

Rethinking aged care

Emphasising the rights of older Australians

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Overview

Australia's aged care system is a mess. A new horror story is revealed almost every day the Royal Commission into Aged Care Quality and Safety sits. Almost every day the COVID-19 death toll mounts in non-government residential aged care facilities in Victoria.

The solutions are not simple. More money and better regulation are both necessary, but won't be enough. Unless Australia fundamentally changes the culture of its aged care system – by changing legislated underlying principles, governance, and financial incentives – the Royal Commission's report will be added to the pile of previous reports which haven't led to the necessary, transformative change.

There is no single cause for the litany of failures of the system. Quality in aged care is difficult to measure and regulation has not kept pace with the increasingly privatised and marketised system. Poor measurement of quality meant external regulation was harder and – as has been shown in the Royal Commission – ineffective. Rather than ensuring an appropriately regulated market, the government's primary focus has been to constrain costs, entangling assessment of need with assessment of eligibility, resulting in many older Australians missing out on the support they need. And all this despite the fact that Australia spends less than other similar countries on aged care.

This recipe for disaster in part stems from ageism in the broader society. The contributions of older people have been devalued. As Australians grow older and become frail, options and autonomy are taken from them, and their life is narrowed. Turning this around requires

wider recognition that older Australians have rights. These rights should shape the way a new system of providing support for older people is organised. The service system should be explicitly designed to help older people maintain as much independence as possible.

This report identifies five principles which should shape system design: Independence, self-fulfilment, and participation in community; Informed and supported choice and control; Universal access to reasonable and necessary supports; Equity and non-discrimination; and Dignity, including dignity in death. A rights-based approach to aged care would also recognise the rights of carers and staff.

The Royal Commission into Aged Care Quality and Safety should use a rights-based approach to shape its recommendations. A new system, based on the rights of older people, will look very different from the provider-centric system Australia has now. Older people would be more empowered and be assisted to make informed choices. Older Australians would be better able to participate in the community and fulfil their goals and aspirations. This would then, over time, reshape the system to better meet the desires and aspirations of older Australians.

This is the first of two Grattan Institute reports on aged care. This first report provides an overarching rights-based framework that should form the basis of a long-overdue redesign of the aged care system. The second report will deal with the implications of a rights-based framework and provide practical reform proposals.

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1 The aged care system fails older Australians

Australia's aged care system has produced a litany of failures: unpalatable food, poor care, neglect, abuse, and, most recently, the tragedies of the pandemic.¹ This should not come as a surprise. Successive governments have put the interests of providers ahead of the needs of older Australians. Governments' poor commitment to assure older Australians' adequate care and support reflects society's culture and attitudes towards older people. That some aged care services are exemplary, delivering high-quality support despite the funding and regulatory incentives, is a tribute to their professionalism and commitment.

Older Australians, particularly those seeking aged care and support, are often seen as a burden and no longer valuable or contributing members of society.² They are pushed out of sight and out of mind. The result is an aged care system that is under-funded, poorly regulated, and often unable to give older Australians the support they need to live meaningful lives.

Over the past two decades the aged care sector has increasingly become a 'market'. Residential facilities got bigger, and for-profit providers flooded into the system. Regulation did not keep pace with the changed market conditions. There was no underlying framework that sought to ensure the interests of older Australians sat at the heart of the system.

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1. Evidence to the Royal Commission into Aged Care Quality and Safety revealed many stories of poor care. Some of these stories have been used as case studies in this report to illustrate system failures.
 2. Note that older Australians – those aged 65 and older – are a diverse group. In this report we are primarily referring to older Australians in need of support and care.

This report shows that the fundamentals of the community system to support older people needs to change. The Royal Commission into Aged Care Quality and Safety is an opportunity for Australia to ask: what is the system here for? We argue that the aim should be to support older Australians to continue to live meaningful lives as they age. This new goal should be underpinned by a recognition that older people have rights and that these rights should be realised.

This chapter outlines the evolution of Australia's aged 'care' system, and its current problems. This report does not seek to provide a comprehensive review of all the problems in the system, which in our view are symptoms of underlying failures of system design.³ This report focuses primarily on these key failures that undermine the rights of older Australians and shape an inherently problematic system.

1.1 The evolution of Australia's aged care system

The evolution of Australia's aged care system has been largely a story of piecemeal, incremental change, progressively introducing more government assistance to provide basic personal and nursing care. For much of the past 100 years, policy focused on providing care and support in institutional settings. More recently, the focus has shifted to greater support for older people to continue to live at home.

1.1.1 Institutionalisation

Government support for older Australians evolved out of intersecting three policy areas: health, housing, and age pensions.⁴ Over the

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3. A second Grattan Institute report on aged care will provide further analysis of the structural problems in the aged care system.
 4. Royal Commission into Aged Care Quality and Safety (2019b, p. 42).

first half of last century, the Commonwealth government introduced successive policies to provide the Age Pension and subsidised health care and housing for poorer older people.⁵

Up to the 1950s, there was some Commonwealth government funding to support older people in ‘rest homes’ or ‘asylums’, but provision was primarily by states or charities. Whole-of-life institutional care dominated.⁶ After Commonwealth constitutional authority over social welfare expanded in 1946,⁷ Commonwealth support for aged care also expanded.

Over the following decades, the number of ‘nursing homes’ grew rapidly due to increased subsidies from the Commonwealth, including for infrastructure. It was cheaper to build more nursing homes than more hospitals.⁸

From the 1960s, a two-tiered residential aged care system was introduced: nursing homes for people needing higher levels of support, and hostels for people with less-intensive needs.⁹ Care was increasingly funded by governments, but provided by not-for-profits such as religious and charitable organisations, and later also by for-profit organisations.¹⁰

Some states, notably Victoria and Western Australia, developed significant public sector aged care facilities. The Victorian government still runs about a quarter of the state’s facilities. However, as the

5. Ibid (p. 42).

6. Kewley (1973); Dixon (1977).

7. Sackville (1973).

8. Funding for care services was through the *National Health Act 1953* (Cth) and funding for infrastructure through the *States Grants (Nursing Home) Act 1969* (Cth): Royal Commission into Aged Care Quality and Safety (2019b, p. 43).

9. This was through the *Aged Persons Homes Act*: Royal Commission into Aged Care Quality and Safety (ibid, p. 43).

10. Ibid (p. 43).

Case Study 1: Mrs CO^a

Mrs CO was born in England in 1934. In 2010, she was diagnosed with dementia. In February 2013 she was admitted to Brian King Gardens in north-west Sydney for respite care, which became permanent a few weeks later.

At the facility, there were a number of instances of substandard care. For weeks, staff did not consistently follow directives to remove and clean Mrs CO’s dentures, which led to significant tooth decay. Her toenails grew very long, causing her to limp and have sore feet. The Royal Commission noted that ‘the failure of staff to identify from their daily care the state of Mrs CO’s toenails, including in circumstances where she was limping, is of particular concern.’ She was also given medicated skin cream that belonged to another resident.

On one occasion, Mrs CO showed some depressive symptoms and was prescribed a psychotropic drug which, as a restricted substance that affects the nervous system, requires consent. Mrs CO was deemed not to have the capacity to consent, but consent was not obtained from her daughters. When the facility did obtain consent from Mrs CO’s daughter three days after it was first administered, she said she was not told that the drug had significant side effects, including increased appetite, weight gain, sedation, and weakness.

a. Royal Commission into Aged Care Quality and Safety (2019a, pp. 107–121).

Commonwealth took greater responsibility for funding aged care, the states reduced their funding.

1.1.2 Move to more home care

By the early 1980s governments had begun to be concerned about the burgeoning costs of residential care for the elderly. Older people increasingly preferred to stay at home as long as possible, rather than being forced to move into residential care as their frailty increased.¹¹

Support for care in the home had existed alongside support for residential care. But in the late-1960s the Commonwealth gave new, more generous grants to states and charitable organisations for home care services, ‘paramedical services’, Meals on Wheels, and home nursing services. At first these programs were ‘siloes’, often overseen by different Commonwealth government departments. But after the McLeay Report in 1982,¹² the disparate home care programs were consolidated into a more coherent ‘home and community care’ (HACC) program.

Higher-intensity care in the home was also seen as a less costly option for government, because it could delay a person’s admission to a more costly residential aged care facility.¹³ What evolved though was an incoherent approach to services at home: a home and community care program with costs shared between the Commonwealth and the states, and the parallel development of ‘community aged care packages’ (CACP) and ‘extended aged care at home’ (EACH) arrangements fully funded by the Commonwealth (albeit with a personal contribution from

recipients). The CACP and EACH packages were counted as part of the planning ratios used for residential aged care policy and funding.¹⁴

1.1.3 Streamlining and marketisation

A new *Aged Care Act* in 1997 was designed to bring some coherence to the residential care side of age support. It brought together the previously separate systems of ‘nursing homes’ and ‘hostels’. The latter were almost exclusively not-for-profit, and so this change also expanded opportunities for for-profit providers. The public mantra was to allow ‘ageing in place’, so older people did not have to shift from hostels to nursing homes. Rather, as they needed more support, it could be provided in their current location. The new Act also harmonised and increased resident co-payments.

The next round of changes – *Living Longer, Living Better* – was phased in from 2012, and was aimed principally at community-based care.¹⁵ The *Living Longer, Living Better* changes introduced a Commonwealth Home Support Program that brought all basic home support together into one program.¹⁶ Not-for-profit and for-profit organisations were funded under the Home Support Program to provide support to people in line with their needs as assessed by Regional Assessment Services.

The Home Support Program has a wellness and re-ablement focus and provides a range of ‘entry-level’ services to promote independence and allow people to remain in their home. The program includes food services, domestic assistance, transport assistance, and nursing services.¹⁷

11. Howe (1997).

12. House of Representatives Standing Committee on Expenditure (Chair: Leo McLeay MP) (1982).

13. Whether care in the home is less costly for government in an individual case depends on the level of support that is provided in the home. When a person needs higher levels of support, care in the home may be more expensive than care in a residential aged care facility.

14. Gibson and Liu (1995).

15. This was in response to recommendations from the Productivity Commission Report on Caring for Older Australians: see Productivity Commission (2011); Jeon and Kendig (2017).

16. Commonwealth of Australia (2012).

17. Department of Health (2015).

Home Care Packages are a separate type of home care program for higher-level care. Home Care Packages have four different levels of funding, to replace the old two-tier system (CACP and EACH) introduced in the 1990s. In 2012 the government introduced the concept of ‘consumer-directed care’ to Home Care Packages, but continued with the CACP and EACH approach of allocating packages to aged care providers.

In 2017, packages were assigned to individuals instead of providers. Individuals were then supposed to be free to choose a provider to deliver care and support funded through their packages. But little advice and assistance was provided to help consumers, with the support of their families, choose providers, leaving older people and their families to fend for themselves with poor information about comparative pricing or quality. Nor was there adequate local system support for older people and their families to help them plan and manage services on behalf of consumers. A 2017 review called for further reform in information, assessment, consumer choice, means-testing, and equity of access.¹⁸

1.2 Where we are now: a top-down, provider-dominated system

Today, Australia’s aged care system is in dire straits. The system failures over the past 20 years have been exposed by more than 20 reviews of the sector, each demonstrating further flaws, with patchwork responses unable to fix the system.¹⁹ Unacceptably, in 2020 many older Australians are still getting inadequate care.

In 2018-19, the Commonwealth Government spent \$19.9 billion on aged care services, with most funding – \$13 billion – going to residential care, \$2.5 billion going to Home Care Packages, and \$2.6

Case Study 2: Mrs CA^a

Mrs CA was born in 1936. She was diagnosed with Alzheimer’s disease in about 2010, and continued living at home with her husband. By October 2017 she needed help with eating, showering, and dressing. She could not speak. In May 2018, Mrs CA was admitted to Oberon Village, west of Sydney, in the residential facility dementia unit on a respite basis.

Previously, in January 2018, Oberon Village had been found non-compliant with a number of accreditation standards, including that ‘the needs of care recipients with challenging behaviours are managed effectively’. By the time Mrs CA arrived, the Quality Agency found that most of the instances of non-compliance had been resolved.

Two other residents in the dementia ward of 12 residents had a history of suspected assault against other residents. Mrs CA was involved in two separate incidents with these two residents about a month into her stay. The first incident resulted in Mrs CA suffering a cut on her mouth. The second incident resulted in her falling over. The Royal Commission noted that despite the facility meeting requirements under the Act, it did not prevent the incidents occurring.

a. Royal Commission into Aged Care Quality and Safety (2019a, pp. 121–134).

18. Tune (2017, p. 12).

19. Royal Commission into Aged Care Quality and Safety (2019b).

billion going to the Community Home Support Program.²⁰ Aged care services were provided to 1.3 million people, including about 243,000 in residential care and about 133,000 in home care.²¹

Australia's aged care is now largely provided by poorly regulated not-for-profit and for-profit organisations. The benefits of consumer-directed care reforms have not been realised. The Royal Commission's 2019 interim report said 'the notion that most care is consumer-directed is just not true', and that 'it is a myth that aged care is an effective consumer-driven market'.²²

Instead, the reforms resulted in for-profit providers increasingly dominating the system. The number of for-profit home care providers has nearly tripled in the past four years, from 13 per cent in 2016 to 36 per cent in 2019.²³

Rather than ensuring an appropriately regulated aged care market, the government's primary focus is on constraining supply to control expenditure. Residential care and community places have both been limited by planning ratios at a particular ratio per thousand population over the age of 70.²⁴

The current funding model has also resulted in larger facilities. Over the last 10 years, the proportion of aged care facilities with more than 60 beds has risen from under 40 per cent to 60 per cent.²⁵ This trend is particularly driven by the for-profit sector, responding

20. Aged Care Funding Authority (2020, pp. xi–xii). In 2018-19, this funding supported 1,458 Community Home Support Programme providers, 928 home care providers, and 873 residential aged care providers.

21. Ibid (p. 19).

22. Royal Commission into Aged Care Quality and Safety (2019b, p. 10). This was particularly so for people needing care in remote areas: see p. 173-174.

23. Aged Care Funding Authority (2020, p. 43).

24. As at 30 June 2019, the overall target provision ratio is 79.6 aged care places for every 1,000 people aged 70 and older: Department of Health (2019, p. 4).

25. Aged Care Funding Authority (2020, p. 62).

Case Study 3: Mr Terry Reeves^a

In 2010, Mr Terry Reeves was diagnosed with Alzheimer's disease. In 2018, at the age of 72, he was admitted to respite residential care for two months. The Garden View facility in Sydney had 70 residential places. He stayed in a wing of the facility that was for people living with advanced dementia.

Mr Reeves was provided with substandard care. The Royal Commission found that, on nearly every day over the two months he was at the facility, Mr Reeves was physically restrained in his chair (by a pelvic or a lap restraint) for half-an-hour to two hours at a time. On some days he was restrained for 13 or 14 hours in total. Over the two months he also had numerous falls and needed help walking. Prior to entering the facility, Mr Reeves had only needed help with showering, dressing, and eating, and could use the toilet himself. He had been mobile, and had never fallen.

In 2019, a Review Audit by the Aged Care Quality and Safety Commission found the facility met only 34 out of 44 expected outcomes – including failing to meet the outcome relating to behaviour management. It found that this had come at a cost to Mr Reeves' 'safety, dignity, and quality of life'.

His wife said that when she came to pick him up, he was incontinent, unable to talk, and unable to walk without assistance. Since then he was reported to have partially recovered, but Mrs Reeves said that 'he never came back 100 per cent after being at Garden View; never came back'. Now, Mr Reeves lives at another facility where 'they don't restrain. They don't medicate. He's free to walk around the halls.'

a. Royal Commission into Aged Care Quality and Safety (2019a, pp. 76–107).

to financial incentives inherent in the current funding arrangements. For-profit providers have on average 20 beds more per facility than not-for-profits.²⁶

Fundamentally, the aged care system's focus on service provision – how much of it there is, and how much the Commonwealth pays for it – has developed without an underlying philosophy that defines the outcomes sought in the system – which should be about meeting needs of people who have a right to support and supporting them to continue living a meaningful life.

Today, Australia's aged care system is in crisis. The system is no longer fit for purpose and is failing older Australians, their families, and their carers. While some aged care providers give high-quality support to older Australians, many do not. The Royal Commission into Aged Care Quality and Safety has demonstrated some fundamental failures – of access to care, and of care provision. The COVID-19 crisis has further exposed existing problems, with tragic outcomes. Thousands of older Australians have been confined to their rooms in residential care facilities for months on end, with their families and friends often prevented from visiting them, and failures in infection protocols have resulted in hundreds dying from the virus (see Box 1).

1.2.1 Access to adequate care is limited

Australia spends less on aged care than similar countries.²⁷ Pressure to manage costs means formal assessment of home care and

26. Aged Care Funding Authority (2020, pp. 61–62). Note that this difference may also be due to not-for-profits having a bigger presence in regional areas, where facilities are usually smaller. For-profit providers have on average 95 beds per facility, whereas not-for-profits have on average 75 beds per facility: Aged Care Funding Authority (ibid, p. 61). Government facilities have on average 30 beds per facility. About 10 per cent of residents still live in 'ward-style' shared rooms with shared bathrooms: Aged Care Funding Authority (ibid, p. 63).
27. Comparable countries with high functioning aged care systems, such as the Netherlands, Japan, Denmark and Sweden, spend between 3 and 5 per cent of

residential care is about eligibility and funding rather than the services that are needed.²⁸ Formal assessment methods vary between home support, and home care and residential care. There are often delays in getting assessed, and between assessment and care planning and service delivery.²⁹

Even after overcoming assessment barriers, support is often not provided. The cost constraint on home care has unacceptably left more than 100,000 people waiting for a care package at their level as at March 2020, with many waiting for more than 12 months.³⁰ Even worse, those who have the highest needs – people assessed for a Level 4 package – have to wait on average nearly two years to receive support.³¹ The Royal Commission heard from one witness that her mother had had to wait for 14 months for a Level 4 package. In this time, her mother received only four hours of formal support a week, and her health deteriorated rapidly.³² Long wait times can result in people going into an institution prematurely, being inappropriately sent to hospital, or dying prematurely.³³

their GDP on long term care. Australia spends 1.2 per cent: Dyer et al (2020, pp. 43–44). Note that there are acknowledged difficulties with comparing international expenditure on aged care.

28. Home Care and Residential Care funding is allocated to individuals (home care) or institutions (residential care) on the basis of an individual's assessed membership of a particular cost group.
29. This is combined with a lack of clarity in the timeframes between requesting an assessment and the assessment being completed.
30. Royal Commission into Aged Care Quality and Safety (2019a, p. 36). Wait times for the home support program are also unknown and unpublished, but older Australians have reported not getting the services they need. See evidence given by Professor Woods to the Royal Commission: Aged Care Quality and Safety (2020b, P-9184).
31. Royal Commission into Aged Care Quality and Safety (2019a, p. 36).
32. Royal Commission into Aged Care Quality and Safety (ibid, p. 37).
33. Royal Commission into Aged Care Quality and Safety (2019b, p. 3). During 2017-18, 16,000 people died while waiting for a package they never received: Royal Commission into Aged Care Quality and Safety (2019a, p. 36).

Box 1: COVID-19 and the rights of older Australians

The Australian Government's failure to adequately prepare residential care facilities for the threat of COVID-19 has contributed to an unacceptably high death toll in aged care. By the end of September 2020, there had been about 2,000 COVID-19 cases and 650 deaths in residential aged care, accounting for about 75 per cent of Australia's COVID-19 death toll. In a pandemic, vulnerable people are of course sadly more likely to die, but Australia's death toll in residential care is still higher than many comparable countries, where about half of all COVID-19 deaths have been in aged care homes.^a

The pandemic exposed Australia's poor governance and regulation of aged care. Despite having ample warning after the Newmarch House disaster in NSW during the first wave, the Australian Government – as the regulator – was belated and reactive in its response to the second wave. Actions were not driven by the need to protect the rights of older people. Even the right to healthcare was not respected; many residents did not receive needed in-hospital care.^b This was highlighted in Counsel Assisting's submission to the Royal Commission:^c

Equal access to the hospital system is the fundamental right of all Australians young or old and regardless of where they live. Many of the residents in aged care homes worked their entire lives to build the world class health system of which Australians are justifiably proud. They have the same right to access it in their hour of need as the

rest of the community. Older people are not less deserving of care because they are old. Such an approach is ageist.

COVID-19 has also brought into focus the tension between autonomy and safety. Many residents were effectively imprisoned in their rooms for months to avoid potential infection from other residents. One resident, Ms Merle Mitchell AM, who lives in a facility in Victoria that had not had any cases and had been in lockdown since early February, gave evidence to the Royal Commission in August 2020. She said: 'From the time I wake up to the time I go to sleep, I'm sitting in my own room in my one chair.'^d

A psychologist providing services to residential facilities, Julie Kelly, gave evidence that she had seen a large increase in depression and anxiety, with suicidal risk increasing and many residents having a strong sense of hopelessness.^e

Individual rights to autonomy and freedom of movement should not be set aside in a crisis. Some providers found creative solutions adapted to the particular circumstances to respect older Australians' right to autonomy.^f These solutions helped ensure residents could continue to have a life rather than be merely confined to their rooms. Visitation is important not only for residents; it is also important for family members who provide care and support.

a. This is based on a June 2020 review of 26 countries including the UK and the US: Comas-Herrera et al (2020, p. 2). Note that there are some acknowledged difficulties with international comparisons of aged care.

b. Note that access to healthcare also involves state government responsibilities.

c. Aged Care Quality and Safety (2020a, para 180).

d. Aged Care Quality and Safety (ibid, para 99).

e. Aged Care Quality and Safety (ibid, para 107).

f. For example, a survey conducted by HammondCare found that residents and families preferred to stay open to visitation, even if it presented a risk. This resulted in HammondCare making a decision to continue allowing visitors by setting up a concierge service, run by corporate staff and volunteers who coordinate and screen visitors. There are more examples of innovative strategies introduced by other providers: Aged Care Quality and Safety (ibid, para 109-114).

At the same time, residential facilities are increasingly becoming a place of last resort for many people. Over the past 20 years, residential care facilities have increasingly moved away from being a lifestyle choice in a retirement living home to more high-level care facilities in larger-scale settings.³⁴ Compared to the past, residents today tend to have more complex care needs, have more disabilities, and are frailer.³⁵ Today, nearly a quarter of permanent residents stay for only six months or less before they die.³⁶ It is no longer clear what the purpose of residential care is; whether it should provide a home-like environment, or clinical care.

Despite their aversion to residential care, many older Australians are left with no choice but to go into institutional care to get the level of care and support they need. Institutionalisation has largely been phased out for Australians with disability or mental health issues, yet this model is still viewed as acceptable in aged care.³⁷ In fact, Australia's aged care system relies more than many other countries on institutional care.³⁸ About 50 per cent of older Australians go into a residential care facility at some point, and about 80 per cent die there or in hospital.³⁹

34. Gibson (2020).

35. Ibid.

36. Based on Grattan analysis of data from the Australian Institute of Health and Welfare (2020a).

37. Bitner and Franz (2017).

38. It was estimated that about 13.9 per cent of Australians older than 80 live in residential care facilities, which is higher than the US at 6.1 per cent, Germany at 11.4 per cent, and Canada at 12.4 per cent, but less than New Zealand at 14.6 per cent and Switzerland at 16.7 per cent: Dyer et al (2020, p. xii); although there are acknowledged difficulties with international comparisons of institutionalisation rates.

39. Royal Commission into Aged Care Quality and Safety (2019c, p. 21); Australian Institute of Health and Welfare (2018a).

1.2.2 Care provision is often substandard

There are too many instances of abuse, neglect, and substandard care in Australia's aged care system (see Case Studies).⁴⁰ It did not come as a surprise when the 2019 interim report from the Royal Commission into Aged Care Quality and Safety concluded that:

Many people receiving aged care services have their basic human rights denied. Their dignity is not respected, and their identity is ignored. It most certainly is not a full life. It is a shocking tale of neglect.⁴¹

Older people receiving aged care can be left feeling lonely and isolated, and with little meaningful activity. A 2014 study of 36 long-term care homes in Sydney found that residents spent most of their time stationary and expressing little emotion, but were happier and less anxious during structured activity.⁴² Residents tend to have high rates of mental health problems, with nearly 50 per cent of residents having a diagnosis of depression.⁴³

A 90-year-old witness at the Royal Commission said that as a resident in a facility she has 'a never-ending battle to be seen as a fully competent adult'. She said she feels that she has no voice living in residential care.⁴⁴ Another 84-year-old resident said 'there's just that feeling that this isn't a proper life, and so there is that feeling that the quicker it's all over, the better it is for everybody'.⁴⁵ Both these witnesses also spoke of difficulties in receiving correct medications,

40. The 2017 Oakden report in particular exposed atrocious conditions for residents at a facility in South Australia. The first review found the facility was run like a mental institution from the middle of the last century, rather than a modern mental health facility for older people: Groves et al (2017, p. 57).

41. Royal Commission into Aged Care Quality and Safety (2019b, p. 12).

42. Casey et al (2014).

43. As at 30 June 2019. Australian Institute of Health and Welfare (2020b).

44. Royal Commission into Aged Care Quality and Safety (2019a, p. 62).

45. Royal Commission into Aged Care Quality and Safety (ibid, p. 62).

problems with continence care, social isolation, and bland food. There were not enough activities in the facility to keep their minds occupied. Staff were also dismissive of their experience of pain.⁴⁶

Older Australians in residential care have little autonomy over basic decisions, such as when they eat and sleep.⁴⁷ Residents often lose their autonomy, dignity, and control, and find it difficult to build meaningful relationships.⁴⁸ Food is often of poor quality, leading to malnutrition. On average, facilities allocate only \$6.08 per day per person to food; less than in prisons (\$8.25 per prisoner per day).⁴⁹

People with dementia – at least 50 per cent of aged care residents – face particular issues of poor care or neglect.⁵⁰ Staff are often inadequately trained, resourced, or supported to properly care for people with dementia. Often, people with dementia are assumed to be incapable of making even the most trivial decisions about their own lives.⁵¹ Evidence from interviews and focus groups shows that people living with dementia do not want to be institutionalised, or locked in a dementia unit.⁵² Instead, they want space, access to the outdoors and recreational activities, and the ability for visitors to come and stay the night.⁵³ But unfortunately, people living with dementia are often confined to certain spaces, and physically or chemically constrained. Many are given little opportunity to participate in the community.⁵⁴

46. Royal Commission into Aged Care Quality and Safety (2019a, p. 63).

47. Ipsos (2020, p. 9).

48. Walker and Paliadelis (2016).

49. Hugo et al (2017).

50. It could be up to 70 per cent of residential aged care residents: Royal Commission into Aged Care Quality and Safety (2019a, p. 67).

51. Royal Commission into Aged Care Quality and Safety (ibid, p. 71).

52. Steele et al (2020).

53. Ibid.

54. Ibid.

Case Study 4: Mrs DE^a

Mrs DE was born in Germany in 1947, and had two daughters. In late 2016, Mrs DE experienced memory loss and confusion, and then had a fall at home. After two rounds of being admitted to hospital and her condition declining, Mrs DE's daughters arranged for her to be put into respite residential care, with the potential for a permanent stay, because her daughters could not provide the support at home. Mrs DE had previously indicated she did not want to go to residential care.

Mrs DE was provided substandard care at Bupa Willoughby residential care facility on Sydney's North Shore. Mrs DE died within a month of being at the residential care facility.

The Royal Commission found numerous instances of substandard care relating to nutrition and eating, failures to incorporate certain recommendations of the speech pathologist, failures to incorporate the recommendations of a hospital regarding the need for a physiotherapist to assess her respiratory issue, its management of hearing and visual aids, and pain management. The facility also did not keep satisfactory records on pressure area care.

a. Royal Commission into Aged Care Quality and Safety (2019a, pp. 135–166).

The Royal Commission also heard many reports of abuse and neglect in residential care,⁵⁵ including the unjustified use of physical or medical restraints to manage difficult behaviour.⁵⁶

Poor culture, lack of training, and inadequate staff numbers can lead to the use of inappropriate chemical or physical restraints. Witnesses to the Royal Commission reported that the use of chemical restraints was common,⁵⁷ despite the *Quality of Care Principles 2014*, Part 4A, designed to discourage the use of restraint.

1.3 Australia's aged care system is a reflection of societal attitudes

The structural and systemic problems in the aged care system are deep-rooted and reflect society's underlying ageism. Although ageist attitudes are not limited to the aged care system, ageism has enabled the failures in the system to persist for decades.

Australia's aged care system assumes older people are a burden on society, rather than empowered individuals who need support to continue making a significant contribution to community life. This is reflected in our language, for example, when using 'care', rather than 'support' to describe service provision. Structurally, this underlying ageism has contributed to the chronic under-investment in aged care and support by governments, resulting in under-funding, poor regulation, and a lack of meaningful reform to fix the system. Practically, this attitude can also lead to care and support that undermines the rights of older people.

Ageing has been constructed as a social problem.⁵⁸ Societal attitudes towards older people are often ageist. A 2013 report commissioned

by the Age Discrimination Commissioner found that 43 per cent of surveyed people over the age of 65 had experienced age-related discrimination.⁵⁹ Dominant myths of old-age include: inevitable mental and physical decline, inevitable dependence, and inability to contribute usefully or productively to society.⁶⁰ This thinking can lead to the assumption that older people must forego their rights – such as their rights to choice and autonomy. But it is societal ideas – not their age – that denies them full enjoyment of their rights.⁶¹

When asked, most Australians view older people positively, and see them as enriching our communities.⁶² Older Australians are after all our mothers, fathers, aunts, uncles, grandparents, and great-grandparents. But ageism can often emerge in well-meaning paternalistic attitudes. These attitudes are sometimes referred to as 'benevolent ageism'.⁶³

When older people develop serious disabilities, others, including sometimes families and health care professionals,⁶⁴ can be too quick to make decisions for them without considering their rights and

55. Royal Commission into Aged Care Quality and Safety (2019b, p. 115).

56. Royal Commission into Aged Care Quality and Safety (ibid, p. 193).

57. Royal Commission into Aged Care Quality and Safety (2019a, p. 70).

58. Fredvang and Biggs (2012, p. 6).

59. This study also found that social media portrays older people as vulnerable and victims: Australian Human Rights Commission (2013). A 2015 survey by the Australian Human Rights Commission also found that 27 per cent of older Australians (age 50+) reported experiencing age discrimination in the workplace: Australian Human Rights Commission (2015).

60. Formosa (2001, p. 17).

61. Fredvang and Biggs (2012, p. 7); Doron and Apter (2010).

62. Surveys show people value older Australians for a range of reasons, including for their work, knowledge, experience, and time spent volunteering and supporting families and communities. See Roy Morgan (2020) and Ipsos (2020).

63. Benevolent ageism is in contrast to hostile ageism. Benevolent ageism relates to perceptions of older people as warm but incompetent. This leads to paternalistic prejudice. Cary et al (2017) uses the example of offering an older person a seat on the bus, which is not necessarily ageist, but then insisting they take the seat offered, even after they have refused. This 'implies their opinion is irrelevant and undermines the ability for them to make their own decisions'. See also Vale et al (2020) and Horhota et al (2019).

64. Ageism is prevalent across society, including in healthcare. For example, a 2016 survey of nursing students found that 97 per cent reported engaging in some kind

aspirations. Often families, acting with the best of intentions, focus on safe, comfortable care that they see is in the older person's 'best interests', rather than first seeking to support the older person pursue their own 'will and preferences'.⁶⁵

A recent example of these paternalistic attitudes was when the Prime Minister, Scott Morrison, answered a question in Parliament on 26 August 2020, by portraying older people as disempowered:⁶⁶

For those of us who have had to make decisions about putting our own family, our own parents, into aged care, we have known that when we've done that we are putting them into pre-palliative care.⁶⁷

We need to stop describing residential care as a place we 'put' people while we wait for them to die. Such language suggests we can lose sight of the person and their choices and aspirations when people get older and develop serious disabilities. Similar to younger people with a disability, older people can suffer discrimination because society idealises physical and mental health and 'ableness'.⁶⁸ This is particularly true when the person is older and has disabilities or other cognitive impairments that affect their capacity to make decisions.⁶⁹

of ageist behaviour: Frost et al (2016). See also a recent review: Jeyasingam (2020).

65. The debate between 'best interests of' versus 'will and preferences' has been particularly explored in the context of disability, and also has implications for substituted decision-making and supported decision-making models. See Smith (2018) and Szukler (2019).
66. Earlier, during the Victorian aged care COVID-19 crisis, Premier Daniel Andrews said, 'I would not let my mum be in some of these places, I just wouldn't.' See McElroy (2020).
67. House of Representatives (2020, p. 5638).
68. Schulmann et al (2017, p. 6). Note that more than 80 per cent of people aged 85 or older have some disability: Australian Law Reform Commission (2017, p. 18).
69. The exclusion of older people (65+) with disabilities from the NDIS is another example of discrimination towards older people.

Ageist attitudes can also make older people more vulnerable to abuse, exploitation, or neglect. Dependence on others to advocate on their behalf, declining health, social isolation, death of a partner, and reducing wealth or poverty can mean their rights are more easily disrespected.⁷⁰

Another bias that plays into the structural and systemic issues in the aged care system is the prevailing patriarchal and sexist attitudes towards women. The aged care system is dominated by women:⁷¹ they make up nearly 90 per cent of direct care workers and nearly 70 per cent of family and friend carers (i.e. informal carers).⁷² The reliance on family and friend carers and systemic under-payment of formal carers in the aged care sector is likely to be a reflection of society's under-valuing of roles and functions dominated by women.⁷³ Not only are most carers women, but many are also (new) migrants and/or people with lower socioeconomic status.⁷⁴ Discriminatory biases, in

70. Lacey (2014, pp. 113–114). Note that elder abuse can occur in both formal and informal (family and friends) carer relationships: Australian Institute of Health and Welfare (2019, p. 146). Elder abuse is 'abuse by people in a position of trust', and is more often committed by a family member, including adult children or the spouse or partner: Australian Law Reform Commission (2017, p. 8).

71. Gibson and Allen (1993).

72. Mavromaras et al (2017, p. 17) and Australian Institute of Health and Welfare (2020c). Note that 60 per cent of care recipients in home care and residential care are also women: Khadka et al (2019).

73. Gibson (1998). There are underlying sexist ideas about the role of the carer – such as the expectation that caring is part of women's natural role. This idea has led to a fundamental undervaluing of the free labour provided by women in the caring of children, the elderly, and the sick.

74. About 30 per cent of the direct care workforce in residential aged care were born overseas, and 40 per cent of recent hires in 2016 were migrant workers: Mavromaras et al (2017). The limited security, casualisation, and low-paid work in residential care facilities was exposed by the COVID-19 pandemic, when the spread was linked to people with no entitlement to sick leave and/or who worked across multiple facilities. Aged Care Quality and Safety (2020a, para 192).

turn, may reduce the priority given in political debates and decisions to addressing the underlying problems of the system.

1.4 The way forward

Before any further changes are made to Australia's aged care system, we need to go back to first principles. We need to ask what the system is for, and what outcomes we are seeking to achieve. It should not be merely providing 'pre-palliative' care, as the Prime Minister suggested. It should support people to continue living meaningful lives into their older age. This requires a fundamental shift away from the ageist and disempowering underpinnings of the system we have today. Overturning biases towards older people will take time, and requires a societal shift in thinking – not just in aged care, but also in healthcare and the broader society.

The remaining two chapters show that a rights-based approach to aged care is needed to re-balance the system towards the rights of older people. Chapter 2 explores the rights of older Australians and sets out rights-based principles that should be emphasised in an aged care context. Chapter 3 argues that rights-based thinking should underpin reform of the aged care system. The Royal Commission into Aged Care Quality and Safety should not merely recognise that rights are important, but recommend that rights-based thinking be embedded throughout the system – from governance and planning all the way down to service delivery.

A future Grattan Institute report will provide more detail about what a rights-based system would look like.

2 The rights of older Australians

Give every other human being every right you claim for yourself.⁷⁵

The aged care system needs to protect older Australians' rights. Human rights were enshrined under international law halfway through last century. This led to rights-based movements in healthcare and disability – both of which have been recognised and implemented in Australian law. Yet rights are still neither well-understood nor adequately protected in Australia's aged care system.

This chapter outlines a set of rights-based principles that are important in the context of care and support for older Australians. Principles of independence, participation, and autonomy mean that older people can continue directing the course of their lives and continue engaging in meaningful activities. Principles of dignity, equity, and non-discrimination ensure that older people are not neglected or abused. And principles of universal access ensure all who need care and support receive it to an adequate standard.

2.1 Rights as a conceptual underpinning for older persons' services

Under international law, all people, regardless of their age, have equal rights. They include the right to life, liberty, privacy, freedom of thought, education, an adequate standard of living, and so on.

Human rights empower individuals to achieve their 'full potential by giving them the authority, capacities, capabilities, and access needed to change their own lives, improve their own communities, and influence their own futures'.⁷⁶ Laws that protect human rights ensure that 'all individuals have the right to choose and participate in all decisions

affecting their lives'.⁷⁷ A rights framework helps re-balance power towards the individual.

Rights-based thinking in the context of health has become increasingly prominent. Human rights have provided the basis for universalism. Australia's Medicare system ensures everyone, no matter their means, has access to adequate healthcare.

More recently, rights-based thinking has been applied in the context of long-term care – care of people with chronic illness, mental health issues, or disability, who have historically been discriminated against and not afforded adequate support.⁷⁸

In Australia, disability policy has adopted a rights-based framework. The recent reform to Australia's disability framework through the National Disability Insurance Scheme (NDIS) was championed by a long-standing rights-based disability movement. This movement sought to shift discriminatory views of people with disability – reflected in Australia's inadequate disability support systems – to a more empowered position where people with a disability have a right to supports that allow them to live full and independent lives, and participate in community life. This movement over the past 40 years achieved the de-institutionalisation of people with disability.⁷⁹

The *NDIS Act 2013* sets out a series of rights-based principles for disability services, drawn from both the Convention on the Rights of People with a Disability, and other Australian international obligations.⁸⁰

77. European Network of National Human Rights Institutions (ibid, p. 4).

78. For example, rights are emphasised in state-based mental health acts. See for example in Queensland: Queensland Health (2020) and in Victoria: Department of Health and Human Services (2020a).

79. Bitner 2017.

80. See Appendix A.

These include to support ‘the independence and social and economic participation of people with disability’, to ‘maximise independent lifestyles and full inclusion in the community’, and to ‘enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports’.

But the rights of older people have often been overlooked in rights-based movements.⁸¹ This is slowly shifting, with countries beginning to adopt rights-based policies or charters. Internationally, there are calls for a convention on the rights of older people. Demographic change is also playing a role in bringing more attention to rights – particularly as the expectations of services for older people are changing with the incoming Baby Boomer generation.⁸²

2.2 Older people have human rights too

The 1948 Universal Declaration of Human Rights is the key document that enshrines universal rights for all.⁸³ Two additional international treaties – both signed and ratified by Australia – articulate more comprehensive human rights. The 1966 International Covenant on Civil and Political Rights enshrines universal civil and political rights such as the right to self-determination and the right to vote.⁸⁴ And the 1966 International Covenant on Economic, Social, and Cultural

Rights enshrines rights such as the right to health, social security, and housing.⁸⁵

Some people are more vulnerable to having their rights disrespected. As a result, numerous international law instruments articulate the rights of women, children, Indigenous peoples, refugees, and people with disability. For example, the 1979 Convention on the Elimination of All Forms of Discrimination Against Women,⁸⁶ and the 2007 Convention on the Rights of Persons with Disabilities.⁸⁷

The Convention on the Rights of Persons with Disabilities frames the rights of people with disabilities, many of who are also older people. The principles of autonomy and self-determination are just as important for older as younger people with disabilities.

But human rights for older people, as a specific group, are not well-defined in international human rights law.⁸⁸ Apart from a few explicit references to older people in human rights treaties,⁸⁹ there is only ‘soft

81. Fredvang and Biggs (2012, p. 5).

82. Fredvang and Biggs (*ibid*, p. 5).

83. UN General Assembly, Universal Declaration of Human Rights, 10 December 1948, 217 A (III). Note that philosophically, there is significant debate about the justification for and function of rights in society. There are a number of streams of philosophy that each justify the existence of rights differently. Natural rights theory has been particularly dominant, and is reflected in the Universal Declaration of Human Rights. In terms of aged care, this conception works given that it applies whether or not an individual has agency to realise their rights.

84. UN General Assembly, International Covenant on Civil and Political Rights, 16 December 1966, United Nations, Treaty Series, vol. 999, p. 171.

85. UN General Assembly, International Covenant on Economic, Social and Cultural Rights, 16 December 1966, United Nations, Treaty Series, vol. 993, p. 3.

86. UN General Assembly, Convention on the Elimination of All Forms of Discrimination Against Women, 18 December 1979, United Nations, Treaty Series, vol. 1249, p. 13.

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

88. Lacey (2014, pp. 114–115).

89. The Universal Declaration includes a right to security in old age. The Convention on the Elimination of All Forms of Discrimination Against Women (1979) includes the equal right of women to social security, including in old age (Article 11.1.e). The International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (1990) prohibits discrimination based on age (Article 1.1 and 7). And the Convention on the Rights of Persons with Disabilities makes explicit mentions of older people in article 25(b), which deals with the right to health, and article 28(2)(b), which includes the right to an adequate standard of living. For the full list of references to older people in human rights law see The Global Alliance for the Rights of Older People (2020).

law’ – law that is not legally binding – that articulates the rights of older people.⁹⁰

The Office of the High Commission for Human Rights found that older people:

are all but completely overlooked by the human rights system such as the rights issues arising in the delivery of home, institutional, or residential care services, or the rights engaged at the end of life and access to palliative care.⁹¹

The 1991 UN Principles for Older Persons encourages countries to adopt five principles in their national programs wherever possible. These principles draw on existing human rights and set out how they should protect older people. The five principles are dignity, independence, participation, care, and self-fulfilment. More recently, a UN action plan, called the 2002 Madrid International Plan of Action on Ageing (MIPAA) – also signed by Australia – articulates an international commitment to the full realisation of the rights of older people, including the empowerment of older people to fully and effectively participate in the economic, political, and social lives of their societies.⁹²

2.3 Australia’s rights-based protections are not enough

Australia does not have strong protections for the rights of older people in need of long-term care. Unlike the US, Australia does not have a

90. There has been a long-standing contested movement to develop a treaty for the rights of older people. Some argue a treaty is needed because older people are vulnerable to having their rights disrespected. Others argue a specific treaty would explicitly define older people as a vulnerable group, further entrenching discrimination: Harpur (2016).

91. Office of the High Commissioner for Human Rights (2012, p. 3).

92. It sets out broad recommendations or ‘actions’ for countries to achieve these goals, such as promoting the development of age-integrated communities: UN Department of Economic and Social Affairs (2002), see paragraph 98.

Bill of Rights.⁹³ International human rights only become enforceable in Australia if the international law is incorporated into Australian law.⁹⁴ Although some laws, such as the *Disability Discrimination Act 1992*, may be applicable for discrimination against older people with a disability, there is no specific Australian law focused on the rights of older people.⁹⁵ And even the *NDIS Act 2013* specifically excludes supporting older people with a disability. Anyone who is over the age of 65 and seeks access to the NDIS is not eligible for support.⁹⁶

On a state level, there are only weak accountability measures for Australians suffering elder abuse. For example, in Queensland, the Office of the Public Guardian can investigate the abuse of adults who have impaired decision-making capacity.⁹⁷ In 2018, South Australia introduced a rights-based framework to protect older people. It legislated for an Adult Safeguarding Unit that places a primary focus on

93. Australians can instead make complaints to the Australian Human Rights Commission about a breach of their human rights, but this does not provide a remedy. Breaches only apply to international human rights treaties that have been scheduled or declared under the *Australian Human Rights Commission Act 1986*. Note that the Universal Declaration of Human Rights and the International Covenant on Economic, Social, and Cultural Rights are not scheduled under the *Australian Human Rights Commission Act 1986*.

94. Note also that ratified treaties not directly incorporated into Australian legislation are still an indirect source of rights. For example, Australian courts interpret Australian laws, so far as possible, consistent with provisions of Australia’s international obligations: Australian Human Rights Commission (2004).

95. The *Age Discrimination Act 2004* only applies to discrimination in employment, and does not provide a remedy. This Act also specifically excludes people with a disability.

96. Older Australians can get NDIS supports only if they were younger than 65 when they applied, and can then continue receiving it past the age of 65 if they choose.

97. NSW has also established an Ageing and Disability Commissioner to respond to abuse, neglect, and exploitation of older people in home and community settings: see Appendix A.

the right to autonomy, rather than just protecting people from abuse.⁹⁸ And more recently, in 2020, the ACT passed legislation to make elder abuse a criminal offence, to take effect in 2021.⁹⁹

Australia's aged care legislation also does not put the rights of older people at the heart of the system. The objects of the *Aged Care Act 1997* focus on the quality, type, targeting, and affordability of care for eligible recipients. One of the 10 objects of the Act says that the purpose is to 'help those recipients to enjoy the same rights as all other people in Australia'. But these rights are not defined, nor are they the main focus of the Act. The User Rights Principles that supplement the Act are largely contractual obligations between care recipients and providers. The principles are narrowly cast to cover payments and fees, security of tenure, access for visitors, restrictions on moving care recipients, and requirements for provision of information.¹⁰⁰

More recently, the aged service system has taken steps to recognise the rights of older Australians. In July 2019, a single Charter of Aged Care Rights for the whole system was introduced.¹⁰¹ The Charter includes 14 fundamental protections, including the right to exercise choice and control, and the right to independence. Providers are

required to assist 'consumers' to understand their rights and to give each 'consumer' a reasonable opportunity to sign the Charter.¹⁰²

But the Charter is merely a Band-Aid on a broken system. It is an aspirational document that sits separate to, rather than being integrated into, the system. There is no guidance on how the listed rights can be applied in practice rather than just in theory. Nor does it sit within a system that has structural pillars that support the fulfilment of rights, such as sufficient resourcing or strong accountability. And these aspirational rights have effect only after a person is granted access to the aged care system, which leaves people languishing on waiting lists in a rights void.¹⁰³

On 1 July 2019, new quality standards – using a new outcomes-based approach to compliance – were introduced for all Australian government subsidised aged care services. One of the eight new standards requires providers to ensure personal dignity and choice.¹⁰⁴ That is rights language, yet there is no clear avenue for the consumer to enforce it or seek redress.¹⁰⁵ Placing the burden on providers alone is insufficient to ensure significant changes to care. And relying on random compliance checks by the regulator may also result in inconsistent subjective assessment against standards.

98. Section 12 of the *Ageing and Adult Safeguarding Act 1995*. Despite the comprehensive rights-based principles that underpin the Act, the unit is limited in power, because it can only investigate and escalate reports of abuse.

99. Note that this law seeks to protect any vulnerable person, such as a person with a disability, or a person over the age of 60, from abuse or neglect by someone responsible for their care. See the ACT *Crimes (Offences Against Vulnerable People) Legislation Amendment Act 2020*.

100. *User Rights Principles 2014 (Cwth)*.

101. In 2014 a Charter of Care Recipients' Rights and Responsibilities was introduced for residential care (Schedule 1 of the *Aged Care Act*), with another separate Charter of Rights and Responsibilities for Home Care (Schedule 2 of the *Aged Care Act*). But on 1 July 2019, a single Charter of Aged Care Rights replaced the previous charters, removing the reference to 'responsibilities'.

102. The language of 'consumer' is inconsistent with a rights-based approach because it reduces older people to mere actors in a market. However, we acknowledge that the language of 'consumer' is at least better than the previous more passive language of, for example, 'care recipient'. See COTA Australia's submission: COTA (2020).

103. Rights are also excluded from the Commonwealth Home Support Program, because it sits outside the Act.

104. The other standards relate to ongoing assessment, personal care, services, and complaints.

105. Steele et al (2020).

2.4 Rights-based principles for aged care

There is no consensus in the literature on a common set of principles that should underpin a rights-based approach for older people needing long-term support – whether that be at-home or in a residential facility.¹⁰⁶ There are multiple ways to conceive of rights (see for example Box 2), but the following sections of the chapter are primarily drawn from principles that are emphasised in the *NDIS Act* and the UN Principles for Older Persons.¹⁰⁷ Although the NDIS has had major implementation issues,¹⁰⁸ its rights-based framework is exemplary. Other rights-based instruments also include an extensive list of important rights not covered here (see Appendix A).

2.4.1 Independence, self-fulfilment, and participation in community

Older Australians have the same rights as any other Australians to realise their potential for physical, social, emotional, and intellectual development and fulfillment.¹⁰⁹ The UN Principles for Older Persons also state that ‘older persons should be able to pursue opportunities for the full development of their potential’.

The support system for older Australians should provide the necessary care and support for older people to pursue what they want, to the extent of their ability. This would mean that older people can be independent and reside at home. It would mean that older people can pursue spiritual or cultural interests, develop new relationships, care for family members, or volunteer in the community. This principle

106.Schulmann et al (2017, p. 41).

107.Note the following sections do not cover all of principles under the NDIS and UN Principles. See Appendix A for the full list.

108.See for example Tune (2019).

109.This draws from the NDIS, Guiding Principle Section 4(1).

Box 2: Rights of older people along the support journey

A 2017 European literature review on rights-based principles for long-term care of older people identified 17 distinct rights.^a It organised them into four categories.

Before entering long-term care

- Equal access to care services
- Affordability of care services
- Right to choose services

While in long-term care

- Right to life
- Right to freedom from torture, degrading, or inhumane treatment
- Right to liberty, freedom of movement, and freedom from restraint
- Right to choose, autonomy, legal capacity
- Right to dignity
- Right to privacy and family life
- Right to participation and social inclusion
- Right to freedom of expression
- Right to highest attainable standard of physical and mental health
- Right to an adequate standard of living
- Equality and non-discrimination
- Right to remedy and redress

End of life

- Right to palliative and end-of-life care

Other

- Rights of carers

a. Schulmann et al (2017, p. 8).

recognises that older people make significant social and economic contributions to society that reach beyond paid economic activities.¹¹⁰

Australia's aged care system – both in home care and residential care – should be able to cater for the differing needs and preferences of individuals, including differences in identity and culture. Indigenous Australians, for example, should be able to maintain and use their language, their kinship ties, and their connection to land and culture.¹¹¹ And about 20 per cent of people in residential care and 24 per cent of people receiving high-level at-home care are from culturally or linguistically diverse backgrounds.¹¹²

This principle also means that the underlying philosophy of service provision should, as much as possible, be rehabilitative, rather than assuming ongoing and increasing dependency.¹¹³ When older Australians are given opportunities for self-determination and independence, they can have better well-being.¹¹⁴

2.4.2 Informed and supported choice and control

Older people who need long-term support have the same rights as other people to lead their own lives and make decisions for themselves. A rights-based approach acknowledges that older people are 'right-holders', who can realise their rights just like any other

person, including their right to retain control over their care.¹¹⁵ The UN Principles for Older Persons say that older people have 'the right to make decisions about their care and the quality of their lives'. This is also consistent with the Medicare principle of choice of services.¹¹⁶

Our language of 'choice and control' is taken from the NDIS Act¹¹⁷ but reflects the right to autonomy. The Productivity Commission's 2011 inquiry into aged care found that recipients of care 'did not want to be passive recipients of services, dependent on funded providers'.¹¹⁸

Older Australians should be able to make decisions about their own health care, and aged care setting; whether that be at-home care or in residential accommodation. They should be able to have complete control over their own personal affairs, including finances, to the extent they are able.¹¹⁹

When older people make choices, those choices should be documented and followed. Retaining agency over even small daily decisions – such as when to wake up, when to take a shower, what to eat, and so on – is important. Older people should not be subject to the vagaries of staffing arrangements, where poorly briefed staff may fail to follow clearly expressed wishes (especially advance care directives).

110. UN Department of Economic and Social Affairs (2002, para 19). The European Charter of rights and responsibilities of older people in need of long-term care and assistance says that: 'As you grow older and may come to depend on others for support and care, you continue to have the right to interact with others, and to participate in civic life, lifelong learning, and cultural activity': AGE Platform (2010).

111. This is drawn from the South Australian Charter of the Rights and Freedoms of Vulnerable Adults.

112. Productivity Commission (2020, p. 14.14). Note that culturally and linguistically diverse (CALD) backgrounds is defined as people born overseas in countries other than UK, Ireland, New Zealand, Canada, South Africa and the USA.

113. Brownie and Nancarrow (2013).

114. Hampson (2018).

115. A key requirement in a human rights-based approach is that 'all key stakeholders are empowered and can participate in achieving the realisation of rights': European Network of National Human Rights Institutions (2017, p. 8).

116. National Health Reform Agreement – Addendum 2020-2025, Clause 8 (a): 'eligible persons must be given the choice to receive public hospital services free of charge as public patients'.

117. Section 3(e).

118. Productivity Commission (2011, p. xxvi).

119. This draws from South Australia's *Ageing and Adult Safeguarding Act 1995*, Section 12(d). This will also help avoid potential exploitation.

This principle also means that older people should be able to make decisions that may involve taking reasonable personal risks.¹²⁰ The right to autonomy should take preference over safety concerns to the extent that it is reasonable and doesn't harm others. This is the case even when others may regard it as wrong, reckless, or inappropriate.¹²¹

But choice and control cannot exist in a vacuum. They can only truly be exercised when an individual is informed about their options. This principle requires that support is available for older people to help them get services they need.

The European Charter of rights and responsibilities of older people in need of long-term care and assistance articulates this right well when it says older people have the right 'to seek and receive personalised information and advice about all of the options available to [them] for care, support, and treatment in order to be able to make informed decisions'.¹²²

In the case of people not being able to make decisions due to mental impairment such as dementia, supported decision-making should get priority over substituted decision-making,¹²³ to avoid potential exploitation.¹²⁴ Supported decision-making makes clear who is to

120. Rights-based approaches mean that their wishes must be respected, and safety considerations take priority over an individual's autonomy only in limited circumstances: European Network of National Human Rights Institutions (2017).

121. This draws from South Australia's *Ageing and Adult Safeguarding Act 1995*, Section 12(e).

122. AGE Platform (2010).

123. The NDIS uses a substituted decision-making model – which means that people can be appointed to make decisions on behalf of other people if they cannot make decisions themselves. This undermines the NDIS's stated objective to further individual autonomy, because nominees may not necessarily fulfil the wills and preferences of the person receiving care. The NDIS has been criticised for on one hand providing the reasonable and necessary supports for social and economic participation, but then on the other undermining the ability to process, access, and manage these participatory supports. See Cukalevski (2019).

124. See Attorney-General's Department (2019, p. 26).

provide support, and 'recognises the wishes of the individual and the trusting relationships they have with people in their network'.¹²⁵ The person should be supported as much as possible to exercise choice and control early through, for example, advance care planning. In the case where people lack agency and capacity to make their own decisions, substituted decision-making may become necessary. It is important that substituted decision-making still emphasises the will and preferences of older Australians over what the decision-maker may think is in their best interests.¹²⁶ And effective legal safeguards need to be in place to avoid abuse or undue influence.¹²⁷

2.4.3 Universal access to reasonable and necessary supports

All older Australians are entitled to the care and support they need. Similar to a principle in the NDIS, older people and their families and carers should have certainty that they will receive the care and support they need for the remainder of their life.¹²⁸ This is consistent with the Medicare principle of universality of services,¹²⁹ which entitles people to healthcare based on need. Services should be of an adequate standard. The Universal Declaration on Human Rights says:

125. Australian Human Rights Commission (2012, p. 17).

126. The language of 'will and preferences' is also emphasised in South Australia's *Ageing and Adult Safeguarding Act 1995*, Section 12(i): 'subject to the laws of the State and Commonwealth, the will, preferences (including sexual preferences and sexual orientation), cultural and heritage beliefs, religious beliefs, racial origin, ethnicity, background, and other beliefs or rights of a vulnerable adult must always be respected.'

127. Australian Law Reform Commission (2014, p. 24). This can include advance care planning for power of attorney, advance care directives, and so on: Australian Law Reform Commission (2017, p. 52).

128. This draws from the NDIS, Guiding Principle Section 4(3).

129. National Health Reform Agreement – Addendum 2020-2025, Clause 8 (b): 'access to public hospital services is to be on the basis of clinical need and within a clinically appropriate period'.

Everyone has the right to a standard of living adequate for the health and well-being of [themselves] and of [their] family, including food, clothing, housing, and medical care and necessary social services, and the right to security in the event of . . . old age.¹³⁰

Although the aged care system should not by default provide for all aspects of life such as everyday living expenses, the system should provide security so that no person is deprived of care and support they need. This means that people should not have to pay out of their pockets for the care and support they need.

A person's need should not be defined based merely on their health or clinical needs, but with respect to what they need to pursue their goals. For example, a key feature of the *NDIS Act 2013* is that people with disability should receive 'reasonable and necessary' supports that help them to pursue their goals and maximise their independence, live independently and be included in the community as fully participating citizens, and pursue activities that enable them to participate in the community and in employment.¹³¹ Reasonable and necessary services are health, personal care, and social support or service related to a person's disability. It does not include ordinary, day-to-day living costs, unless such living costs are substantially above the norm because of care needs. They should represent value for money, be effective, and take account of family and friend carers and other government services provided to recipients and their families.¹³²

In the context of aged care, reasonable and necessary services would be supports that address frailty, illness, and/or impairment that prevents older people exercising their rights to independence, self-fulfilment, and full participation in society. The assessment should also take account of a person's needs based on their culture and identity.

130. Article 25(1) of the 1948 UN Universal Declaration of Human Rights.

131. *NDIS Act 2013*, Section 3(d), Section 4(5) and Section 4(11).

132. NDIS (2019).

Requiring that supports are 'reasonable and necessary' ensures that that entitlement meets broader community expectations that care and support will be targeted, provided efficiently, and be relevant to the needs that have to be met for people to exercise their rights. 'Reasonable and necessary' is not a new concept; it is found in other compensation schemes in Australia.¹³³

2.4.4 Equity and non-discrimination

The UN Principles for Older Persons provide that 'older persons should be treated fairly regardless of age, gender, racial or ethnic background, disability, or other status and be valued independently of their economic contribution'.¹³⁴ This is consistent with the Medicare principle of equity in service provision.¹³⁵

The aged care system must not discriminate. Equal access extends to all groups, including minorities and those with special needs.¹³⁶ One in five people in Australia older than 65 were born in a non-English speaking country.¹³⁷ Differences should be respected, including cultural beliefs, religious beliefs, racial origin, ethnicity, sexual orientation, and other beliefs.¹³⁸ There should be no financial barrier that prevents people from accessing care they need.

133. For example, in state and territory motor accident lifetime care and support schemes: Tune (2019, p. 46).

134. Dignity has similarly been described in disability policy: Department of Social Services (2010), and by the Productivity Commission: Productivity Commission (2004).

135. National Health Reform Agreement – Addendum 2020-2025, Clause 8 (c): 'arrangements are to be in place to ensure equitable access to such services for all eligible persons, regardless of their geographic location'.

136. Australian Human Rights Commission (2012, p. 11).

137. Australian Institute of Health and Welfare (2018b).

138. This draws from South Australia's *Ageing and Adult Safeguarding Act 1995*, Section 12(i).

2.4.5 Dignity, including dignity in death

Older people who need long-term support have the same right as other Australians to respect for their worth and dignity, and to live free from abuse, neglect, and exploitation.¹³⁹ This includes respecting their right to privacy. The UN Principles for Older Persons say that dignity requires that: ‘Older persons should be able to live in dignity and security and be free of exploitation and physical or mental abuse.’

Given that aged care and support – both in home and in residential facilities – is often also end-of-life care, older people’s right to dignity in death must be realised.¹⁴⁰ A person’s right to dignity in life includes a right to a dignified death.¹⁴¹ Dignity in death has been defined as involving autonomy, relieved symptom distress, meaningful relationships, and dignified treatment and care.¹⁴² This is particularly important for residential aged care, where about 60,000 people die each year.¹⁴³

A good death is one where pain and symptoms are well-controlled, and people have their rights to independence, self-fulfilment, and participation protected and supported as they are dying. They should be able to refuse treatment that pointlessly prolongs their life if they choose.¹⁴⁴ Increasingly, this includes the right to choose voluntary assisted dying.¹⁴⁵

139. This draws from the NDIS, Guiding Principle Section 4(6).

140. The European Charter of rights and responsibilities of older people in need of long-term care and assistance also has a right to palliative care and support, and respect and dignity in dying and in death. It says that people have a right to die with dignity in circumstances that accord with their wishes and within the limits of the laws of the country.

141. Schulmann et al (2017, p. 37).

142. Guo and Jacelon (2014).

143. Productivity Commission (2017, p. 109).

144. Swerissen and Duckett (2014).

145. Voluntary assisted dying is now legal and available in Victoria and will become available in mid-2021 in Western Australia.

2.5 The rights of carers and staff

A rights-based approach means all individuals’ rights are protected – including the rights of older people and their carers. Carers (both formal and informal) have rights like other people to, for example, dignity and privacy.¹⁴⁶

Although important on its own, acknowledging the rights of staff and carers is also important because the well-being of older people and their carers is intrinsically connected.¹⁴⁷ By ensuring carers’ rights are respected, carers are better able to protect the rights of older people in their care.¹⁴⁸

The European Charter of rights and responsibilities of older people in need of long-term care and assistance includes the right of both care workers and family and friend carers to be treated with civility and respect and to not be subjected to abuse.¹⁴⁹ This then places a duty on the older person receiving care to uphold the rights of those around them.¹⁵⁰ Article 10(1) of the Charter says that older people receiving care must:

Respect the rights and needs of other people living and working within your environment, and respect the general interests of the community in which you live; your rights and freedoms should be only limited by the need to respect similar rights of other members of the community.

Family and friend carers should be acknowledged for contributing to the care of older Australians.¹⁵¹ But family and friend carers also have the

146. Note that the NDIS Act acknowledges the role of unpaid carers.

147. Schulmann et al (2017, p. 35).

148. Ibid (p. 52).

149. AGE Platform (2010); and Schulmann et al (2017, p. 52).

150. Schulmann et al (2017, p. 52).

151. This is drawn from the *NDIS Act* Section 4(1): ‘The role of families, carers, and other significant persons in the lives of people with disability is to be acknowledged and respected.’

right not to be responsible for providing *all* aspects of care. Family and friend carers have the right to services that support them in their caring duties.

2.6 Moving from theory to practice

Rights-based principles such as those articulated in this chapter should be enshrined in the aged care system. These principles should not merely be labelled and treated as aspirational goals – they should be real guiding principles for all actions and decisions in the aged care system and should shape policy, funding, and regulatory design. The next chapter shows how this could be achieved, by outlining the key practical features of a rights-based system.

3 Where we need to be: embedding rights

A paradigm shift in the way we support older Australians is long overdue. Throwing more funding at a broken system will not solve the underlying problems. Those problems are cultural; they are not amenable to being fixed by application of yet another Band-Aid. The system needs to be transformed so it supports Australians to continue living meaningful lives into old age.

A rights-based approach will ensure the system is re-balanced in favour of older Australians, rather than in the interests of service providers who have demonstrably failed to provide appropriate care. A rights-based approach will promote a cultural shift away from ageist attitudes, resulting in a more positive, participatory, and engaged view of older age. This will of course take a long-time, because it requires a shift in society's attitudes towards older people, but rights-based reform is an important step in this direction.

This chapter sketches the key practical elements of a rights-based approach. An upcoming Grattan Institute report on supporting older Australians will show how a rights-based approach would work in practice.

3.1 Rights are fundamental to aged care reform

Further reform of Australia's aged care system cannot proceed until there is a framework that clearly defines the purpose of the system and the outcomes it is seeking to achieve. As Chapter 1 showed, the current system does not have a clearly defined purpose. As a result, Australia has a patchwork system that cannot adequately support the needs of older Australians.

A rights-based framework should underpin reform, because it would empower older Australians and focus on meeting their goals and

aspirations. Rights would not be merely aspirational – they would be embedded in the system.

The time is ripe to start the required re-orientation. The Royal Commission into Aged Care Safety and Quality is lifting the lid on the problems which fester in the current system. The Royal Commission has the authority to stimulate a fundamental rethink.

But the Royal Commission to date has not placed enough emphasis on the rights of older people. The 2019 Interim Report stated only that having *younger people* (aged 65 and under) in residential care is a human rights issue, and that the use of physical and chemical restraints undermines rights.¹⁵²

The Commission must support radical change of the system, underpinned by a rights-based approach. It must clarify and define the purpose of the system. The new system should support older Australians to continue to live meaningful lives, recognising their rights to independence and participation in community life.

3.2 A new rights-based Act for aged care and support

Embedding rights into the aged support system would require a fundamental reform of the current system. Rights cannot sit separate to the system – they must have practical implications for service delivery and funding.

152. Royal Commission into Aged Care Quality and Safety (2019b, pp. 193, 241). Although the Royal Commission's consultation paper 1 states that the design of the system should be informed by some rights-based principles, a stronger commitment and articulation of these rights is needed: Royal Commission into Aged Care Quality (2019, p. 4).

The Royal Commission should recommend development of a new Act that enshrines rights-based principles. These principles should both be in the objects of the Act for interpretative benefits, and within the substantive Act for enforceability.¹⁵³ This would mean that the principles could not be changed without an act of Parliament. If the principles are merely articulated in subordinate regulation they could be more easily varied or removed by the whim of the government of the day.

The Commission should recommend a set of rights-based principles to be articulated in a new Act as outlined in Chapter 2. The Commission should ensure the rights-based principles apply to all older Australians needing care and support – giving them a right to care and support even before they enter the formal aged care system. And once in the system, the Commission should make explicit that care and support must be provided in a way which maximises older Australians' rights.

The Royal Commission should also recommend that accountability mechanisms are rights-based, to ensure that all actions and decisions made under the Act are in accordance with the rights-based principles and outcomes. This would mean that rights are incorporated into practice standards and accreditation requirements for providers. It should also place obligations not just on providers, but also individuals in the system, including carers and care managers. Ongoing monitoring and transparency are vital to ensuring that rights are upheld. This should include regular public reporting against compliance with rights-based standards and practices. And there should be enforceability mechanisms available to older people and carers in the

153. Similar to the NDIS Act, the objects of the aged care Act should make reference to the international human rights treaties Australia has ratified, using the external affairs head of power under the Constitution.

case of a breach of the principles.¹⁵⁴ An accountable governance body should be made responsible for ensuring rights are respected.

3.3 Structural features of a rights-based system

Beyond enshrining rights into the legislative framework of the system, a rights-based approach would also have significant implications for service delivery and funding. Even if rights are articulated and emphasised, they will not be upheld without structural reform.

The concept must be followed through at every level of the system – from the government through to the provider and carer. Rights will float in a void unless support systems make them real. Structural support systems include accountability, adequate funding of supports, sufficient staffing, and availability of services. Appropriate funding and regulatory incentives will be needed to promote cultural change in both government and service providers towards a focus on rights and outcomes rather than efficiency and profit.

3.3.1 Independent governance and support

Rights re-balance a system in favour of individuals over the interests of governments or service providers. But individuals cannot effectively realise their rights if there are no independent structures to help them achieve rights-based outcomes.

A rights-based system needs to have independent system governors – both at a national and a local level – who protect the rights of individuals. Independent advocates who do not act in the government's or providers' interests should support older people to navigate the system. Advocates would ease the burden on the individual to assert

154. Importantly, this should not merely rely on people making complaints. The current Charter of Aged Care Rights stating that people should not have fear of reprisal is ineffective.

their rights, and would give more voice to older Australians (Hungary is a good role model in this respect – see Box 3). Independent support and advocacy is particularly important where an older person, such as someone with severe dementia, may not have full decision-making capacity.

3.3.2 Personalised care and participation

Each person has different care needs and aspirations, depending on their personality, identity, and cultural and/or spiritual needs.

Care plans can help personalise care provision, by articulating the needs and preferences of individuals (Belgium provides a model – see Box 3). Older Australians should play a central role in developing their own care plan where they can articulate their goals and aspirations and make choices about their care and support. This should extend beyond listing specific care needs, to outlining supports needed to participate in cultural and economic activities in the community.

3.3.3 Available, accessible, and good-quality services

Older Australians' right to autonomy is undermined if there are inadequate services available to them. There is no choice if there are no options, or people are not provided with adequate information about services and quality on which to base their choice.¹⁵⁵ A rights-based aged care system would need to carefully monitor services available and their quality – and commission additional services where needed. Independent system governors (see Section 3.3.1) should have the authority to commission services on behalf of older Australians. Information on service availability and quality should be publicised

155. This has been an issue with the implementation of the NDIS, highlighted by the 2019 Legislated Review into the NDIS: Tune (2019). People in regional and rural areas particularly face barriers to choice.

widely in a way which is accessible and can inform individuals making decisions about their needs.

Given that a rights-approach should reflect the preferences of individuals to age at home, the system should support more in-home care and support. An emphasis on independence, self-fulfilment, and participation in the community may result in a shift to smaller residential care facilities.

3.3.4 Sufficient funding

Without sufficient government funding of the aged care system, rights will be undermined.¹⁵⁶ Insufficient funding means that people are unable to get care and support they need, when they need it. And when they do get care and support, those services may be low quality.

Sufficient funding will uphold universal access and equity. This means support should be available when people need it, with care costs paid for by the government. Everyday living and accommodation costs should be paid by users, with means-tested support for low-income earners to cover these costs.

3.4 An adequately supported workforce

Having carers and workers who are adequately paid, trained, and supported is a prerequisite for a rights-based approach. Without this, rights become mere aspirations. Staff should have the time to treat people with dignity in every interaction, and to build relationships with the individuals they are caring for. (Germany provides a model – see Box 3). Meaningful relationships make it easier for people to be treated

156. Enough funding is necessary but not sufficient – funding rules have to be designed to ensure the funding is appropriately allocated across staffing and other requirements.

Box 3: Australia can learn from international experience

Internationally, there is growing support for rights-based approaches to long-term care for older people. Countries, particularly in Europe, are drawing on rights-based thinking in different ways. Here are some examples.^a

In **Germany**, many residential care facilities have adopted a model of care that is rights-based.^b The approach emphasises that older people are not mere beneficiaries but rights holders who have unique needs. Residential homes are managed through three teams. The care team provides the everyday care, the social team empowers residents to engage in activities with the community, including bed-ridden residents and people with dementia. The third team manages the facility. Training of managers and carers provides a deep understanding of people's rights to dignity and autonomy.^c

In **Belgium**, there is an emphasis on the right to autonomy. Surveys show that many people report having free choice about how to spend their time. Care homes reported undertaking personal care planning that takes into account each person's life story, and sets out their personal preferences. Residents can also participate in decision-making at the facility through a Residents' Committee.^d

In **Hungary**, there is a strong emphasis on rights of patients. 'Advocates' or 'rights representatives' visit care homes regularly to check-in with residents. The advocates inform older people of their rights, and follow-up on any complaints and concerns residents may have. Other complaints systems have also been set up, including structured meetings between the care home and residents, and anonymous complaints boxes.^e

In the **United Kingdom**, a leading advocacy group has established a five-step rights-based approach for service providers in health and social care. The first step is to ensure the organisation's board commits to a human rights approach and understands the role of human rights in delivering services. The second step is to incorporate human rights into the strategic objectives of the organisation. The third step is to change practice, which includes writing action plans, designating responsibilities, and monitoring progress. The fourth step is to engage and empower staff, including managers and carers, through training programs and guidance specific to their role. The fifth step is to engage and empower service users by giving them opportunities to voice their views and make suggestions. There must also be a clear and effective process to make a complaint.^f

- a. These examples are cited in: European Network of National Human Rights Institutions (2017, p. 22). Although Australia's aged care system is different to European countries, these examples are illustrative of how rights can be realised in practice.
- b. It is called 'Supportive Processual Care' (in German: Foerdernde Prozesspflege), developed by a German nurse and gerontologist.
- c. Aronson and Mahler (2016, pp. 11–13); and European Network of National Human Rights Institutions (2017, p. 22).
- d. UNIA (2016); and European Network of National Human Rights Institutions (2017, p. 24).
- e. Budapest (2016); and European Network of National Human Rights Institutions (2017, pp. 30–31).
- f. Age Concern (2008, p. 2); and European Network of National Human Rights Institutions (2017, p. 18).

as whole humans.¹⁵⁷ Poorly designed funding policies can mean that staff lose their professional autonomy, and relationship-building is crowded out by unrealistic workloads.¹⁵⁸

Providers must also ensure their own governance standards for care provision are underpinned by a rights framework. This flows through to ensuring that employees – both managers and carers – are adequately trained to understand what rights mean in practice (the UK provides an example – see Box 3).

3.4.1 A broad range of services

Providing aged services does not mean just providing basic living standards or basic health care. A rights-based approach ‘promotes a broad, whole-of-system government and society approach to the health and well-being of older people’.¹⁵⁹ It requires well-coordinated and multi-disciplinary services. This includes providing health, housing, personal, social, and community support in the least restrictive way possible.¹⁶⁰ The system should ensure that older people receiving support are not denied access to GPs or hospital, as was seen during the COVID-19 crisis. Integrated services such as health services should similarly be obliged to uphold the rights of older people.

3.4.2 Accountability

Rights do not operate unilaterally. They are multi-lateral – with all actors owing duties to one another. In the context of aged care and support – older people, their carers, and managers all owe duties to respect each other’s rights. These rights-based duties should be reflected in

157. Relationship-centred approaches to care are important to avoid the commonly reported problems of lack of autonomy and difficulty in forming meaningful relationships with others: Bradshaw et al (2012).

158. Kerasidou (2019); and Dougherty and Purtilo (1995).

159. Baer et al (2016).

160. See for example Department of Health and Human Services (2020b).

the formal accountability mechanisms of monitoring and compliance, coupled with adequate transparency to older people and the public.¹⁶¹ See specific recommendations in Section 3.2.

Respecting rights does not only mean refraining from doing something bad. It can also require positive action to ensure a right is upheld, such as the rights to autonomy and choice. Rights-holders, particularly vulnerable people, should not be seen as self-sufficient, solely responsible for asserting their rights. A properly accountable service system should ensure broader structures are in place to protect people’s rights – beyond merely relying on a person or their family making a complaint. Complaints-based mechanisms are insufficient to address violations of rights. The Royal Commission heard that family members of residents feared recourse if they made a complaint.¹⁶²

3.5 Emerging models of care consistent with a rights-based approach

A rights-based approach is consistent with a number of innovative models and approaches to care that are emerging internationally.¹⁶³

A person-centred approach to care acknowledges a person’s experiences, values, and culture. Its emphasis on relationships supports a care environment that is ‘home-like’ rather than ‘institutional’, and empowers staff as well as the people they are caring for.¹⁶⁴ Smaller-scale residential care with home-like settings, such as the Green House project in the United States, emphasise person-centred care.¹⁶⁵ Some studies have shown that person-centred care approaches in residential care have improved the job satisfaction

161. Australian Human Rights Commission (2012, p. 1).

162. Royal Commission into Aged Care Quality and Safety (2019b, p. 65).

163. Dyer SM et al (2019).

164. Ibid (p. v).

165. Ibid (pp. 8–10).

of staff while also improving their capacity to meet individual needs of residents with dignity and respect.¹⁶⁶

Re-ablement and restorative approaches to care seek to promote the physical functioning of older people, rather than viewing care as supporting an inevitable decline in an older person's functioning and health.¹⁶⁷

Other models of supported accommodation that empower older people include community-based shared housing and inter-generational communities.¹⁶⁸ There are also numerous innovative home care models emerging, including models that support community participation through seniors-friendly community living.¹⁶⁹

3.6 System-level design principles

Rights-based principles for older Australians and carers should be at the heart of the system. But when redesigning the aged care system, system-level principles that reflect broader community expectations should also be taken into account. These include, for example, accountability, transparency, efficiency, feasibility, and equity. System-level principles will often work alongside or strengthen rights-based principles. They may also provide practical boundaries within which rights operate.¹⁷⁰ For example, as noted in Section 2.4.3, universal access to support should be reasonable and necessary

166. Brownie and Nancarrow (2013) and Dyer SM et al (2019, p. vi). This has also led to more social interaction between residents. Note that these care approaches also come with increased personal risk – two studies found person-centred care resulted in a higher rate of falls. See Brownie and Nancarrow (2013).

167. Dyer SM et al (2019).

168. See more in: Dyer SM et al (ibid).

169. See more in: Dyer SM et al (ibid).

170. Some rights need to be balanced between the rights of the individual and the broader community: European Network of National Human Rights Institutions (2017, p. 5). This paper argues that restricting a right is only permissible if there is a clear legal basis with a legitimate and proportionate aim.

to meet community expectations that taxpayer money is spent in a targeted and efficient way.

3.7 Starting afresh

Australia needs a new approach to aged care. The pandemic has been another tragic reminder that the current system fails older Australians. We need to abandon the top-down, market-driven, provider-centric approach. Instead, we need a system that does not regard older people as passive recipients of care. The new system should support older people to participate in society as much as they can, and give them as much autonomy as possible. This is best achieved through a rights-based philosophy.

A future Grattan Institute report will detail how Australia can build such a system.

Appendix A: Examples of rights-based instruments

A.1 UN Principles for Older Persons 1991

The UN Principles were adopted by the General Assembly resolution 46/91 on 16 December 1991. Governments are encouraged to incorporate the following principles into their national programs whenever possible:

- 1) Older persons should have access to adequate food, water, shelter, clothing, and health care through the provision of income, family and community support, and self-help.
- 2) Older persons should have the opportunity to work or to have access to other income-generating opportunities.
- 3) Older persons should be able to participate in determining when and at what pace withdrawal from the labour force takes place.
- 4) Older persons should have access to appropriate educational and training programmes.
- 5) Older persons should be able to live in environments that are safe and adaptable to personal preferences and changing capacities.
- 6) Older persons should be able to reside at home for as long as possible.
- 7) Older persons should remain integrated in society, participate actively in the formulation and implementation of policies that directly affect their well-being, and share their knowledge and skills with younger generations.
- 8) Older persons should be able to seek and develop opportunities for service to the community and to serve as volunteers in positions appropriate to their interests and capabilities.
- 9) Older persons should be able to form movements or associations of older persons.
- 10) Older persons should benefit from family and community care and protection in accordance with each society's system of cultural values.
- 11) Older persons should have access to health care to help them to maintain or regain the optimum level of physical, mental, and emotional well-being and to prevent or delay the onset of illness.
- 12) Older persons should have access to social and legal services to enhance their autonomy, protection, and care.
- 13) Older persons should be able to utilise appropriate levels of institutional care providing protection, rehabilitation, and social and mental stimulation in a humane and secure environment.
- 14) Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care, or treatment facility, including full respect for their dignity, beliefs, needs, and privacy and for the right to make decisions about their care and the quality of their lives.
- 15) Older persons should be able to pursue opportunities for the full development of their potential.
- 16) Older persons should have access to the educational, cultural, spiritual, and recreational resources of society.
- 17) Older persons should be able to live in dignity and security and be free of exploitation and physical or mental abuse.

- 18) Older persons should be treated fairly regardless of age, gender, racial or ethnic background, disability, or other status, and be valued independently of their economic contribution.

A.2 National Disability Insurance Scheme Act 2013

Section 4 of the *NDIS Act* sets out general principles guiding actions under the Act:

- 1) People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional, and intellectual development.
- 2) People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability.
- 3) People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime.
- 4) People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports.
- 5) People with disability should be supported to receive reasonable and necessary supports, including early intervention supports.
- 6) People with disability have the same right as other members of Australian society to respect for their worth and dignity and to live free from abuse, neglect, and exploitation.
- 7) People with disability have the same right as other members of Australian society to pursue any grievance.
- 8) People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage

as equal partners in decisions that will affect their lives, to the full extent of their capacity.

- 9) People with disability should be supported in all their dealings and communications with the Agency and the Commission so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs.
- 10) People with disability should have their privacy and dignity respected.
- 11) Reasonable and necessary supports for people with disability should:
 - a) support people with disability to pursue their goals and maximise their independence; and
 - b) support people with disability to live independently and to be included in the community as fully participating citizens; and
 - c) develop and support the capacity of people with disability to undertake activities that enable them to participate in the community and in employment.
- 12) The role of families, carers, and other significant persons in the lives of people with disability is to be acknowledged and respected.
- 13) (Continued...)

A.3 South Australian Ageing and Adult Safeguarding Act 1995

Section 12 of the Act sets out the following principles which apply to operations under the Act to the extent that it relates to vulnerable adults:

- a) all vulnerable adults are entitled to be treated with respect for their dignity, autonomy, and right to self-determination;

- b) it is presumed that a vulnerable adult has decision-making capacity, unless there is evidence to the contrary;
- c) except in those cases involving serious and imminent harm, the primary consideration in the operation of this Act is to ensure that a vulnerable adult's autonomy is respected and maintained, rather than safeguarding the person from abuse;
- d) vulnerable adults must be allowed to make their own decisions about their health care, residential and accommodation arrangements, financial affairs, and other personal affairs to the extent that they are able, and be supported to enable them to make such decisions for as long as they can;
- e) dignity in risk must be observed through acknowledging the right of all vulnerable adults to take informed risks and to make decisions that others (no matter their experience or background) may regard as wrong, reckless, or inappropriate;
- f) a vulnerable adult with decision-making capacity who is experiencing abuse has the right to decline support, assistance or other measures designed to safeguard them from abuse;
- g) vulnerable adults must be involved in, and their wishes must directly inform, decisions made or actions taken to support and safeguard them;
- h) the best approach to safeguarding vulnerable adults from abuse is through coordinating a multi-agency and multi-disciplinary response, drawing on the expertise of relevant persons and bodies in order to effectively support and empower vulnerable adults to safeguard their rights and mitigate against abuse;
- i) subject to the laws of the State and Commonwealth, the will, preferences (including sexual preferences and sexual orientation), cultural and heritage beliefs, religious beliefs, racial origin, ethnicity, background and other beliefs or rights of a vulnerable adult must always be respected;
- j) safeguarding measures should consist of those which are the least interventionist and the least intrusive to the vulnerable adult, thus ensuring that any consequential erosion of that person's rights is kept to a minimum;
- k) safeguarding vulnerable adults from abuse is ultimately achieved through preventing abuse in the first place, and therefore awareness raising and community education programs must be a priority in the administration and operation of this Part.

A.4 New South Wales Ageing and Disability Commissioner Act 2019 No 7

The objects and principles of the Act (Section 4) say that when exercising a function under this Act, the Commissioner or any other person must have regard to the objects of the Act and the following principles:

- a) adults with disability and older adults have the right to respect for their worth and dignity as individuals and to live free from abuse, neglect, and exploitation;
- b) adults with disability and older adults have the right to respect for their cultural and linguistic diversity, age, gender, sexual orientation, and religious beliefs;
- c) adults with disability and older adults have the right to privacy and confidentiality;
- d) adults with disability and older adults have the right to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports and services;

- e) families, carers, and other significant persons have a crucial role in the lives of adults with disability and older adults and it is important to respect and preserve those relationships.

A.5 Other rights-based instruments

- The European Charter of rights and responsibilities of older people in need of long-term care and assistance.¹⁷¹
- The Inter-American Convention on Protecting the Human Rights of Older Persons (A-70).¹⁷²

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