her mother has since passed away with COVID-19.¹⁷⁸ The lack of access to health information and records of what took place within the RACFs that have been independently reviewed had no doubt severe impacts on the enjoyment of both the right to health and access to information of persons in RACFs, as well as their family members seeking updates on their wellbeing.

Issue 2: Visitation policies

As noted in section 2.3.3 above, the Australian Government adopted a voluntary code of practice regarding visits to aged care facilities.¹⁷⁹ As a family member in Victoria observed:

'it was really for the facilities to determine whether they allow people in – the problem is if the manager is afraid of risk and doesn't have proper protocols – they're going to lock people in'. 180

This was the case at several RACFs in Victoria, for example at the two independently reviewed facilities with the highest death tolls.¹⁸¹ One family member noted that at one point, they were even prevented from accessing the grounds around the facility.¹⁸²

As the Independent Expert has indicated, lockdown measures can have a severe impact on the mental and physical health of persons in RACFs and that of their families. Accordingly, these needs must be balanced against the need to prevent the spread of the virus and control infection. Lockdown measures and restrictions can also affect the enjoyment of the right to family life. One family member in Victoria described the inability to visit her mother as traumatic and noted that she could notice that her mother's verbal skills had decreased and she looked dishevelled as a result.

Gilbert and Lilly, *Independent Review of St Basil's and Epping Gardens* (n 57) 27, 28.

¹⁷⁶ Interview 1 (n 1).

¹⁷⁷ Interview 4 (n 170).

¹⁷⁸ Ibid.

¹⁷⁹ Voluntary Industry Code of Practice for Aged Care (n 62).

¹⁸⁰ Interview 1 (n 1).

Gilbert, Independent Review of Dorothy Henderson Lodge (n 74) 1, 2; Gilbert and Lilly, Independent Review of St Basil's and Epping Gardens (n 57) 32.

¹⁸² Interview 3 (n 163)

¹⁸³ Gilbert, Independent Review of Dorothy Henderson Lodge (n 74) 1; See also Kornfeld-Matte (n 148).

¹⁸⁴ CESCR, General Comment No 14 (n 141) [28]-[29].

¹⁸⁵ Interview 1 (n 1).

The lack of updates and information from the facility and authorities, as noted above, in combination with policies on visitation meant that some families and their loved ones had no direct or indirect contact for days and weeks. As noted above, lack of sufficient staff also meant a lack of timely updates from the facilities, and difficulty in supporting alternative modes of direct communication between family members and their loved ones. For example, at a home in Victoria, many persons in RACFs were dependent upon staff assisting with calls and video conferencing as they had disabilities or other health conditions which made them unable to independently utilise phones or iPads. For example, at a

Issue 3: Cultural and linguistic minorities

Accessibility, without discrimination, and acceptability of health care that respects culture are essential aspects of the right to health. As the independent review of two RACFs in Victoria pointed out, most persons receiving care at St Basil's RACF had Greek or Serbian background and spoke little to no English. Impacts of changes, such as the complete changeover of staff at St Basil's, were exacerbated as it made communication challenging, including crucial communication about health and wellbeing. There were reports of new staff being unable to communicate with persons living at the RACF and mix-ups of medications and other care needs. One family member noted that her biggest concern was that her mother would not understand what was going on as she did not speak English.

One family member notes that her mother's end of life care did not align with Greek Orthodox faith, despite a negative COVID-19 test, also impacting on the right to freedom of religion. While there is a need to balance the right to health, including infection prevention and control, with other rights such as freedom of religion, limitations must be made on a case-by-case basis and it is not clear whether this was indeed the case in this instance given that the resident in question had tested negative for COVID-19.

More broadly, persons in RACFs must not be discriminated against with regards to access to and quality of healthcare provided, a minimum core obligation of the right to health as well as a separate non-discrimination obligation.¹⁹⁵

Issue 4: Access to food, water and sanitation

Gilbert and Lilly, Independent Review of St Basil's and Epping Gardens (n 57) 21, 34.

¹⁸⁷ Ibid 8

¹⁸⁸ Interview 2 (n 167); *Interview* 3 (n 163).

¹⁸⁹ CESCR, General Comment No 14 (n 141) [12].

¹⁹⁰ Gilbert and Lilly, *Independent Review of St Basil's and Epping Gardens* (n 57) 25, 26.

¹⁹¹ Ibid 26.

¹⁹² Ibid 25, 26, 58.

¹⁹³ See HRC, General Comment No 22: Article 18 (Freedom of Thought, Conscience or Religion) UN Doc CCPR/C/21/Rev.1/Add.4 (30 July 1993).

¹⁹⁴ Ibid [8].

¹⁹⁵ CESCR, General Comment No 14 (n 141) [19].

As the CESCR has noted, the right to health 'embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life', including for example, food, nutrition, water and sanitation. Access to minimum essential levels of food, water and sanitation are core minimum obligations of the right to health that must never be limited. The Human Rights Committee has similarly interpreted the right to life broadly to mean a life in dignity rather than bare survival.

The independent reviews of the selected RACFs found that many staff feared going to work during the outbreak resulting in further depletion of the workforce. ¹⁹⁹ Shortage of staff was so dire that one day, Newmarch House, with more than 100 persons receiving care, had only four staff members turning up for a shift. ²⁰⁰

Shortage of staff, including staff with adequate qualification and knowledge of the care needs of persons in RACFs with outbreaks, saw both health care professionals, hospitals and family members raise concerns as to basic care needs of their relatives during COVID-19 outbreaks in the RACFs.²⁰¹ This included, as noted in the independent reviews of RACFs in New South Wales and Victoria, observations of weight loss, dehydration and conditions such as pressure sores associated with lack of movement.²⁰²

A family member in Victoria was told by hospital staff that persons transferred from the RACF, including the family member's own father-in-law, needed food, water and bathing upon arrival.²⁰³ Another family member told the authors that she had witnessed her mother being fed only a pasty, spring roll and fruit when she normally required a vitamised diet.²⁰⁴

Issue 5: Access to healthcare services

Access to and quality of healthcare services, facilities and goods without discrimination are other important aspects of the right to health which may never be compromised.²⁰⁵ This includes the availability of sufficient skilled medical staff to provide treatments and adequate sanitation of facilities.²⁰⁶ The CESCR has also specified access to essential medication as a core minimum obligation under the right to health which must not be limited.²⁰⁷

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<sup>196</sup> Ibid [11].
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¹⁹⁷ Ibid [47].

¹⁹⁸ HRC, General comment No 36 (n 139) [3].

¹⁹⁹ See e.g. Gilbert and Lilly, *Independent Review of Newmarch House* (n 73) 17.

²⁰⁰ Gilbert and Lilly, *Independent Review of St Basil's and Epping Gardens* (n 57) 50.

²⁰¹ Ibid 27-28.

²⁰² See e.g., Gilbert and Lilly, *Independent Review of Newmarch House* (n 73) 27.

²⁰³ Interview 3 (n 163).

²⁰⁴ Interview 2 (n 167).

²⁰⁵ CESCR, General Comment No 14 (n 141) [12].

²⁰⁶ Ibid.

²⁰⁷ Ibid [47].

In addition to reports of omission of basic care needs of persons in RACFs during outbreaks in Victoria and New South Wales, issues concerning access to healthcare and other clinical needs were also raised both in the independent reports of selected RACFs, as well as in interviews with family members for this submission.²⁰⁸ For example, the independent reviewers of the outbreak at Newmarch House where care was provided through a 'Hospital in the Home' program found that there was a lack of relevant medical and nursing support which in turn meant that hospital-standard care could not always be provided to persons in the RACF with COVID-19 and that other medical and clinical care needs were neglected or delayed.²⁰⁹

In Victoria, it has been reported that persons from various RACFs were refused admission and treatment for COVID-19 upon arrival at hospital.²¹⁰ In the independent review of St Basil's, the reviewers also observed the limited capacity of hospitals to accept persons who were transferred from RACFs.²¹¹ The review also observed that there appears to have been "different expectations or poor communications between St Basil's and DHHS/hospital authorities about the indications for hospital admission of residents with COVID-19".²¹²

Further, the reviewers of St Basil's noted reports from interviewees regarding administration of medication and one instance of a person being hospitalised due to provision of insulin without food.²¹³ One family member told the authors of this submission that her father-in-law was transferred to hospital without his regular medication and was later informed by hospital staff that he had been without his medication for five days.²¹⁴

There have also been reports of persons without COVID-19 being treated as though they were positive. For example, a family member in Victoria told the authors that her mother who had never tested positive had to reside in a corridor where four people had been diagnosed with COVID-19 and when she visited, doors to rooms of persons with the virus were kept open. Another family member at the same RACF was told by a nurse that they treated everyone at the home as COVID positive which links to the issue of lack of communication and access to accurate information discussed above. After a COVID-19 negative test at hospital after a fall, an elderly woman was not permitted to be taken home by her daughter and was instead sent back to the RACF which at the time was experiencing an ongoing outbreak.

Issue 6: Restrictive practices

²⁰⁸ Gilbert and Lilly, *Independent Review of St Basil's and Epping Gardens* (n 57) 50.

²⁰⁹ Gilbert and Lilly, *Independent Review of Newmarch House* (n 73) 20.

See e.g., 'Aged care residents with coronavirus turned away from hospital, providers say', SBS News (24 July 2020) at https://www.sbs.com.au/news/aged-care-residents-with-coronavirus-turned-away-from-hospital-providers-say.

²¹¹ Gilbert and Lilly, *Independent Review of St Basil's and Epping Gardens* (n 57) 6.

²¹² Ibid 20.

²¹³ Ibid 27-28.

²¹⁴ Interview 3 (n 163).

²¹⁵ Interview 2 (n 167).

²¹⁶ Interview 1 (n 1).

²¹⁷ Interview 3 (n 163).

As noted in section 2.2.1 above, excessive use of restraints in Australian RACFs has been an ongoing concern for many years, often connected to other systemic issues, such as staffing shortages and lack of adequate training.²¹⁸ Chemical restraint is an especially concerning practice in aged care with impacts on the wellbeing, dignity and rights of persons in RACFs.²¹⁹

The use of restraints has been reported to be exacerbated by the pandemic as limits to social interactions with family members and other residents may trigger behaviours that could in turn result in the use of restraints to control behaviour. Preventive measures, such as isolation (which is itself a form of restraint), are concepts that may be difficult for persons with dementia and other cognitive conditions to understand which can cause unease and uncertainty. A family member in Victoria recalled this with regards to her mother who had a cognitive impairment:

'When we got there, [the provider] did not tell us that we cannot visit [our mother] in her room - only through a window. Mom couldn't understand why we cannot see, touch, or put her to bed. [She] thought we left her in there to die.'222

The same family member also told the authors that her mother had been given medication without her consent (as power of attorney), raising concerns of chemical restraint:

'We saw [our mother] one morning - she looked like she [had] been given something that made her look like [a] zombie. [The staff] told me that [my mother] was yelling and couldn't settle, so they gave her this tablet very early in the morning.'223

The daughter had previously arranged for the facility to give her a call if her mother was feeling unsettled to calm her down which had not happened in this instance.²²⁴ As noted above, the use of chemical restraint is an ongoing issue in Australian aged care and there have been various concerns raised with regards to the existing regulation in place which permits chemical restraint and does not regulate it to the same extent as other forms of restraint.²²⁵

Gilbert and Lilly, *Independent Review of Newmarch House* (n 73) 18.

²¹⁹ Human Rights Watch (n 28).

Naaman Zhou, 'Q+A: 'catastrophic' Covid-19 outbreaks in aged care could have been prevented, doctors say', *The Guardian* (4 August 2020) at https://www.theguardian.com/australia-news/2020/aug/04/qa-catastrophic-covid-19-outbreaks-in-aged-care-could-have-been-prevented-doctors-say.

²²¹ UNDESA (n 147) 2.

²²² Interview 4 (n 170).

²²³ Ibid.

²²⁴ Ibid.

See i.e. Royal Commission into Aged Care Quality and Safety, Background Paper 8 (n 29).

4. CONCLUSION

This submission raises various concerns regarding the wellbeing, dignity and rights of persons in Australian RACFs during outbreaks in 2020, and the ongoing need for systemic reforms to the aged care sector which was called for before the pandemic hit. We have noted the various impacts which the COVID-19 response has had on individuals residing in RACFs and their families, including impacts on the rights to health, life, family life, access to information and non-discrimination. While some rights may be limited in order to protect public health, States parties have the burden to first assess whether limitations are justified and to explain how a limitation meets each step of the test for limitation. They must also ensure that limitations do not affect rights which are non-derogable or parts of rights that may never be limited, such as minimum core obligations.

While some impacts have been caused at the provider-level (some of which are being investigated and legal action taken), what appears evident is also a lack of measures at the Government-level to adequately regulate and prepare providers for crises. While notable steps have been taken and efforts made, what is lacking, and which undoubtedly will determine whether responses to prevent and control infection respects human rights, is a rights-based approach to aged care which places the wellbeing, dignity and rights of persons receiving care at the centre.

For example, measures such as a full stand down of regular staff at St Basil's had severe consequences which impacted on various rights of the persons receiving care at the RACF, as well as their families. Impacts included lack of staff with adequate training in aged care and knowledge of the persons they were caring for, including the ability to communicate in a language in which they understood. A rushed handover and lack of clarity of respective roles of the actors involved in maintaining the outbreak added to the confusion, which ultimately resulted in persons at the home not receiving the medical and routine care they needed and had entrusted to the RACF. This suggests, for example, limitations of minimum core obligations of the right to health, including access to essential medication, food and water.

The difference in the access to and quality of care for persons in RACFs compared to persons receiving care at hospitals is a worrying concern which adds to the broader issue of how persons in aged care are treated and valued in society. As the Independent Expert's mandate clearly outlines, older persons - including older persons in RACFs - have the right to enjoy all human rights and participate in society on an equal basis as others.

The COVID-19 pandemic and its response in a system with existing weaknesses demonstrates that the lack of a rights-based system to aged care in the first place has fatal consequences. We must acknowledge and remedy past violations, and reform the system in order to put in place effective non-repetition measures.

We hope that this information is useful to the Independent Expert and other special procedures to which this information is relevant. It is hoped that the information may feed into future reports and actions by the Independent Expert, both in connection with COVID-19, but also in respect

²²⁶ CESCR, General Comment No 14 (n 141) [28]-[29].

of reforms necessary in the aged care sector more broadly. Given the lack of national and regional human rights mechanisms for family members to voice concerns, and the ongoing challenges posed by the COVID-19 pandemic international acknowledgement of human rights violations is more important than ever.

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