



**Royal
Commission
into Aged
Care Quality
and Safety**

**Final Report:
Care, Dignity
and Respect**

Volume 2
The current system



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Table of Contents

Introduction to Volume 2	1
1. The Current System	5
1.1 Introduction	5
1.2 What is aged care?	6
1.2.1 Historical development of aged care	7
1.3 Accessing aged care	12
1.3.1 Allocating places	13
1.3.2 People with diverse backgrounds	15
1.3.3 My Aged Care	15
1.3.4 Assessing eligibility	16
1.4 What care is available?	16
1.4.1 Care at home	16
1.4.2 Respite care	20
1.4.3 Residential aged care	22
1.4.4 Flexible care	23
1.4.5 Dementia support	25
1.4.6 Community Visitors Scheme	27
1.5 Who provides care	27
1.5.1 The aged care workforce and volunteers	28
1.5.2 Informal carers	30
1.5.3 Aged care providers	31
1.6 Who pays, and for what?	33
1.6.1 Residential care funding	34
1.6.2 Home care funding	38
1.6.3 Other programs	41
1.7 How aged care is regulated	41
1.7.1 The statutory framework	42
1.7.2 Approval of providers	42
1.7.3 Provider responsibilities	43
1.7.4 Accreditation and quality monitoring	46
1.7.5 Complaints handling	48
1.8 Conclusion	48

2.	Problems of Access	59
2.1	Introduction	59
2.2	Accessing aged care	59
2.2.1	Problems entering and navigating the system	59
2.2.2	Accessing home care	62
2.2.3	Respite care	66
2.2.4	Allied health care in aged care	67
2.3	Access for groups already at a greater disadvantage	69
2.3.1	Older people in regional, rural and remote areas	70
2.3.2	Aboriginal and Torres Strait Islander people	73
2.3.3	Other disadvantaged groups with diverse needs	75
2.4	Aged care and other systems	78
2.4.1	Access to health care	78
2.4.2	Accessing care for people with disability	81
2.5	Conclusion	83
3.	The Nature and Extent of Substandard Care	91
3.1	Introduction	91
3.2	What is substandard care?	92
3.3	What we heard about substandard care	93
3.3.1	Abuse	94
3.3.2	Complex care	100
3.3.3	Routine care	109
3.3.4	Conclusion: nature of substandard care	139
3.4	Extent of substandard care in the aged care sector Commissioner Pagone	139
3.5	Extent of substandard care in the aged care system Commissioner Briggs	142
3.5.1	Administrative data and research	144
3.5.2	Poor quality data	146
3.5.3	Extent of high quality care	147
3.5.4	Extent of substandard care	148
3.5.5	Low expectations of care	158
3.6	Extent of substandard care in particular areas of care	159
3.6.1	Assault—mandatory reporting data	159
3.6.2	Quality indicator data	161
3.6.3	Medication management	163
3.6.4	Hospitalisation data	164
3.6.5	Staffing data	165
3.6.6	Extent of substandard care in particular provider types Commissioner Briggs	166
3.7	Conclusion	169

4.	Systemic Problems in the Aged Care System	185
4.1	Introduction	185
4.2	An absence of leadership and governance at the system level	186
4.3	Insecure, insufficient Government funding	188
4.3.1	Limiting expenditure and rationing access	189
4.3.2	Funding models and funding levels	195
4.4	Financing arrangements that do not support sustainability	197
4.5	Inequitable means testing	200
4.6	Inattention to market structure, evolution and local conditions	201
4.6.1	Changes in market structure and composition	202
4.6.2	Limited focus on local and regional context	203
4.7	Piecemeal approach to reform	204
4.8	Variable provider governance, management and leadership Commissioner Pagone	206
4.9	Provider behaviour Commissioner Briggs	208
4.10	An undervalued aged care workforce	211
4.11	Attitudes and assumptions about ageing and aged care	217
4.12	A reactive model of care	220
4.13	The lack of voices of older people and diverse communities	223
4.14	Ineffective regulation	226
4.15	An absence of transparency Commissioner Briggs	233
4.16	Missed opportunities for research and innovation	236
4.17	Poor cooperation across the health and aged care systems	238
4.18	Conclusion	241

Introduction to Volume 2

In this volume, we focus on the current aged care system. We outline the key structures and services within the current system. We identify circumstances where older people have had difficulty in accessing those services. We consider the standard of aged care, and the circumstances in which it falls short. Building on that, we identify systemic problems in Australian aged care.

Central to this volume is our obligation, under our Terms of Reference, to inquire into:

the quality of aged care services provided to Australians and the extent to which those services meet the needs of people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response.¹

This, our Final Report, is generally about the future: tomorrow, a decade from now, twenty years from now, and beyond. It is about setting a course for a new aged care system. It is also about recognising the complex interconnections between the many elements of the aged care system and between the aged care system and other systems.

Volume 3 of this report focuses on solutions—our recommendations for action in response to the problems we identify. To arrive at those recommendations, we need to understand the aged care system as it exists today, including the problems in the system. That is the purpose of this volume.

The problems we identify in this volume are widespread, and hence systemic. Our focus is not on simple error. We have heard about failures in the delivery of aged care caused by accident, mistake and human error. These may occur in any system despite excellent governance and systemic design, good policy, thorough training, adequate staffing and the best of intentions. Isolated errors may result in unnecessary suffering, even tragedy, but they are not the primary focus of our inquiry.

Systemic failures are serious and recurrent failures: they stem from problems inherent in the system. They may be caused by faults embedded in its structural design, or the lack of any discernible design. They may be caused by funding, policy, cultural or operational issues. Commissioner Briggs notes they may also be caused by a lack of focus on purpose, values and mission. The common characteristic of the problems we identify is that, in our view, they significantly and consistently contribute to the system failing to deliver high quality care and support to older people.

Systemic problems must be thoroughly understood if they are to be effectively corrected. It is possible to simply list every error or fault. But faults are not necessarily causes, let alone the root causes of systemic failures. Issues identified as problems or failures may be the inescapable results of government policy decisions and under-funding. Poor policy, honestly and diligently administered, may cause serious but unintended consequences. Persisting with poor policy, in ignorance of its effect or in the face of clear evidence of its failure, is another matter.

Competing interests and needs converge within the aged care system. What is needed is a deep understanding of—and, at times, empathy for—the difficulties experienced by various actors within the system, while remembering that the system’s pre-eminent purpose is to facilitate high quality, safe and compassionate care for older people. Commissioner Briggs observes that it should not, of course, be forgotten that all providers of aged care have particular responsibilities to provide high quality and safe aged care, and they need to attend to those responsibilities vigilantly.

This volume concentrates necessarily on negatives but not everything about Australia’s aged care system is bad. It is important to bear in mind the many good things done, frequently by carers within the system who labour for relatively little reward, doing the best they can. We heard from Ms EA, whose partner, Ms EB, suffered from younger onset Alzheimer’s disease. Ms EA paid honour to the thoughtful and sensitive care that Ms EB received. Ms EB’s statement was motivated by a desire, and a conviction that Ms EA would share this desire, ‘to contribute to building the knowledge of the Royal Commission about what good care and good work looks like’.²

Ms Elsie Scott described how her residential care was not provided in a bulk institutional setting but in one of several individual houses, each with a small number of people living together: ‘I live here, happily, because I am just old. I turn 90 this year, with gratitude’.³ In her view, the familial form of residential care she enjoyed is ‘light years ahead in concept and reality’.⁴

We also heard from aged care workers who were passionate about their work and genuinely respected and cared for the people they supported. Ms Sharai Johnson, Aged Care Coordinator at Larrakia Nation Aboriginal Corporation in the Northern Territory, described the personal rewards she experienced when one of Larrakia Nation’s social support programs produced positive outcomes for their clients with dementia:

And what we’ve found with clients of ours who have dementia is taking them out of their homes into public places or places that would be fairly familiar to them and it brings back positive memories of theirs that they wouldn’t generally discuss on a daily basis. So reminiscing about things in their past, people that they have met, being in a certain place could remind them of what they were doing at a certain time in their lives. It has been a wonderful experience to watch a lot of our clients show positive—positive signs. So that’s because we have had such a positive outcome in doing that that’s something that we are now providing regularly and it has been great.⁵

Ms Michelle McCall, Aged and Disability Program Manager at Larrakia Nation Aboriginal Corporation, agreed. She said that the social support program had resulted in a ‘stark improvement’ in an older person who had previously displayed significant complex behaviour on a daily basis: ‘we can’t remember the last time that client actually had a complex behaviour issue’.⁶

We are profoundly grateful for the opportunity to learn from the direct experiences of older people, their families and carers, and aged care workers. These positives, set in balance with the negatives, provide an encouraging start to building a better system. They are concrete examples of what works well. The formulation of practical recommendations depends on developing insights into how aged care can work better. That is the purpose of this volume.

It is necessary for us to focus on problems in the aged care system from different perspectives. In Chapter One, we describe the current aged care system and identify key changes since the inception of this current system in 1997. This is a descriptive chapter, providing the context for the following chapters and the report as a whole.

In Chapter 2, we describe problems older people and their carers have in accessing the care and support they need. The ability to access the aged care system is a prerequisite for receiving high quality care. Here, we identify three areas where there are problems of access. First, different parts of the aged care system are difficult to access. This includes difficulties: entering aged care through My Aged Care; accessing the right type of home care services when it is needed; problems accessing respite care; and problems accessing allied health across the system. Second, we identify inequities of access for people with diverse characteristics, backgrounds and experiences, including people in regional, rural and remote Australia and Aboriginal and Torres Strait Islander people. Third, we look at issues of access that are dependent on other systems and programs, such as health care or disability services.

In Chapter 3, we outline our conclusions about the nature and extent of substandard care. We give voice to the personal experiences of people who have provided and received care to understand the common stories of the substandard care they receive. This can include abuse and inappropriate use of restrictive practices. It can also occur in the provision of complex care, such as dementia care, mental health care and palliative and end-of-life care. We also identify the nature of poor care in routine care, such as in the care for wounds, oral health, and food and nutrition. We then turn to exploring what the available data can tell us about the extent of substandard care. The data is variable, inconsistent and often of poor quality. It does not build on a clear understanding of substandard or high quality care. Viewed as a whole, however, it tells a story of unacceptably high levels of substandard care. We conclude that the number of people who have experienced substandard care is inexcusably high.

In Chapter 4, we identify the contributing factors to poor quality and safety in the current system. We outline numerous systemic problems in the aged care system, in the areas of funding and finance, system governance and leadership, workforce, culture, policy, and interactions with other systems. The extent of these problems necessitates a comprehensive overhaul of the aged care system. The existing piecemeal approach is not sufficient.

The aged care system exists to provide care for people in older age: our grandparents, parents, partners, wives and husbands, our entire extended family and friends, and, ultimately, ourselves and our descendants. It can, and must, be better.

Endnotes

- 1 Commonwealth of Australia, *Letters Patent*, 6 December 2018, paragraph (a).
- 2 Transcript, Perth Hearing, EA, 25 June 2019 at T2426.7–10.
- 3 Exhibit 6-51, Darwin and Cairns Hearing, Statement of Elsie Scott, 17 July 2019, WIT.0266.0001.0001 at 0004 [32].
- 4 Exhibit 6-51, Darwin and Cairns Hearing, Statement of Elsie Scott, 17 July 2019, WIT.0266.0001.0001 at 0004 [32].
- 5 Transcript, Darwin Hearing, Sharai Johnson, 12 July 2019 at T3427.7–15.
- 6 Transcript, Darwin Hearing, Michelle McCall, 12 July 2019 at T3427.7–15; T3428.1–5.

1. The Current System

1.1 Introduction

The Australian aged care system provides subsidised care and support through a range of services to older people. It has evolved over time, including during our inquiry. Some changes to the system have been far-reaching and others incremental, but all have contributed to the piecemeal development of the aged care system. It is evident that the current system is complex and difficult to navigate. These factors have hindered the smooth administration of the system. They have made it more difficult to provide high quality and safe services. Critically, they have operated as a barrier to those seeking to access aged care services.

The Interim Report and Background Paper 2 discuss in detail the demographic factors affecting aged care. In summary, the aged care sector is facing an ageing population with increasing frailty. Australians are living longer than ever before. It is projected that the number of Australians aged 85 years and over will continue to increase, from 515,700 in 2018–19 (2.0% of the Australian population) to more than 1.5 million by 2058 (3.7% of the Australian population).¹

Although the projected increases are significant, it is important to note that the rates of increase in the absolute number of Australians aged 85 years and over, and in the share of the Australian population aged 85 years or older, will both be lower in the next 40 years than in the last 40 years. The share of the Australian population aged 85 years or older will increase by 83% in the next 40 years, compared with 216% in the last 40 years. Hence, although the magnitude of population ageing is such that there will have to be significant adjustments to the Australian economy and systems that support older people over the next 40 years, the size of these are unlikely to be any greater than those that have occurred over the last 40 years.²

In 2019, there were 4.2 working age (15–64 years) people for every Australian aged 65 years or over. By 2058, this will have decreased to 3.1.³ This decline has implications not only for the financing of the aged care sector, but also for the aged care workforce. There will be relatively fewer workers available to pay taxes to fund the aged care system and to meet the growing demand for services.⁴ Again, although this is a significant change, it is not insurmountable. In particular, the magnitude of the decrease over the next four decades is smaller than that which occurred over the last four decades, noting that the ratio of working age people to Australians aged 65 years or over was 7.0 in 1978.⁵

With advanced age comes greater frailty. Older people are more likely to have more than one health condition (comorbidity) as their life expectancy increases.⁶ As the population of older people increases, more people are expected to have memory and mobility disorders. About 550,000 to 559,000 Australians are expected to be living with dementia by 2030 compared to the estimated 400,000 to 459,000 Australians who were living with dementia in 2020.⁷ These changing demographics, together with changes in the patterns of disease

and dependency, and in the expectations of older people and society, will affect the future demand for aged care in a number of ways, including: the length of stay in residential aged care; the type of care that will be required; the increase in care needs; the demand for a variety of care choices; and the desire of older people to remain in their own homes for as long as possible.

Our report is necessarily focused on the future. But to appreciate the recommendations we make, it is necessary to understand the aged care system as it existed during our inquiry, and how it came to be what it is. In this chapter, we describe the fundamental elements of the current aged care system. In the rest of this volume, we turn our attention to deficiencies and systemic flaws in the current system.

1.2 What is aged care?

Aged care is not a single service. It is a large and complex system that includes a range of programs and policies designed to support older people.⁸ It is one of Australia's largest service industries and represented more than 1.6% of the gross domestic product in 2018–19.⁹ In that year, services were delivered to around 1.3 million people through over 3200 aged care providers.¹⁰ In 2016, there were over 366,000 paid workers and 68,000 volunteers in the sector.¹¹

The care that is provided ranges from low-level support to more intensive services. Aged care includes:

- assistance with everyday living activities, such as cleaning, laundry, shopping, meals and social participation
- equipment and home modifications, such as handrails
- personal care, such as help getting dressed, eating and going to the toilet
- health care, including nursing and allied health care
- accommodation.¹²

Aged care is provided in people's homes, in the community and in residential aged care settings. People commonly think of nursing homes, or residential care, when they think about aged care.¹³ While the bulk of the aged care budget is spent on residential aged care, more than two-thirds of people using aged care services do so from home.¹⁴

Aged care services are funded by the Australian Government, the States and Territories and by individuals. Australian Government outlays include expenditure administered by the Department of Health (home support, home care, residential aged care, flexible care) and the Department of Veterans' Affairs (Veterans' Home Care and Community Nursing). In 2018–19, which is the last year for which all data is currently available, a total of \$27.0 billion was spent on aged care, including \$19.9 billion by the Australian Government (see Table 1). This means that total expenditure on aged care from all sources in 2018–19 (excluding spending on carer support) accounted for 1.4% of gross domestic product.¹⁵

Table 1. Expenditure on aged care from all sources 2018–19

Area of expenditure	Australian Government	State and Territory Governments	Individuals	Others	Total \$m
Assessment and information services	229.7				229.7
Home support services	3432.8		252.0		3684.8
Home care	2469.3		107.0	74.5	2650.8
Residential care	13,015.3	179.2	5160.3	1137.1	19,491.9
Residential care capital	78.1	79.6			157.7
Flexible care services	519.4		117.9		637.4
Aged care quality	146.9				146.9
Total expenditure on aged care	19,891.1	258.8	5637.2	1211.6	26,999.2

Source: Exhibit 21-1, Sydney Hearing 5, general tender bundle, tab 134, RCD.9999.0530.0002.

It is also important to note, for context, that aged care is not the only form of government assistance provided to older people. In 2017–18, the Australian Government spent \$97.8 billion on care and support for older people, which represented 21.4% of all Australian Government expenditure.¹⁶ As well as expenditure on aged care and support for carers of older Australians, this includes income support and concessions for older people and expenditure on health care for older people.

1.2.1 Historical development of aged care

Australia's aged care system has developed in an ad hoc and piecemeal way over time, reflecting the circumstances and concerns of the day. Until the second half of the nineteenth century, the prevailing view in Australia was that families were responsible for providing care for older people. Older people without family support, or whose care needs exceeded their family's capacity, had few options except to live in 'asylums for the destitute'.¹⁷ Towards the end of the nineteenth century, a number of official inquiries investigated the conditions of older people living in these asylums and found them unsatisfactory.¹⁸ A desire to provide a non-institutional way of supporting older people led to the introduction of old-age pensions.¹⁹ By 1909, the Australian Government had taken responsibility for payments under the non-contributory Old-Age Pension Program.²⁰ Australia's old-age pension was means tested and paid at the age of 65 years, or 60 years for women and for people who were permanently incapacitated for work. At this time, men had a life expectancy of 55 years and women 59 years.²¹

Until the Second World War, income support was the primary contribution that the Australian Government made to older people. During the war, and in the decade following, the Government started to subsidise health care, such as through a Pharmaceutical Benefits Scheme to subsidise the cost of medicines.²² In 1954, with the introduction of the *Aged Persons Homes Act 1954* (Cth), the Australian Government began supporting accommodation for older people by providing capital grants to religious and charitable organisations to cover the costs of building ‘homes for the aged’.²³ In 1956, the Australian Government first became involved in community care by providing assistance to home nursing organisations.²⁴ In the late 1960s, it began to provide grants to State and Territory Governments to support the delivery of care services into people’s homes and in the community.²⁵

In 1963, the Australian Government began to pay a subsidy for care services to approved nursing homes for each qualified resident.²⁶ Known as the Nursing Home Benefit, this resulted in a shift away from hospitals and asylums looking after older people to an ‘immediate and dramatic increase in the provision of nursing home care’.²⁷

In 1970, a review found that the care needs of almost 25% of residents were not high enough to warrant their admission to a nursing home.²⁸ In an effort to control the expansion of nursing home beds, the Australian Government ‘introduced growth and admission controls, and fee control arrangements’ such as the Participating Nursing Home Scheme.²⁹ In that scheme, the resident paid fees and the Government made a contribution. The maximum level of fees paid by a resident was 87.5% of the sum of the maximum age pension and rent assistance.³⁰

The Australian Government also made changes to address the issue of nursing homes being used by people who did not need them. It did this through providing recurrent support for another level of residential care through the payment of Personal Care Subsidy to the residents of approved hostels. This change was made to enable frail older people who might otherwise enter nursing homes to continue to live in more homelike conditions, with lower costs both for them and for the Australian Government.³¹

The *Aged Persons Hostels Act 1972* (Cth) responded to a shortage of suitable accommodation for older people. The Honourable William Wentworth, the then Minister for Social Services, explained that the primary intention for the Act was to ‘stimulate the building of additional hostel accommodation in order to reduce admissions to nursing accommodation of people who have no real medical need for nursing care’.³²

In 1972, the Australian Government introduced a Domiciliary Nursing Home Benefit to support carers to care for older people in their own homes.³³

The Australian Government introduced the Deficit Financed Nursing Home Scheme in 1975. Through this scheme it provided ‘recurrent funding for nursing homes operated by non-profit religious, charitable or benevolent organisations’.³⁴

In the mid-1980s, there were major changes to aged care following a 1982 review of aged care, known as the McLeay Report. In 1985, in response to the McLeay report, the Australian Government and the State and Territory Governments brought together disparate existing community-based services into a single jointly-funded Home and Community Care Program. The program provided a range of support services, such as 'home help or personal care', 'home maintenance or modification', transport, meals, 'community respite', a 'community paramedical service', 'community nursing', 'assessment or referral' and education, information and coordination.³⁵ One objective of the consolidation was to promote a comprehensive range of care services to enhance the independence of older people and, as the Act put it, 'avoid their premature or inappropriate admission to long term residential care'.³⁶

In 1986, the Australian Government introduced multidisciplinary geriatric assessment teams. The teams assessed a person's care needs to determine whether it was appropriate for the person to enter a nursing home.³⁷ These were the forerunners of the current Aged Care Assessment Teams. Prior to this, there was no satisfactory way to assess people's care needs.³⁸

Also in 1986, the Australian Department of Community Services conducted a Nursing Homes and Hostels Programs Review. The review found that the significant expansion of nursing homes and hostels that followed the introduction of the nursing home benefits in 1963 was largely 'unseen, unplanned and unco-ordinated' by the Australian Government.³⁹ The review made recommendations aimed at 'redistributing resources away from intensive residential care towards a higher quality of care in less institutionalised hostel settings or through enhance community services'.⁴⁰ It also recommended that there should be ratios set for new places in hostels and nursing homes.⁴¹ This would set a target on the number of aged care places subsidised by the Australian Government.

The Australian Government adopted this recommendation. It set an initial target ratio of 100 residential aged care places, comprised of 40 nursing home places and 60 hostel places, for every 1000 people aged 70 years or over.⁴² Over time, the Australian Government used the target ratio to rebalance what it considered to be an excessive reliance on nursing homes. This reduced the number of nursing home beds from 67 per 1000 in 1985 to 51 in 1995, and increased hostels from 33 per 1000 in 1985 to 43 in 1995.⁴³

In 1987, the Australian Government introduced specific outcome standards and quality of care requirements for nursing homes to address inadequate quality of care and quality of life. It also, in the same year, introduced uniform funding for costs across nursing homes to encourage efficiency, and nursing homes were allowed to retain unspent funds as profit.⁴⁴ In 1991, standards monitoring was introduced for hostels.⁴⁵

In 1988, the Australian Government introduced resident classifications as a way of directly linking nursing home benefits with the level of a resident's need. These classifications also created an incentive for nursing homes to admit the frailest older people, due to the higher level of funding attached to higher categories of care need.⁴⁶

Following a review in 1989, Ms Chris Ronalds recommended a series of initiatives aimed at promoting the rights of older people, which were implemented. This included a charter of residents' rights, phased introduction of advocacy mechanisms and a Community Visitors Scheme.⁴⁷

In the 1992–93 Budget, the Australian Government introduced the Respite for Carers Program. In 1996, the program was changed to the National Respite for Carers Program. This program facilitated access for carers to respite services, information and other support or assistance. It provided grants for respite services and a national network of 'Carer Respite Centres' and 'Carer Resource Centres'.⁴⁸ These forms of respite care are now provided under the Commonwealth Home Support Programme. Respite care is also provided in residential aged care facilities.

The provision of care services for older people at home increased in the early- to mid-1990s. In 1992, the Australian Government introduced Community Aged Care Packages.⁴⁹ Expenditure on Community Aged Care Packages was \$3.3 million in 1992–93.⁵⁰ From 1993, an intensive package of care services was trialled in South Australia. It was introduced nationally in 1997 as the Extended Aged Care at Home Program. The Australian Government intended these packages as an alternative to nursing home care.⁵¹

In the 1996–97 Budget, the Australian Government announced a major structural change to aged care. The Aged Care Bill 1997 was introduced. The Bill replaced the provisions of the *National Health Act 1953* (Cth) and the *Aged or Disabled Persons Care Act 1954* (Cth) under which nursing homes and hostels were administered. The *Aged Care Act 1997* (Cth) came into force on 1 October 1997. It made fundamental changes and set the foundation for the current aged care system, including combining hostels and nursing homes into what became known as residential aged care. This change meant a person could stay in one location as their care needs increased—or 'age in place', as it has become known. Previously, there had been complaints from providers that the people in hostels had become increasingly dependent—in some cases, more so than those in nursing homes—and that the level of government funding was not adequate to meet their increased care needs.⁵²

Internal quality assurance measures were replaced with external accreditation.⁵³ In 1998, the Aged Care Standards and Accreditation Agency started managing accreditation, which was linked to payment of government subsidies.⁵⁴ From 2001, services that were not accredited did not receive government subsidises.

People who entered residential aged care after 1 March 1998 were subject to income testing, as a result of which some residents were required to pay additional income tested care fees. All residents were required to pay daily fees as a contribution to daily costs of living, such as nursing and personal care, meals, and heating and cooling.⁵⁵ High-care residents with sufficient means were required to pay a daily accommodation charge as well as the Basic Daily Fee.⁵⁶

The Aged Care Act also introduced refundable accommodation bonds for people receiving low-level care, in line with the entry contribution arrangements that had existed in hostels before the reforms.⁵⁷ A refundable accommodation ‘bond’ or ‘deposit’ is a lump sum payment for accommodation in residential aged care. It effectively acts as a loan from a resident to an aged care provider.

Care at home continued to increase during the late 1990s. The Community Aged Care Packages program grew steadily. The Australian National Audit Office indicated this program was a cost-effective option, being one-third of the equivalent residential care subsidy.⁵⁸ In 2000–01, the Australian Government expanded the Extended Aged Care at Home packages program to 290 packages.⁵⁹ In 2006, Extended Aged Care at Home Dementia Packages provided higher funding for people with the behavioural and psychological symptoms of dementia.⁶⁰

The Australian Government introduced Home Care Packages into the target ratio in the early 1990s. The Government took two of the hostel places and allocated them to Home Care Packages, but kept the target the same.⁶¹ In the mid- to late-2000s, the Government increased the target ratio a number of times. This increased the number of actual care places. In 2004, the target ratio increased to 108 per 1000 people aged 70 years and over. In 2007, it increased to 113. In 2012, it was adjusted to increase progressively to 125 operational places by 2022. Home care has gradually increased as a proportion of the overall target provision ratio since that time.⁶²

In 2011, under the National Health Reform Agreement, the State and Territory Governments and the Australian Government agreed that the Australian Government would take full responsibility for the public funding of aged care.⁶³ In 2012, the Australian Government assumed funding, policy and administrative responsibility for older people using the Home and Community Care program in all States and Territories, except Victoria and Western Australia.⁶⁴ Victoria joined in 2016 and it was fully implemented in 2018 when Western Australia joined the national framework.⁶⁵ This change meant that, for the first time, the Australian Government controlled all policy, administration, funding and planning for all aged care services.

In 2011, the Productivity Commission finalised its review into the aged care system. It concluded that the aged care system required ‘fundamental reform’ to address the challenges facing it.⁶⁶ The Productivity Commission found that the aged care system was difficult to navigate, services and consumer choice were limited, quality was variable, and the coverage of needs, pricing, subsidies and user contributions were inconsistent or inequitable.⁶⁷

The Australian Government introduced significant changes in 2012, under the 'Living Longer. Living Better' package.⁶⁸ Key changes included introduction of:

- a single point of entry to the aged care system through the establishment of My Aged Care⁶⁹
- home care to replace community aged care packages and certain types of flexible care delivered in the home, including a decision to introduce more levels of Home Care Packages. This was provided on a 'consumer directed care' basis, which means, in this context, that people receiving care receive an individual budget which allows them to decide what type of care and services they purchase and who delivers those services.⁷⁰

In 2015, the Commonwealth Home Support Programme was introduced. It consolidated the Commonwealth Home and Community Care Program, the planned respite component of the National Respite for Carers Program, the Day Therapy Centres Program, and the Assistance with Care and Housing for the Aged Program.⁷¹ The Home and Community Care programs in Victoria and Western Australia transitioned to the Commonwealth Home Support Programme in 2016 and 2018 respectively.⁷² From 2017, Home Care Package funding was allocated to older people receiving care, rather than providers.

While there have been changes to the system in the last 25 years, including a continued rebalancing of the system towards home care, the broad architecture of the system as it is in 2021 has its foundations in the 1997 changes, as well as the 2012 'Living Longer. Living Better' package of reforms.

1.3 Accessing aged care

Eligibility for aged care depends on an assessment of whether someone needs care services. While there is no formal age of eligibility in the Aged Care Act, generally a person needs to be aged 65 years or older to receive government-subsidised aged care services. Aboriginal and Torres Strait Islander people can access aged care services from the age of 50 years. People aged under 65 years who are facing homelessness may also be able to access some aged care services.⁷³ A person who is not an aged person can only be found eligible for aged care if 'there are no other care facilities or care services more appropriate to meet the person's needs'.⁷⁴

1.3.1 Allocating places

The Australian Government uses what is now called the ‘Aged Care Target Provision Ratio’ to control the supply of subsidised aged care places. The ratio caps the number of aged care places available in Home Care Packages, residential care and restorative aged care. For 2022, the overall Target Provision Ratio is 125 aged care places per 1000 people aged over 70 years of age. Home Care Packages are increasing as a proportion of the Target Provision Ratio. Between 2012 and 2022, the target for Home Care Packages will increase from 27 to 45 places per 1000 people aged over 70 years. In contrast, the ratio for residential care will reduce from 86 to 78 places per 1000 people aged over 70 years. The remaining two places are for the Short-Term Restorative Care Programme.⁷⁵

Residential aged care places are allocated to approved providers through a process called the Aged Care Approvals Round. This is a competitive application process under which approved aged care providers apply for new or additional Australian Government-funded residential and restorative aged care places.⁷⁶ In the 2018–19 Aged Care Approvals Round, the Australian Government allocated 13,500 new residential aged care places.⁷⁷ Applications were received for a total of 37,802 residential aged care places.⁷⁸

The Australian Government also allocated 775 short-term restorative care places in the 2018–19 Aged Care Approvals Round. These were expected to take effect in 2018–19 (350 places) and 2019–20 (425 places). Applications were received for 11,289 short-term restorative care places.⁷⁹

There was no Aged Care Approvals Round in 2019–20 and the 2020 process was postponed due to the COVID-19 pandemic. Applications opened on 18 December 2020, for 2000 residential aged care places and 1028 short-term restorative care places.⁸⁰

Since February 2017, Home Care Package places are not included in the approval rounds, although the Australian Government still manages the supply of these services. People who are approved to receive a Home Care Package are placed on the National Prioritisation System, which is a queue for services based on when they applied for a Home Care Package, their level of need, and their assessed priority for services.⁸¹ As at 30 June 2020, about 142,000 people were receiving a Home Care Package.⁸² While the number of packages may increase each year, the total number of packages at each funding level is capped in line with the Target Provision Ratio and the available budget.⁸³

Approximately 1.3 million people accessed Australian Government-funded aged care services in 2018–19.⁸⁴ The most commonly used service was the Commonwealth Home Support Programme (about 841,000 people), followed by residential aged care (about 243,000 people) and Home Care Packages (about 133,000 people)—see Table 2.⁸⁵ (It is notable that between 2013–14 and 2018–19, the number of people receiving Home Care Packages increased by 60%. We discuss this increase below.

Table 2. Number of people cared for by residential aged care, home care, and home support between 2013–14 and 2018–19⁸⁶

	2013–14	2014–15	2015–16	2016–17	2017–18	2018–19	Increase (2013–14 to 2018–19)
Residential aged care	231,515 (21.2%)	231,255 (20.5%)	234,931 (18.8%)	239,379 (21.3%)	241,723 (20.0%)	242,612 (19.9%)	4.8%
Home Care Package	83,144 (7.6%)	83,838 (7.4%)	88,875 (7.1%)	97,516 (8.7%)	116,843 (9.7%)	133,439 (11%)	60.5%
Home support*	775,959 (71.1%)	812,384 (72.1%)	925,432** (74.1%)	784,927 (70.0%)	847,534 (70.3%)	840,984*** (69.1%)	8.4%

Sources: The Aged Care Financing Authority's third and eighth annual reports on funding and financing of the aged care sector.

* including Commonwealth Home Support Programme and the Commonwealth, Victorian and Western Australian Home and Community Care program

** Home support users for 2015–16 were likely overstated.⁸⁷

*** Commonwealth Home Support Programme client numbers for 2018–19 are not perfectly comparable with home support client numbers reported for previous years, which combine Commonwealth Home Support Programme client counts with the Home and Community Care programs that operated in Victoria and Western Australia. These Home and Community Care programs have now ceased providing aged care. The methods used to collect data and measure client numbers are different across programs, and any comparisons over time should be treated with caution.⁸⁸

On 30 June 2020, the total number of flexible care places, under the various flexible care programs outlined in Table 3, was just over 10,000.

Table 3. Number of flexible care places as at 30 June each year from 2014 to 2020⁸⁹

	2014	2015	2016	2017	2018	2019	2020
Transition care	4000	4000	4000	4019	4060	4060	4180
Short-term restorative care	N/A	N/A	N/A	400	475	825	1241
Multi-Purpose Service	3525	3545	3592	3636	3624	3646	3668
Innovative care	92	84	75 ⁹⁰	62	54	41	36
NATSIFACP	739	802	820	820	860	1072	1264
Total	8356	8431	8487	8937	9073	9644	10,389

Sources: Data collated from 2013–14 Report on the Operation of the Aged Care Act 1997 to the 2019–20 Report on the Aged Care Act 1997 inclusive.

1.3.2 People with diverse backgrounds

An object of the Aged Care Act is ‘to facilitate access to aged care services by those who need them, regardless of race, culture, language, gender, economic circumstance or geographic location’.⁹¹ Section 11-3 of the Aged Care Act gives effect to this object, listing the following groups as having ‘special needs’:

- people from Aboriginal and Torres Strait Islander communities
- people from culturally and linguistically diverse backgrounds
- people who live in ‘rural or remote’ areas
- people who are financially or socially disadvantaged
- veterans
- people who are homeless or at risk of becoming homeless
- care leavers
- parents separated from their children by forced adoption or removal
- lesbian, gay, bisexual, transgender and intersex people.⁹²

The Secretary of the Australian Department of Health is required to take into consideration the particular needs of these groups of people when planning and allocating aged care places.⁹³ The Department also takes these groups into consideration for the payment of flexible care subsidies.⁹⁴

The same diversity groups are also recognised through the Commonwealth Home Support Programme Guidelines and in the Aged Care Diversity Framework. These documents also mention other diverse communities, including people with disability, people with mental health problems and mental illness, and people living with cognitive impairment, including dementia.⁹⁵

1.3.3 My Aged Care

To access Australian Government-subsidised aged care, people use the single entry point known as My Aged Care. My Aged Care is a contact centre and website, with no local ‘shopfront’ or physical infrastructure. My Aged Care provides information on aged care and helps people find appropriate care services in their local area. My Aged Care is also responsible for referring people for assessment of their eligibility for Australian Government-subsidised aged care services. Such an assessment determines the level of care and support for which the person may be eligible.⁹⁶

My Aged Care is administered by the Australian Department of Health. In 2019–20, the My Aged Care contact centre answered about 1.5 million calls and the website had about four million visits.⁹⁷

1.3.4 Assessing eligibility

When a person wants to access aged care services that are subsidised by the Australian Government, they first undergo an eligibility check. Typically, an older person, or their family member or carer, will have an initial conversation with a staff member from the national My Aged Care contact centre. The My Aged Care staff member will usually ask questions about the person's health, current support, and how they are managing at home.⁹⁸

If a My Aged Care employee decides that a person is eligible for aged care services, that person is referred for a face-to-face assessment. This is generally done at the person's home or in a hospital for those who are hospitalised and need an urgent assessment.⁹⁹

The Regional Assessment Service assesses people seeking entry-level support at home provided under the Commonwealth Home Support Programme. In 2019–20, the Australian Government allocated funding of about \$114.4 million for 17 Regional Assessment Service providers to deliver assessment services in all States and Territories. In 2019–20, those service providers completed almost 243,000 assessments.¹⁰⁰

Aged Care Assessment Teams undertake comprehensive assessments to determine eligibility for residential aged care, transition care, Home Care Packages and residential respite care. The Australian Government engages State and Territory Governments to manage and administer Aged Care Assessment Teams. In 2019–20, about \$129 million was allocated to 80 Aged Care Assessment Teams to deliver these comprehensive assessments. In 2019–20, Aged Care Assessment Teams completed close to 187,000 assessments.¹⁰¹

1.4 What care is available?

The aged care system offers care under three key types of service: the Commonwealth Home Support Programme, Home Care Packages and residential care. There are also several models of flexible care available to people receiving aged care and, in some circumstances, their carers. We provide an overview of these below.

1.4.1 Care at home

There are two main programs through which care and support for older people is provided to help them continue living in their homes. Depending on their care needs, a person can access services through the Commonwealth Home Support Programme or through a Home Care Package, or both.

Commonwealth Home Support Programme

The majority of older people who receive support services at home do so through the Commonwealth Home Support Programme. An Australian Institute of Health and Welfare study found that 76% of people accessing aged care used this program before any other aged care program.¹⁰² In 2019–20, the Commonwealth Home Support Programme provided support to about 839,000 people. The average age of access to the programme was 80.1 years.¹⁰³

The Commonwealth Home Support Programme is intended to provide entry-level services focused on supporting older people to maintain their health, independence and safety at home and in the community. It also aims to keep people connected with their community. Services under the program are provided on an ongoing or short-term basis depending on a person's needs. They can include:

- allied health and therapy services
- domestic assistance
- goods, equipment and assistive technology
- home maintenance
- home modifications
- meals and other food services
- nursing
- personal care
- social support
- specialised support services
- transport
- centre-based respite, flexible respite and cottage respite.¹⁰⁴

People most commonly access assistance with housekeeping (domestic assistance), followed by allied health and therapy services, transport to places out of walking distance, home maintenance, social support (group or individual), nursing and meals delivered to their home.¹⁰⁵ In 2018–19, about 330,000 people received assistance with housekeeping, accounting for nearly 20% of all service contacts in home support. The second most used service was allied health and therapy services, with close to 245,000 people using this service. While many people used allied health and therapy services, they tended to use a limited range of service types and received few services of each type over the 12-month period.¹⁰⁶

Home Care Packages Program

Home Care Packages are delivered on a 'consumer directed care' basis. Since February 2017, Home Care Packages have been assigned directly to people receiving care rather than allocated to providers. This means that people can choose the provider to deliver their

services and can choose to change providers.¹⁰⁷ Services that may form part of a Home Care Package include:

- support services, such as help with washing and ironing, house cleaning, gardening, basic home maintenance, home modifications related to care needs, transport to help with shopping, doctor visits or attending social activities
- personal services, such as help with showering or bathing, dressing and mobility
- care-related services, such as nursing and other health support, including physiotherapy (exercise, mobility, strength and balance), services of a dietitian (nutrition assessment, food and nutrition advice, dietary changes) and hearing and vision services
- care management, such as coordinating care and services.¹⁰⁸

A Home Care Package can, and often does, contain many of the same support services that are available under the Commonwealth Home Support Programme. However, Home Care Packages are provided as a more structured and comprehensive bundle of services.

The Home Care Packages Program has four levels:

- Level 1—to support people with basic care needs
- Level 2—to support people with low care needs
- Level 3—to support people with intermediate care needs
- Level 4—to support people with high care needs.¹⁰⁹

A StewartBrown summary of average hours of service per Home Care Package in 2018–19 shows that personal care represented the largest share of total package hours, at 27%. The proportion of average hours spent on personal care increases with package level. For Level 1, in 2018–19, it was 16% of total care hours, while Level 2 was 19%, Level 3 was 26% and Level 4 was 33%. Cleaning and household tasks represented the second largest share of total package hours, at 22%. Here, the proportion of average hours spent on cleaning and household tasks decreases with package level. For Level 1, it was 31% of total care hours, while Level 2 was 29%, Level 3 was 21% and Level 4 was 17%. The proportion of the hours that were spent on social supports and community access was reasonably constant across package levels, varying between 15% and 19%.¹¹⁰

Services that represented the lowest portion of average package hours were nursing care, in-home respite (overnight), and allied health practitioners. Each of these represented 1% or less of the hours of service per Home Care Package. Nursing care and allied health use do not appear to increase as the package level increases. Care management represented 13% of the hours of service per Home Care Package. The proportion of average hours spent on care management decreases with package level from 21% for Level 1 to 11% for Level 4, but the absolute number of hours spent on care management increased from 0.65 hours per fortnight for Level 1 to 2.01 hours per fortnight for Level 4.¹¹¹

Once assessed as eligible for a Home Care Package, a person is placed on the National Prioritisation System and is offered a package when one becomes available.¹¹² Home Care Packages are tightly rationed and periodically released and assigned directly to people by the Australian Department of Health through My Aged Care. Packages are assigned to people according to when their entitlement for home care was approved and the urgency of their need.¹¹³

In 2019–20, the average age of people accessing a package was 81 years.¹¹⁴ At 30 June 2020, there were about 142,000 people with a Home Care Package. The total number of Home Care Packages has significantly increased over recent years, as Table 2 illustrates.

Despite the increase in the number of packages, about 102,000 people were waiting for care at their assessed level of need as at 30 June 2020.¹¹⁵ People may be offered an interim package at a lower level while they wait for their assessed package. At 30 June 2020, people approved for a Level 4 package could wait over 12 months to be assigned a package at any level. People approved for a Level 3 package could wait up to six months for an interim package at Level 1, but still wait more than 12 months for their assigned package level.¹¹⁶ Table 4 shows that reported waiting times for interim and approved packages were unchanged between September 2018 and June 2020.

Table 4: Estimated wait time for people entering the Home Care Package Program by package level¹¹⁷

30 September 2018			
Package level	Interim package assigned	Time to interim package	Time to approved package
Level 1	Level 1	3–6 months	3–6 months
Level 2	Level 1	3–6 months	12+ months
Level 3	Level 1	3–6 months	12+ months
Level 4	Level 2	12+ months	12+ months

30 June 2020			
Package level	Interim package assigned	Time to interim package	Time to approved package
Level 1	Level 1	3–6 months	3–6 months
Level 2	Level 1	3–6 months	12+ months
Level 3	Level 1	3–6 months	12+ months
Level 4	Level 2	12+ months	12+ months

Source: Australian Department of Health, *Home Care Packages Program: Data Report 2nd Quarter 2018–19*, 2019 and *Home Care Packages Program: Data Report 4th Quarter 2019–20*, 2020.

The available data as at 30 June 2020 is inadequate as it does not indicate exactly how long people can wait for a package, with wait times reported in three-month blocks and with no indication if a person waits longer than a year. The Australian Department of Health told Commissioners Tracey and Briggs that in 2017–18, one-quarter of people eligible for a Level 4 package waited more than 30 months to get a Level 4 package.¹¹⁸

Veterans' programs

The Veterans' Home Care Program provides practical help at home for eligible veterans to continue to live independently in their own homes. Carers and family members of eligible veterans may also receive assistance under the Veterans' Home Care Program. Services available under this program include domestic assistance, personal care, respite care, and safety-related home and garden maintenance. The program is not designed to meet complex or high-level care needs.¹¹⁹ People are eligible for an assessment if they have a Veteran Gold Card or Veteran White Card for a service-related injury or condition. Carers and family members of Gold Card and White Card holders may be eligible for an assessment.¹²⁰

The Australian Department of Veterans' Affairs Community Nursing Program offers nursing and personal care services provided by qualified nurses and support staff to eligible veterans. Services can include help with medication, wound care, hygiene, showering and dressing.¹²¹

In 2018–19, over 40,200 older veterans were approved for Veterans' Home Care services—around 32% of older eligible veterans. In the same year, over 15,600 veterans received community nursing services—around 12% of older eligible veterans.¹²²

Veterans can receive care from both the designated veterans' programs and from mainstream aged care programs, including the Commonwealth Home Support Programme and the Home Care Packages Program.

1.4.2 Respite care

Respite care provides short-term support and care services for older people and their carers. Its primary purpose is to give a carer or the person being cared for a break from the usual care arrangements. Respite is available in the community through the Commonwealth Home Support Programme, and for stays in residential facilities through the provisions of the Aged Care Act.¹²³

Community respite is provided under the Commonwealth Home Support Programme, which provides flexible planned respite services, including flexible respite, cottage respite, and centre-based respite. Flexible respite is available during the day or overnight. It can be provided in an older person's home or in the community. It usually involves a paid carer coming to the home of the person receiving care so that the usual carer can take a short break.¹²⁴

Centre-based respite is available during the day. It provides older people with the opportunity to talk and interact with other people, and usually takes place at a day centre, club or residential aged care setting. Cottage respite is available overnight or over a weekend. It takes place in the community or in the home of a host family. It can be taken for two to three days at a time.¹²⁵ In 2019–20, nearly 51,000 people received Commonwealth Home Support Programme respite services.¹²⁶

Residential respite provides short-term care in Australian Government-subsidised aged care homes. It may be used on a planned or emergency basis. It is available for a few days through to a few weeks at a time. It is best suited for people who need ongoing, continuous carer support for most tasks.¹²⁷ To access residential respite, a person must be assessed as eligible by an Aged Care Assessment Team, and will be approved for either low- or high-level care. This will determine the level of respite subsidy the aged care provider will receive. Being approved for high-level care allows people to access low-level care.¹²⁸ A person receiving care can access residential respite for up to 63 days per financial year, with extensions possible when an Aged Care Assessment Team considers it necessary.¹²⁹ According to the Australian Department of Health:

People receiving residential respite are entitled to receive the same services as someone receiving permanent residential aged care, including assistance with meals, laundry, room cleaning, personal grooming, and nursing care.¹³⁰

In 2019–20, close to 67,000 people received residential respite care. During 2019–20, the average length of stay per episode of residential respite care was just over 27 days. Most people only have one respite stay per year, but about one in five have two or more respite stays per year.¹³¹ In the same year, after a period of residential respite care, around 58% of people exited either back to their home or community, 6% to hospital, 5% to other residential aged care, and 3% died (28% other).¹³²

The Aged Care Financing Authority has reported a noticeable increase in the use of residential respite care in recent years.¹³³ It identified a significant increase in the proportion of people who were admitted to permanent residential care on the same day they were discharged from residential respite. In 2017–18, 44% of all admissions to permanent residential aged care were people who were receiving respite care on the day before their admission to permanent care.¹³⁴ This reflects, at least in part, a demand for the use of respite as a ‘try before you buy’ test before a person enters permanent residential care, rather than a break from usual care arrangements.¹³⁵ In his *Legislated Review of Aged Care 2017* report, Mr David Tune AO PSM made similar observations.¹³⁶

1.4.3 Residential aged care

Residential aged care provides support and accommodation for older people who are unable to continue living independently in their own homes and who need ongoing help with everyday tasks. It assists people who have been assessed by an Aged Care Assessment Team as needing higher levels of care than can be provided in the home. After a person has been assessed as eligible for residential aged care, they may choose a residential aged care facility. This is subject to the aged care facility having an available place, agreeing to admit them, and being able to meet their care needs. Residential care is provided on either a permanent or a temporary (respite) basis.¹³⁷

Under the *Quality of Care Principles 2014* (Cth), approved providers of residential aged care must provide a range of care and services to residents, whenever they may need them. The type of care and services provided include:

- social care, such as recreational activities and emotional support
- accommodation services and help with day-to-day tasks—often referred to as ‘hotel-like services’—such as bedding, furniture, toiletries, cleaning, cooking, and laundry
- personal care, such as bathing, dressing, grooming, and assisting with going to the toilet
- clinical care, such as wound care and management, help with administering medication, and nursing services.¹³⁸

In 2019–20, just over 244,000 people received permanent residential aged care at some time during the year. At 30 June 2020, almost 184,000 people were receiving permanent residential care.¹³⁹

People entering residential aged care have the highest average age of any of the three mainstream programs of aged care.¹⁴⁰ In 2019–20, the average age, on entry, was 82.5 years for men and 84.8 years for women.¹⁴¹ The average length of stay for long-term residential care was almost 30 months.¹⁴²

With the increase in the availability of support in the community, the average frailty of people receiving permanent residential aged care has increased significantly in recent years. Since 2009, the proportion of people with high care needs has generally increased in each care domain under the Aged Care Funding Instrument. The biggest overall change was in complex health care, which rose from 13% in 2009 to 61% in 2016, and then fell to 52% in 2019. This fall followed changes to the rating method for complex health care that applied from January 2017.¹⁴³ In 2019, some 31% of permanent residents were classified as having the highest care needs in all three care domains: activities of daily living, cognition and behaviour, and complex health care. Some 85% of all permanent residents were classified as having the highest care needs in at least one of the three care domains.¹⁴⁴

1.4.4 Flexible care

There are five ‘flexible care’ programs that respond to the needs of older people who may require a care approach that is different to what is provided through mainstream residential and home care services. These programs are:

- Transition Care
- Short-Term Restorative Care
- Innovative Care
- Multi-Purpose Services
- National Aboriginal and Torres Strait Islander Flexible Aged Care Program services, known as NATSIFACP.

At 30 June 2020, there were just over 10,000 operational flexible care places.¹⁴⁵ We provide a brief outline of the five flexible care programs below.

Transition Care Program

The Transition Care Program helps older people recover after a hospital stay. The program provides short-term specialised care and support to help older people regain their functional capacity, improve their levels of independence and avoid the need for longer-term care and support services.¹⁴⁶

Older people may receive transition care for up to 12 weeks, with a possible extension of another six weeks, in either a home or residential aged care setting. To be assessed for transition care, older people must be in hospital at the time of the assessment. Once they enter the Transition Care Program, they may receive a range of goal-oriented and therapy-focused support services, such as allied health services, nursing support and personal care.¹⁴⁷

At 30 June 2020, there were close to 4200 transition care places nationally, with almost 3500 people receiving transition care. During 2019–20, about 24,800 people received transition care.¹⁴⁸

The Transition Care Program is jointly funded by the Australian Government and State and Territory Governments, which manage the program in their respective jurisdictions as the approved providers of transition care.¹⁴⁹ Most State and Territory Governments then subcontract and fund health services and aged care providers to deliver these services.

Short-Term Restorative Care Program

The Short-Term Restorative Care Program, which is funded by the Australian Government, provides early intervention care to help older people improve their physical functioning, wellbeing and independence. It may also help to reduce or delay an older person’s need for further aged care services and reverse or slow functional decline.¹⁵⁰

The Short-Term Restorative Care Program can be delivered in a home care setting, a residential care setting, or a combination of both. The care provider will typically work with an older person to identify their goals and then put together a tailored package of care and services that is delivered over a period of eight weeks. Support services might include rehabilitative therapy services, personal care, assistance with preparing meals, minor home modifications, emotional support and arranging social activities.¹⁵¹

At 30 June 2020, there were 94 operational Short-Term Restorative Care services being delivered by 58 approved providers to 809 people. During 2019–20, over 4500 people received care under the Short-Term Restorative Care program.¹⁵²

Innovative Care Programme

The Australian Government established the Innovative Care Programme in 2001–02 to pilot new approaches to providing aged care where mainstream programs were not meeting the needs of a particular group of people.¹⁵³ The current Innovative Care Program is an extension of pilots established in 2003.¹⁵⁴ These projects were designed for younger people living with disability who:

- lived in state-funded supported accommodation services
- were at risk of entering residential aged care.¹⁵⁵

The program stopped funding new projects on 25 May 2006.¹⁵⁶ Since then, no new entrants have been accepted into the program. This means that the number of people receiving such care is gradually decreasing as people leave the projects. At 30 June 2020, there were eight projects operating under the program, with 36 operational innovative care places.¹⁵⁷

Multi-Purpose Services Program

The Multi-Purpose Services Program is a joint initiative between the Australian and State and Territory Governments. One of its primary objectives is to provide integrated health and aged care services for regional, rural and remote communities in both residential aged care and home care settings. The program helps older people living in regional, rural and remote areas to receive the aged care services they need in their own community.¹⁵⁸ It operates in all States, the Northern Territory and the External Territories (Norfolk Island).¹⁵⁹

The majority of services are co-located with a hospital or health service. The Multi-Purpose Services Program facilitates the presence of health and aged care services in regions that could not viably support a standalone hospital or residential aged care facility.¹⁶⁰ It seeks to provide:

- improved access to a mix of health and aged care services that meet community needs
- more innovative, flexible and integrated service delivery
- flexible use of funding and/or resource infrastructure within integrated service planning

- improved quality of care
- improved cost-effectiveness and long-term viability of services in rural, regional and remote areas.¹⁶¹

At 30 June 2020, there were 179 Multi-Purpose Services across Australia offering close to 3700 residential care and home care places.¹⁶²

NATSIFACP

The National Aboriginal and Torres Strait Islander Flexible Aged Care Program, known as NATSIFACP, also provides a type of flexible aged care. Under this program, the Australian Government funds aged care services to provide culturally appropriate aged care to older Aboriginal and Torres Strait Islander people and to allow them to remain close to home and community.¹⁶³ Services can be delivered in either a residential or home care setting and are administered outside the Aged Care Act.¹⁶⁴ Most of these services are delivered in remote and very remote areas.¹⁶⁵

As at 30 June 2020, NATSIFACP funded 1264 residential and home care places across Australia.¹⁶⁶

1.4.5 Dementia support

The Australian Government funds various programs and services that aim to improve understanding and awareness of dementia and to increase the skills of health professionals, volunteers and people who care for people living with dementia. The programs include:

- National Dementia Support Program¹⁶⁷
- Dementia Training Program¹⁶⁸
- Dementia Behaviour Management Advisory Service¹⁶⁹
- Severe Behaviour Response Teams¹⁷⁰
- Specialist Dementia Care Program.¹⁷¹

The National Dementia Support Program funds information, education programs, services and resources about dementia. Initiatives funded under this program aim to:

- improve awareness and understanding about dementia
- empower people living with dementia, and their carers and families, to make informed decisions about the support services they access.¹⁷²

The Australian Government has allocated \$326.6 million over the 2019–23 financial years for the Dementia and Aged Care Services fund. This fund provides support for existing and emerging programs in dementia care, including funding for the Dementia Training Program and Dementia Behaviour Management Advisory Service.¹⁷³ The Dementia Training Program provides:

- continuing professional development training on dementia assessment, diagnosis and management
- accredited dementia care vocational level training courses
- tailored onsite training to aged care providers who request assistance, including a dementia skills and environment audit, followed by a tailored training package.¹⁷⁴

The Dementia Behaviour Management Advisory Service is the first tier in the Australian Government's set of support programs for carers of people experiencing behavioural and psychological symptoms of dementia. The service provides free support and advice to aged care providers and individuals caring for people living with dementia. Services can include:

- assessment of the person with dementia, and their carer and support network
- clinical support, information and advice
- care planning, case conferences, referrals and short-term case management
- mentoring and clinical supervision for care providers
- building care providers' capacity and knowledge
- help to link to current research, literature and evidence-based practice guidelines
- translation and interpreting services for clients from culturally and linguistically diverse backgrounds
- behaviour consultants with Aboriginal and Torres Strait Islander and culturally and linguistically diverse portfolios
- advice and support that is relevant to other special needs groups (for example, younger or working-age dementia, learning disability and dementia)
- referrals to the Severe Behaviour Response Teams.¹⁷⁵

Severe Behaviour Response Teams build on the work of the Dementia Behaviour Management Advisory Service. They are a mobile workforce of clinical experts who provide advice to residential aged care providers who request assistance to care for people with the most severe behavioural and psychological symptoms of dementia. The Severe Behaviour Response Teams can provide expert support, including:

- assessing the causes of the behaviours
- assisting care staff until the immediate crisis is resolved
- developing a care plan to address and deal with behaviours
- providing follow-up assistance.¹⁷⁶

The Specialist Dementia Care Program provides specialised care for people:

- who live with very severe dementia complicated by physical aggression or other behaviours
- whose residential care facility or carers cannot manage the behaviours, even with help from other services.¹⁷⁷

The Australian Department of Health estimates that up to 1% of all people living with dementia are in this target group. The Department expects that by 2022–23, there will be at least one Specialist Dementia Care Program unit in each of the 31 Primary Health Network regions across Australia.¹⁷⁸ A prototype Specialist Dementia Care Program unit was established in 2019 at Brightwater Care Group's The Village, a residential aged care facility in Western Australia. In 2020, nine more units opened across Australia in New South Wales, Victoria, South Australia, Queensland and the Australian Capital Territory, with another scheduled to open in South Australia in 2021. The next round of funding for more units is scheduled for 2021–22.¹⁷⁹

1.4.6 Community Visitors Scheme

The Community Visitors Scheme program supports volunteer visits to older people who are socially isolated or at risk of social isolation or loneliness. It is a free service that aims to provide friendship and companionship to older people and help develop social connections.¹⁸⁰

The Australian Government funds community-based organisations to recruit, train and support volunteers to make regular visits to people living in residential aged care services or receiving Home Care Packages.¹⁸¹ These visits can take the form of one-on-one or group visits to residential aged care homes or one-on-one visits to people receiving Home Care Packages. Volunteers visit each person or group of people about 20 times per year.¹⁸² Older people can refer themselves to the Community Visitors Scheme, which also accepts referrals from aged care providers, family members and friends.¹⁸³

In 2019–20, approximately 11,000 volunteers conducted around 221,000 visits.¹⁸⁴

1.5 Who provides care

The aged care workforce makes a valuable and sustained contribution to the care of older people. Older people in Australia are often reliant on their loved ones—informal carers—or volunteers to care for them or to supplement the care provided to them by those in the paid aged care workforce.

The COVID-19 pandemic gave rise to unprecedented challenges for the paid aged care workforce as well as for informal carers and volunteers. These challenges highlighted the existing stressors on the workforce, which we examine in greater detail in Chapter 4 of this volume, on systemic problems.

1.5.1 The aged care workforce and volunteers

The National Aged Care Workforce Census and Survey is conducted around every four years, most recently in 2016.¹⁸⁵ Previous surveys were conducted in 2003, 2007 and 2012. The next one was scheduled to take place in late 2020 or early 2021, but at the time of writing had not occurred.

The 2016 results revealed there were around 434,000 people working in the aged care sector (see Table 5). Of these, there were around 366,000 paid workers (84%) and 68,000 volunteers (16%). Sixty per cent of these people worked in a residential aged care setting and 40% in home care and home support outlets.¹⁸⁶

This data on the paid workforce excludes non-pay as you go workers—that is, agency, brokered and self-employed workers. During the relevant fortnight of the survey, about 28,000 non-pay as you go staff were engaged across the aged care sector. About 27% of home care and home support outlets reported engaging one or more non-pay as you go workers in the relevant fortnight, compared with 50% of residential aged care providers.¹⁸⁷

There was a greater percentage of home care and home support outlet volunteers (26%) compared with residential aged care volunteers (9%). The average hours worked per volunteer per fortnight was similar for both home care and home support outlets (4.6 hours) and residential aged care volunteers (4.9 hours), equalling a total of almost 207,000 and 115,000 hours volunteered per fortnight respectively.

Table 5: Paid workers and volunteers in the aged care workforce

	Residential aged care	Home care & home support outlets	Total
Paid workers	235,764	130,263	366,027
Volunteers	23,537	44,879	68,416
Total	259,301	175,142	434,443

Source: National Aged Care Workforce Census and Survey – The Aged Care Workforce, 2016

The remainder of our discussion in this section focuses on pay as you go workers, based on the available data.

The bulk of the aged care workforce is comprised of people in direct care roles. In 2016, of the approximately 366,000 paid workers, around 240,000 (or 66%) were in direct care roles.¹⁸⁸ Table 6 shows the number of direct care workers in residential aged care and home care in 2016.¹⁸⁹

Table 6: Direct care workers in the residential aged care and home care and home support outlets by occupation, 2016

	Residential Aged care	Home care & home support outlets	Total
Nurse practitioner	386	53	439
Registered nurse	22,455	6969	29,424
Enrolled nurse	15,697	1888	17,585
Personal care attendant/ Community care worker	108,126	72,495	180,621
Allied health professional	2210	4062	6272
Allied health assistant	4979	995	5974
Total*	153,853	86,463	240,317

Source: National Aged Care Workforce Census and Survey – The Aged Care Workforce, 2016.

The aged care workforce is predominantly made up of women, although more men are working in aged care than previously. The 2016 Workforce Census and Survey showed that 87% of direct care workers in residential care and 89% of direct care workers in home care were women.¹⁹⁰

The median age of direct care workers in residential care is 46 years, and 52 years in home care.¹⁹¹ The median age for all workers in Australia is 39 years.¹⁹² The direct care residential workforce is getting younger, while the home care and home support workforce is getting older.¹⁹³

The 2016 Workforce Census and Survey estimated that the residential aged care workforce grew by 17% between 2012 and 2016 and by about 50% since 2003.¹⁹⁴ This can be compared with the number of residential care places available, which increased by 44% between 2003 and 2020.¹⁹⁵ However, the estimated proportion of the residential aged care workforce in direct care roles fell significantly. In 2016, 65% of residential aged care employees worked in direct care roles, compared with 74% in 2003.¹⁹⁶

Registered nurses comprised 21% of the residential direct care workforce in 2003, but by 2016 this had dropped to around 15%. The proportion of enrolled nurses dropped from 13% to 10% over the same period. The proportion of direct care employees working in allied health roles also dropped from around 7% to around 5%. Over the same period, the proportion of the residential direct care workforce who were personal care workers increased from around 58% to around 70%.¹⁹⁷

In home care and home support, the total workforce decreased by 13% between 2012 and 2016. During the same period, the overall direct care workforce in home care and home support fell by 7%.¹⁹⁸

In 2016, most aged care workers in residential and home care services were permanent part-time (78% and 75% respectively).¹⁹⁹ The remainder were either permanent full-time (12% in residential care and 11% in home care) or employed on a casual or contract basis (10% in residential care and 14% in home care).²⁰⁰ As this data is limited to the pay as you go workforce and excludes the agency, brokered and self-employed staff, this does not present a complete picture of the extent of casual employment in the aged care sector.

1.5.2 Informal carers

Informal carers are a critical element of the care system for older people. They reduce the need for formal care, supplement the care provided by aged care services, and maintain critical social and community connections. Not only is their role important, the scale of the assistance provided by informal carers is significant.

In 2018, of 2.65 million carers in Australia, one-third (861,000) were the primary carers who provided the most informal support to a family member or friend. Around 428,500 primary carers provided care to someone aged 65 years or older. Seven out of 10 primary carers were women.²⁰¹ A 2013 report estimated that between one-quarter and one-third of informal carers were from culturally and linguistically diverse backgrounds.²⁰²

Older people receive informal care from a number of sources, and often from more than one source. About half (46.7%) receive it from a partner, 29.6% from a daughter and 23.8% from a son. In addition, 14.3% receive assistance from a more distant female relative or friend and 17.8% receive assistance from a more distant male relative or friend.²⁰³

Deloitte Access Economics estimate the replacement value of unpaid care across the total carer population in 2020 at nearly \$80 billion.²⁰⁴ The replacement cost method measures the cost of 'buying' an equivalent amount of care from the formal sector if the informal care were not supplied. Another important measure of the cost of informal care is the opportunity cost method, which measures the formal sector productivity losses associated with caring, as time devoted to caring responsibilities is time that cannot be spent in the paid workforce. The earnings foregone for primary and non-primary carers in 2020 has been estimated to be \$11.4 billion and \$3.8 billion respectively.²⁰⁵

The Australian Government pays the Carer Payment and the Carer Allowance to informal carers who spend a considerable amount of time providing informal care. The Department of Social Services reports that some 270,694 people aged over 65 years were being assisted by people in receipt of the Carer Allowance and 119,895 people aged over 65 years were being assisted by people in receipt of the Carer Payment in June 2020. About 40% of the people who receive informal care from a person receiving Carer Allowance or Carer Payment are aged 65 years or older.²⁰⁶ In 2018–19, the Australian Government spent \$3.4 billion on Carer Payments, Carer Allowances and Carer Supplements for informal carers of older people.²⁰⁷

1.5.3 Aged care providers

The Aged Care Financing Authority reported that in 2018–19, there were over 3000 providers of aged care services. This included 873 residential aged care providers, 928 home care providers (as at 30 June 2019) and 1458 Commonwealth Home Support Programme providers.²⁰⁸

Most aged care providers are organisations owned by community, charity or religious organisations—‘not-for-profits’, though they may or may not be run like a commercial business—or are privately owned organisations that run as a commercial business. In addition, there is a smaller group of State and Territory Government and local government providers.²⁰⁹ Research indicates these structural factors play a role in quality outcomes.²¹⁰

Table 7 shows the number of aged care providers operating in each care program by ownership type.

Table 7. Number of providers by ownership and program, 2018–19*

Program	For-profit	Not-for-profit	State, Territory or local government	Total
Residential	288	488	97	873
Home Care Packages (at 30 June 2019)	335	479	114	928
Commonwealth Home Support Programme	102	1006	350	1458

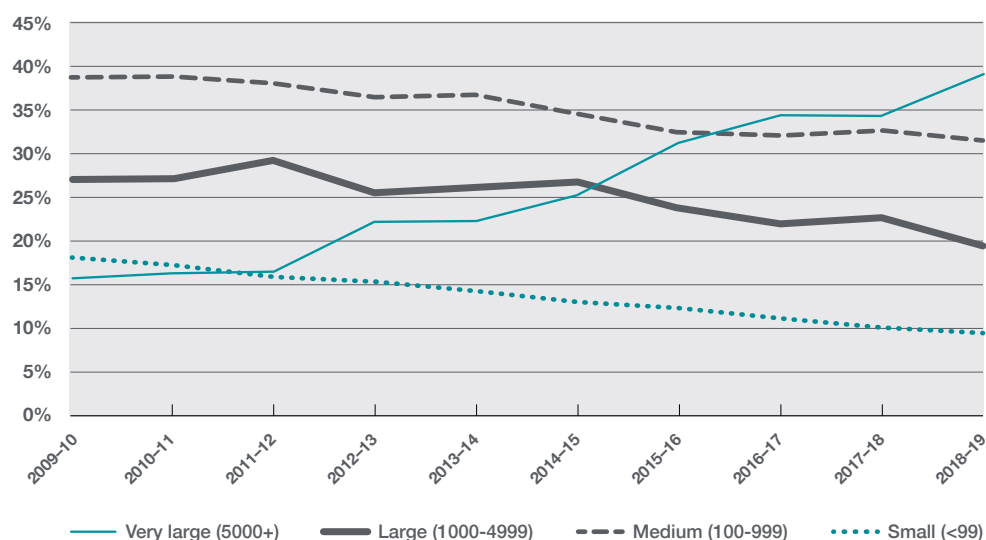
Source: Aged Care Financial Authority, *Eighth Report on the Funding and Financing of the Aged Care Sector*, 2020.²¹¹

* Providers can operate in more than one program

There has been a shift towards consolidation of the aged care sector in the hands of fewer large-scale operators.

In residential and home care, some providers are associated by joint ownership and/or religious denomination. Taking these associations into account, in 2018–19 there were a small number of large providers or provider groups that accounted for close to half of all services nationwide.²¹² In 2009–10, there were just two very large providers or groups in residential care, operating 16% of all places, whereas by 2018–19 this had grown to 10, operating 39% of all places (see Figure 1, below). Aged Care Financing Authority data suggests that there are also a large number of single facility operators in residential aged care (547 in 2018–19), although their potential affiliations are unknown.²¹³

Figure 1: Share of residential care operational places by size of the provider or associated provider group

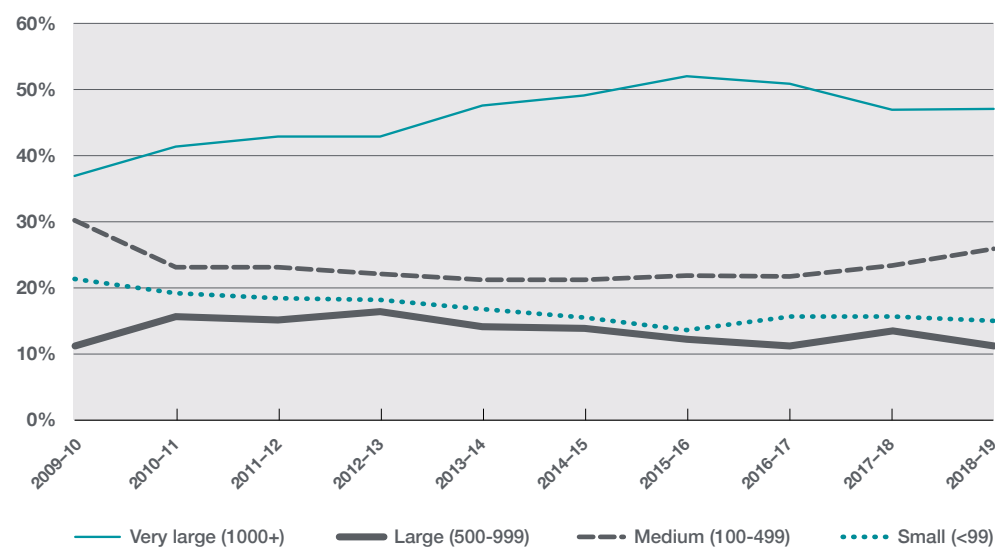


Source: Office of the Royal Commission into Aged Care Quality and Safety, *Picture of the residential aged care and home sector, 2020*.²¹⁴

Note: The size ranges in brackets are the number of residential care operational places

In home care, the change from 2009–10 to 2018–19 is less pronounced because the dramatic increase in Home Care Packages, discussed above, has increased the number of providers or provider groups of all sizes (see Figure 2). In 2009–10, there were five very large providers or groups delivering 37% of all Home Care Packages. In 2018–19, there were 16 very large providers or groups delivering 47% of all Home Care Packages.²¹⁵

Figure 2: Share of Home Care Packages places or recipients by size of provider or associated provider group



Source: Office of the Royal Commission into Aged Care Quality and Safety, *Picture of the residential aged care and home sector, 2020*.²¹⁶

Note: The size ranges in brackets are the number of Home Care Package places or recipients. From 27 February 2017, all Home Care Packages have been provided to individuals. Previously, Home Care Packages were awarded to approved providers. Accordingly, information up to and including 2015–16 is for Home Care Program operational places, while from 2016–17 it is for individuals who have been assigned a package.

The larger, for-profit providers now represent a greater share of the market, while the proportion of not-for-profit and government providers has declined. The market share of for-profit providers of residential aged care has increased from 34% in 2009–10 to 40% in 2018–19, taking share from the not-for-profits and government services. In home care, the shift is even more marked, increasing from 6% in 2009–10 to 21% in 2018–19.²¹⁷

1.6 Who pays, and for what?

The Australian Government subsidises the majority of aged care services in Australia. Older people are currently required to contribute to the costs of their care and accommodation if they can afford to do so. People contribute to the cost of their care and accommodation in the form of co-payments and means tested fees. Co-payments are the fixed fees paid by people towards the services that are subsidised by the Australian Government. Means tested fees are determined through a combined assessment of a person's income and assets. Funds for aged care are also raised through public and private capital financing.

People receiving aged care services contributed \$5.6 billion to the cost of their aged care in 2018–19, of which \$5.2 billion was spent on residential aged care.²¹⁸

In 2019–20, the Australian Government's total expenditure on aged care programs administered by the Department of Health was \$21.2 billion. Residential aged care accounted for 64%, or \$13.4 billion, of this spend.²¹⁹ The Australian Government's total expenditure on aged care programs administered by the Department was \$18.1 billion in 2017–18 and \$19.9 billion in 2018–19.²²⁰

According to the Aged Care Funding Authority, growth in residential care expenditure from 2017–18 to 2018–19 was largely driven by a 1.9% increase in the number of days of care provided due to an increase in residents and a 4.7% increase in average care subsidy and supplement payments. Growth in home care expenditure from 2017–18 to 2018–19 was driven by a 19.5% increase in the number of days of care provided due to an increasing number of Home Care Packages.²²¹ While at the time of writing the Aged Care Funding Authority had not released its report on aged care funding for 2019–20, we understand Australian Government expenditure was impacted during this period by large releases of Home Care Packages and increased funding in response to the COVID-19 pandemic.²²² The Australian Government announced that it would increase its total funding for aged care in the context of the COVID-19 pandemic, to \$23.9 billion funding for the aged care programs administered by the Department of Health for 2020–21, \$24.5 billion in 2021–22, \$25.9 billion in 2022–23 and \$27.1 billion in 2023–24.²²³

Australian Government spending on aged care as a proportion of gross domestic product is less than government spending in many other developed countries that are part of the Organisation for Economic Cooperation and Development.²²⁴ In this context, Australia has

a relatively younger population than many other developed countries.²²⁵ However, an increasing proportion of the Australian population is made up of older people. This trend is projected to continue.²²⁶ The Aged Care Financing Authority has indicated that the cost of aged care will continue to grow over time due to the combined effects of this demographic change, the increasing costs of services, and expectations of improvements in the quality of services from older people and their families.²²⁷ It has also identified other contributing factors, including increasing complexity of chronic health conditions in ageing populations.²²⁸

In 2020, the Parliamentary Budget Office projected that, over the next decade, Australian Government spending on aged care will increase by 4.0% a year, after correcting for inflation. This increase will mean that aged care spending will be growing significantly faster than the rate of all Australian Government spending (2.7%). The Parliamentary Budget Office predicts that by 2030–31, aged care will account for 5.0% of all Australian Government expenditure compared to 4.2% in 2018–19.²²⁹ Aged care spending is projected to increase by 0.3% of gross domestic product over the next decade, from 1.0% of gross domestic product in 2018–19 to 1.3% by 2030–31.²³⁰

The Aged Care Financing Authority reports on the profitability of the aged care sector based on audited data on revenue and expenditure provided by aged care providers, although results for any related parties are not accounted for in this reporting. According to the Aged Care Financing Authority, approximately 25% of home care providers and 42% of residential aged care providers reported an operating loss in 2018–19.²³¹ The Aged Care Financing Authority reports that the financial performance of residential aged care providers would have been significantly worse but for the Australian Government's one-off \$320 million increase in the Aged Care Financing Instrument in the final quarter of the 2018–19 financial year.²³² The impact of the COVID-19 pandemic on the financial performance of aged care providers is not known at the time of writing. The Aged Care Financing Authority has suggested that the pandemic may increase pressure on the sector, particularly for providers in regional, rural and remote Australia.²³³

1.6.1 Residential care funding

Residential aged care is proportionally more costly than other forms of care, with almost two-thirds of all aged care funding being directed to 21% of the people receiving aged care.²³⁴ This is at least partly attributable to the relatively higher care needs of people in residential aged care. Australian Government funding for residential aged care is made up of:

- operational funding, which supports day-to-day services such as nursing and personal care, living expenses and accommodation expenses
- capital financing, which supports the construction of new residential aged care facilities and the refurbishment of existing facilities.²³⁵

The operational funding in residential aged care is made up of Australian Government funding and resident contributions.

The Government determines its funding by setting:

- a basic care subsidy for personal and nursing care
- the rates of supplements paid to support aspects of residential care that incur higher costs to deliver
- the maximum rate of accommodation supplement for those residents who cannot afford to pay their accommodation costs.²³⁶

The relevant Australian Government Minister determines the rates for subsidies and care supplements to be paid from 1 July each year, and the rates of accommodation-linked supplements on 20 March and 20 September each year.²³⁷

An older person living in an aged care facility has both their income and assets means tested to determine the fees they can be asked to pay. A resident may be required to pay a number of fees and costs that relate to their care, accommodation and any other services they may receive. In 2018–19, residents in aged care contributed \$3.4 billion towards their living expenses, \$822 million towards accommodation costs by way of Daily Accommodation Payments, and \$513 million towards care costs.²³⁸

Paying for care

The majority of residential aged care funding is made up of the basic care subsidy which supports the costs of providing personal and nursing care to people living in residential care. The Aged Care Funding Instrument is the funding tool used to determine the amount of funding paid to a residential aged care provider on behalf of a resident for their care. It is used to assess the relative care needs of residents to allocate government funding.²³⁹ Providers undertake their own Aged Care Funding Instrument assessments by assessing care needs across three funding domains: activities of daily living, behaviour, and complex health care. A resident is allocated a nil, low, medium or high classification (A, B, C or D) across these domains, which determines the level of subsidies provided to the aged care provider for that resident.²⁴⁰

The Australian Government sets the prices and rules for claiming Aged Care Funding Instrument care subsidies.²⁴¹ At 1 July 2020, the daily Aged Care Funding Instrument subsidy rates ranged from \$0.00 a day (for someone rated as nil in all three domains) to \$223.14 a day (for someone rated as high in all three domains).²⁴²

There is variability in the average Aged Care Funding Instrument claim per resident per day between providers. This reflects differences in resident profiles and the claiming processes of providers. Data from the Aged Care Financing Authority showed that in 2018–19 some facilities averaged less than \$70 per day in Aged Care Funding Instrument payments while others averaged over \$210 per day.²⁴³

In addition to payments under the Aged Care Funding Instrument, a provider may receive residential care supplements depending on the provider / residents meeting eligibility criteria. For example, an accommodation supplement assists residents who do not have the means to meet that cost themselves; a viability supplement assists providers that are smaller or in rural and remote areas; and a homeless supplement exists for eligible facilities. There are other supplements based on high clinical needs.²⁴⁴

All older people living in residential aged care can be asked by their aged care provider to pay a basic daily fee to cover day-to-day living costs. This equates to 85% of the single rate of the basic age pension. In September 2020, the basic daily fee was \$52.25 a day, or just over \$19,000 a year.²⁴⁵ The Australian Government sets this maximum charge, but it is at a residential aged care provider's discretion whether they charge the maximum level of fees.²⁴⁶

Means tested care fees are designed to ensure that wealthier older people contribute to the cost of their personal and clinical care. The fees are calculated quarterly by Services Australia based on an assessment of a person's income and assets, including a part of the value of their family home (except where it continues to be occupied by a protected person). There are annual and lifetime caps on means tested fees, which are indexed twice a year. Older people do not have to pay more than these caps in care fees. In September 2020, there was an annual cap of \$28,087.41, and a lifetime cap of \$67,409.85.²⁴⁷

Paying for accommodation

Residential aged care providers charge for accommodation. People living in residential aged care may choose to pay for accommodation through a lump sum Refundable Accommodation Deposit, a Daily Accommodation Payment or a combination of the two.²⁴⁸ Residents with low means have their accommodation costs subsidised by the Australian Government.²⁴⁹

A Refundable Accommodation Deposit is a lump sum payment from an older person to an approved provider for accommodation. A Refundable Accommodation Deposit effectively acts as an interest-free loan from the person living in aged care to an aged care provider. These lump sum payments are refunded when the person leaves residential aged care.²⁵⁰

Providers must publish the maximum 'accommodation price' that they propose to charge for each room on My Aged Care and their own website.²⁵¹ The 'accommodation price' is the amount of the Refundable Accommodation Deposit that the provider is seeking from the resident. The amount of the Refundable Accommodation Deposit agreed between the provider and the resident is often below the level of the published accommodation price.²⁵²

The average accommodation cost in 2013–14 was \$296,000 for people entering residential care. By February 2017, the Aged Care Financing Authority reported that the average had increased to \$350,000.²⁵³

Prices above a threshold of \$550,000 must be approved by the Aged Care Pricing Commissioner.²⁵⁴ The Aged Care Pricing Commissioner receives applications from residential aged care providers to charge accommodation prices above the threshold. The Commissioner reviews and approves these prices, as well as applications for changes to extra services fees. In 2018–19, the Commissioner received 230 new applications from residential aged care providers for accommodation costs above \$550,000, and approved just over 400 applications, some of which were received in the previous financial year.²⁵⁵ Accommodation costs above \$550,000 were approved in relation to 8117 rooms in that year.²⁵⁶

The average refundable accommodation deposit held by providers in 2018–19 was \$318,000. This had increased from \$229,000 in 2013–14.²⁵⁷

Refundable Accommodation Deposits play a role in funding a residential aged care provider's capital investment to build new facilities and refurbish older ones. Refundable Accommodation Deposits accounted for around 57% of residential aged care providers' total reported assets in 2018–19.²⁵⁸

At 30 June 2019, the residential aged care sector held \$30.2 billion in Refundable Accommodation Deposits.²⁵⁹ The total number of these deposits held by providers at 30 June 2019 was almost 95,000.²⁶⁰

A person may also choose to pay their accommodation costs through a rental-style Daily Accommodation Payment. If a person is eligible (through means testing) for Australian Government assistance, they need only pay a contribution to this daily fee.²⁶¹

Accommodation costs are income and asset means tested. People with an income below \$27,840.80 and assets below \$50,500, at September 2020, are not required to pay for their accommodation.²⁶² Some people will pay a partial contribution to their accommodation, and those with higher income (above \$70,320) or assets (above \$171,535.20) are required to pay the full cost of their accommodation.²⁶³ There is a limit on the value of the family home that can be considered as part of the means test, set at \$171,535.20. The value of the home above this amount is excluded from the calculation of a residential aged care resident's assets.²⁶⁴ Different thresholds may apply for couples.

The Australian Government pays accommodation supplements to assist with the accommodation costs of people living in residential aged care who do not have the means to pay for all of these costs themselves. The Government determines the amount of accommodation supplement payable by setting the maximum rate of accommodation supplement and determining the share paid by residents based on a means test.²⁶⁵

Fees for extra and additional services

Under the Aged Care Act, approved providers may charge extra service fees.²⁶⁶ These fees are set by individual providers, based on the extra services they wish to provide, and include services such as higher standards of accommodation, a broader range and higher quality of food, and non-care services such as recreational and personal interest activities.²⁶⁷ The Aged Care Pricing Commissioner must approve the fees.²⁶⁸

Aged care providers may also charge for additional services, provided they have the agreement of the person who is to receive them. There are limits on what can be provided as an ‘additional service’. An aged care provider can only charge an additional service fee for services that:

- it can demonstrate are better than what must be provided under Schedule 1 of the Quality of Care Principles
- are not specified care and services in Schedule 1 of the Quality of Care Principles
- are not covered by the payment of an extra services fee or accommodation payment
- are not services that a provider is required to deliver.²⁶⁹

There has been a significant decrease in recent years in the number of places with extra service status. The Aged Care Financing Authority has indicated that this is likely to be because the changes that were made to the accommodation pricing arrangements on 1 July 2014 reduced the need and motivation for providers to seek extra service status, and that providers can offer additional care and services for additional fees outside the extra service framework.²⁷⁰

1.6.2 Home care funding

Home Care Packages

In 2019–20, the Australian Government spent a total of \$3.4 billion on Home Care Packages.²⁷¹ This sum mainly consisted of subsidies to home care providers. At 20 September 2020, the basic subsidies for home care per person were:

- Level 1—to support people with basic care needs—\$24.46 a day
- Level 2—to support people with low care needs—\$43.03 a day
- Level 3—to support people with intermediate care needs—\$93.63 a day
- Level 4—to support people with high care needs—\$141.94 a day.²⁷²

In addition to the basic subsidy, there are a number of supplements available depending on care need, such as for dementia care or for the provision of oxygen therapy.²⁷³

People who receive a Home Care Package can be asked to pay a basic daily fee and an income-tested care fee by their home care provider. These fees are charged for every day a person is on a package, irrespective of whether they receive a service that day. In 2018–19, these contributions to home care totalled approximately \$107 million.²⁷⁴ People may also pay an additional fee for services that are not covered by their package.

The maximum basic daily fee that may be charged by a home care provider is 17.5% of the basic single age pension for a Level 4 Home Care Package.²⁷⁵ This is \$10.75 a day, as of 1 July 2020. The basic daily fees for lower-level packages are capped at only marginally lower rates: \$10.48 a day for a Level 3 package, \$10.19 a day for a Level 2 package, and

\$9.63 a day for a Level 1 package.²⁷⁶ This means that people on a lower care package may contribute a proportionately higher amount to their cost of care.

A person on a Level 1 package, worth around \$9000 per year in Australian Government contributions, may pay up to an additional 39% of the value of their package. A person on a Level 4 package, worth about \$52,000 per year, may pay up to an additional 8% of the value of their package.

The amount of Australian Government contribution to the package is reduced by the amount of the assessed income-tested care fee, irrespective of whether the provider actually charges that fee.²⁷⁷ There are annual and lifetime limits to how much a person has to pay in income-tested care fees. As at 20 September 2020, the maximum annual amount of income-tested care fees a person can be asked to pay is:

- \$15.43 per day or \$5617.47 per year for people with incomes below \$53,731.60 (single person income rate)
- \$30.86 per day or \$11,234.96 per year for people with incomes above \$53,731.60 (single person income rate).²⁷⁸

The lifetime cap for income-tested care fees is \$67,409.85, for home care and residential care combined. This means any income-tested care fees paid while a person is receiving home care will be counted towards the cap if that person moves into residential care.²⁷⁹ People on a full age pension do not pay an income-tested care fee.²⁸⁰

The Aged Care Financing Authority reported that in 2018–19, it was likely many providers were not charging basic daily fees and income tested fees for home care.²⁸¹ Similarly, the Tune review noted in 2017:

Well over 80 per cent of consumers of home care are pensioners, and contribute only a very small proportion of the costs of care. Most providers are not charging consumers the full basic daily care fee, despite it being a modest amount, while consumers are contributing less than 3 per cent of the income-tested component of care costs.²⁸²

While noting the limitations of the data, the Aged Care Financing Authority reported that there was a significant decline in the financial performance of home care providers in 2017–18, with the mean operating income per person more than halving from \$2989 in 2016–17 to \$1217. In 2018–19, this stabilised to \$1211.²⁸³ The drop in operating income corresponds with the transfer, in 2017, of funding for Home Care Packages to the older person instead of the provider.²⁸⁴ During this time, there was also a significant increase in the number of home care providers, from 496 providers as at 30 June 2016 to 928 as at 30 June 2019.²⁸⁵

The rise of ‘unspent funds’ is a significant issue from both a service delivery and financial performance perspective.²⁸⁶ Prior to 2017, when people receiving home care moved between home care providers or exited care (often to enter residential care), unspent package funds could be retained by their former provider. Since 2017, unspent package funds follow the older person to their new provider or are returned to the Australian Government and the older person, based on their respective proportions paid.²⁸⁷ This

means that home care providers' income streams have become less stable because people receiving care can move between providers. It also means that care providers need to ensure good prudential arrangements so that they are able to repay unspent funds.

According to the Aged Care Financing Authority, at 30 June 2019, home care providers reported holding unspent funds of \$751 million. This is an increase from \$539 million at 30 June 2018.²⁸⁸ The Aged Care Financing Authority has explained that unspent funds may accumulate for a number of reasons, including that:

consumers wish to save a proportion of their budget for future events; the services that the consumer wants are not available; the consumer is reluctant to allow people into their home; misconceptions that the money not spent under the package [Home Care Package] belongs to the consumer; or because the consumer does not require all the funds allocated to them.²⁸⁹

The Aged Care Financing Authority has also commented that:

if the consumer does not need all the funds they have been allocated, these funds could be used more effectively elsewhere, including meeting unmet demand. Unspent package [Home Care Package] funds also raises prudential issues since these funds held by providers need to be available should the consumer leave their care (either transferring to another provider or leaving home care).²⁹⁰

In the 2019–20 Budget, the Australian Government announced that payment arrangements in home care would be changed from payment in advance to payment in arrears for services delivered—that is, payment for service already delivered. This change is intended to avoid Australian Government funding for subsidies and supplements being held as unspent funds by providers.²⁹¹ At time of writing, this change was intended to begin in February 2021.²⁹²

Commonwealth Home Support Programme

During 2019–20, the Australian Government provided \$2.6 billion for the delivery of services under the Commonwealth Home Support Programme, which provides grants to service delivery organisations, often not-for-profit community groups.²⁹³ Periodically, organisations can apply for grants on the Grant Connect website to fund services under the Commonwealth Home Support Programme.²⁹⁴ In 2019–20, the Australian Government also provided just under \$160 million to My Aged Care, the Regional Assessment Service, and other initiatives in support of the program. In total, with these other initiatives included, Government expenditure for the program in 2019–20 was nearly \$2.8 billion.²⁹⁵

The Commonwealth Home Support Programme has no formal means testing for contributions from people receiving care. Instead, a Client Contribution Framework outlines a number of principles that providers should adopt when setting and implementing their own client contribution policy. The principles seek fairness and consistency, aiming to ensure that those who can afford to contribute to their cost of care do so.²⁹⁶

In 2018–19, contributions from older people to the Commonwealth Home Support Programme totalled \$252 million, around 10% of the program's total funding. This is a stable proportion from the previous year.²⁹⁷

The 2017 *Legislated Review of Aged Care* recommended that mandatory contributions based on a person's financial capacity be introduced for services under the Commonwealth Home Support Programme.²⁹⁸ This would introduce means testing to the program and bring it more in line with the funding regimes of home care and residential care. The Government is yet to respond to this recommendation.

1.6.3 Other programs

The Australian Department of Health refers to a number of other services as 'flexible care'. In 2019–20, Australian Government funding for flexible care programs exceeded \$575 million.²⁹⁹ Funding for these programs, with the exception of NATSIFACP, is by way of the Flexible Care Subsidy.³⁰⁰ These initiatives, other than NATSIFACP and the Short-Term Restorative Care Program, are jointly funded by the Australian Government and State and Territory Governments.³⁰¹

Transition Care Program providers and Short-Term Restorative Care providers may charge people a daily care fee, if the person is in a financial position to contribute to their care. Contributions are charged at 85% of the aged pension for care delivered in a residential aged care setting, or 17.5% for care delivered in the person's home. This aligns these two programs' daily care fees with the basic daily fees in residential and home care respectively.³⁰²

NATSIFACP is administered outside of the Aged Care Act, and is grant funded by the Australian Government.³⁰³ In 2019–20, NATSIFACP providers received nearly \$60 million in grant funding.³⁰⁴

1.7 How aged care is regulated

In Australia's federal system of government, administration of aged care falls within the Australian Government's health portfolio.³⁰⁵ The Minister for Health and Aged Care, in Cabinet, and the Minister for Senior Australians and Aged Care Services have responsibility for the policy, program and regulatory oversight of the quality and safety of Australian Government-funded aged care services, assisted by the Australian Department of Health.³⁰⁶ Prior to the ministerial reshuffle announced on 18 December 2020, the aged care portfolio was assigned to the Minister for Aged Care and Senior Australians, outside of the Cabinet.³⁰⁷

On 1 January 2019, the Aged Care Quality and Safety Commission was established as an independent statutory body, replacing the Australian Aged Care Quality Agency and the Aged Care Complaints Commissioner.³⁰⁸ Additional regulatory functions previously carried out by the Secretary of the Australian Department of Health were transferred to the Aged Care Quality and Safety Commissioner on 1 January 2020.

1.7.1 The statutory framework

The statutory framework of the aged care system sets out the requirements to be an approved provider, for the allocation of aged care places and the eligibility and classification of people receiving care. It also sets out the responsibilities of approved providers, including in relation to aged care quality and safety.

The statutory framework is a patchwork of legislation and other instruments. The Aged Care Act and the *Aged Care Quality and Safety Commission Act 2018* (Cth) are the primary pieces of legislation governing aged care in Australia. The Aged Care Act permits the Minister to make Principles about various matters.³⁰⁹

The Aged Care Quality and Safety Commission Act establishes the Aged Care Quality and Safety Commission and, together with the *Aged Care Quality and Safety Commission Rules 2018* (Cth), sets out the functions of the Aged Care Quality and Safety Commissioner. The Commissioner's functions include 'protecting and enhancing the safety, health, well-being and quality of life of aged care consumers'. Other functions include approving aged care providers, regulating them, imposing sanctions, handling complaints, undertaking consumer engagement, and providing education.³¹⁰ The Commissioner's regulatory functions include accrediting aged care services, conducting quality reviews, and monitoring the quality of care.³¹¹

1.7.2 Approval of providers

An entity must be approved as a provider of aged care services to receive subsidies under the Aged Care Act.³¹² Since 1 January 2020, the Aged Care Quality and Safety Commissioner has been responsible for the approval of providers. Before this, the Secretary of the Australian Department of Health held this responsibility.

The requirement to be an approved provider does not apply to services under the grant-funded Commonwealth Home Support Programme and NATSIFACP. However, these providers are subject to quality reviews by the Aged Care Quality and Safety Commissioner.³¹³

To be approved as a provider, a non-government applicant must satisfy the Commissioner that it is a corporation, is 'suitable to provide aged care', and that none of its 'key personnel' is a 'disqualified individual'.³¹⁴ The Commissioner must consider a range of factors when deciding whether an applicant is 'suitable to provide aged care'. These include the applicant's experience in delivering aged care, or any other relevant form of care, its demonstrated understanding of its responsibilities as an aged care provider, and the systems it has, or will have, in place to meet its obligations. Key among these are systems to ensure sound financial management. The Commissioner must also consider, among other factors, the applicant's conduct in delivering aged care, or any other type of relevant care, including its compliance with its obligations and responsibilities.³¹⁵

The Commissioner must revoke a provider's approval if they are satisfied that the approved provider is no longer suitable to provide aged care, and may revoke approval if satisfied that the provider has not complied with one or more of its responsibilities.³¹⁶

The decision not to approve a provider or to revoke the approval of a provider is subject to review. In the first instance, the review of the decision is undertaken by an internal decision reviewer as a delegate of the Commissioner. Applications may be made to the Administrative Appeals Tribunal for review of a reconsideration decision of an internal decision reviewer.³¹⁷

1.7.3 Provider responsibilities

The Aged Care Act and the Aged Care Principles together set out providers' obligations and responsibilities. These obligations and responsibilities span the quality of care that must be provided, the rights of those receiving care, described as 'user rights', and accountability for the care provided and the suitability of key personnel.³¹⁸

Quality of care

Part 4.1 of the Aged Care Act describes the quality of care approved providers must provide, including:

- providing the care and services specified in the Quality of Care Principles, including complying with the Aged Care Quality Standards
- maintaining an adequate number of appropriately skilled staff to meet the care needs of people
- providing care and services of a quality that is consistent with any rights and responsibilities of people receiving care, as specified in the User Rights Principles.³¹⁹

The Quality of Care Principles set out the care a provider must or may provide in different care settings and for people with different levels of need. The Principles also set out whether the provider can charge a fee for those services. The Principles provide that physical and chemical restraint should only be used as a last resort.³²⁰

Aged Care Quality Standards

Approved providers must comply with the Aged Care Quality Standards. These Standards, contained in a schedule to the Quality of Care Principles, apply to residential care, home care and flexible care.³²¹ The Standards came into force on 1 July 2019, replacing the Accreditation Standards, the Home Care Standards and those that previously applied to NATSIFACP and Transition Care. Providers of services under the Commonwealth Home Support Programme are also required to meet the Aged Care Quality Standards as a condition of their grant agreements.³²²

The eight Standards are:

- Standard 1—consumer dignity and choice
- Standard 2—ongoing assessment and planning with consumers
- Standard 3—personal care and clinical care
- Standard 4—services and supports for daily living
- Standard 5—organisation’s service environment
- Standard 6—feedback and complaints
- Standard 7—human resources
- Standard 8—organisational governance.³²³

Each standard includes a statement of outcome for the person receiving care; a statement of expectation for the provider; and the requirements a provider must demonstrate in order to meet the Standard.

The Aged Care Quality and Safety Commissioner can monitor the compliance of approved providers with their responsibilities and performance against the Aged Care Quality Standards.³²⁴ Failure to meet these Standards may lead to sanctions being imposed under the Aged Care Quality and Safety Commission Act.³²⁵

User rights

Part 4.2 of the Aged Care Act and the User Rights Principles set out the general responsibilities an aged care provider has to people receiving care and to people preparing to enter aged care. Failure to meet those responsibilities may lead to sanctions being imposed under the Aged Care Quality and Safety Commission Act.³²⁶ The User Rights Principles require an approved provider to give each person receiving care, and help them to understand, a copy of the Charter of Aged Care Rights.³²⁷ The Charter states:

I have the right to:

1. safe and high quality care and services;
2. be treated with dignity and respect;
3. have my identity, culture and diversity valued and supported;
4. live without abuse and neglect;
5. be informed about my care and services in a way I understand;
6. access all information about myself, including information about my rights, care and services;
7. have control over and make choices about my care, and personal and social life, including where the choices involve personal risk;
8. have control over, and make decisions about, the personal aspects of my daily life, financial affairs and possessions;
9. my independence;

10. be listened to and understood;
11. have a person of my choice, including an aged care advocate, support me or speak on my behalf;
12. complain free from reprisal, and to have my complaints dealt with fairly and promptly;
13. personal privacy and to have my personal information protected;
14. exercise my rights without it adversely affecting the way I am treated.³²⁸

Accountability

Part 4.3 of the Aged Care Act, together with the Accountability Principles, details various responsibilities of approved providers, including in relation to: complying with record keeping, data collection and financial reporting requirements; cooperating with anyone exercising powers under the Aged Care Act or the Aged Care Quality and Safety Commission Act; and ensuring the suitability of any key personnel, staff members and volunteers. Approved providers are required to inform the Secretary of the Australian Department of Health of any changes in circumstances that may materially affect their suitability to provide aged care. They must also conduct appraisals and reappraisals of people's care needs as required.³²⁹

Since 1 July 2007, the Australian Government has required approved providers of residential aged care to report certain alleged or suspected physical and sexual assaults against residents.³³⁰ This requirement does not apply if the alleged perpetrator is a fellow resident with a diagnosed cognitive or mental impairment and the provider puts in place arrangements to manage the alleged perpetrator's behaviour.³³¹

In June 2020, the Australian Government announced that it would introduce a Serious Incident Response Scheme from July 2021.³³² This scheme will require reporting of a broader range of serious incidents, including incidents of abuse in aged care where the resident who allegedly commits an incident has a cognitive or mental impairment.³³³

National Aged Care Mandatory Quality Indicator Program

On 1 July 2019, the National Quality Indicator Program became mandatory. Previously, this was voluntary. Approved providers of residential care are required to provide information on three quality indicators to the Australian Department of Health.³³⁴ These are:

- pressure injuries
- use of physical restraint
- unplanned weight loss.³³⁵

From 1 July 2021, providers will also be required to report against falls and major injury indicators and medication management indicators.³³⁶

The quality indicators are reported at a national and State and Territory level on the Australian Institute of Health and Welfare GEN Aged Care Data website.

1.7.4 Accreditation and quality monitoring

The Aged Care Quality and Safety Commissioner is responsible for accrediting and re-accrediting residential aged care services. The Commissioner is also responsible for conducting quality reviews of home care services and for monitoring the quality of care and services.³³⁷

Residential aged care services are required to be accredited by the Aged Care Quality and Safety Commission to receive Australian Government subsidies. Once an aged care provider is approved, it can apply to the Commissioner for accreditation (or re-accreditation) of a service.³³⁸ Applications for accreditation and re-accreditation must include an undertaking that the ‘provider will undertake continuous improvement in relation to the service as measured against the Aged Care Quality Standards’.³³⁹

The Aged Care Quality and Safety Commissioner conducts periodic full audits of an aged care provider’s compliance against the Aged Care Quality Standards. When considering whether to re-accredit a residential aged care service, the Commissioner must arrange a site visit and meeting with the person in charge of the service and at least 10% of people receiving care or their representatives. The Commissioner must deliver a performance report to the provider and decide whether to re-accredit the service. If the Commissioner decides to re-accredit a service, he or she must specify the period for re-accreditation.³⁴⁰

There is no accreditation requirement for home care services. An approved provider is able to begin providing home care services before the Aged Care Quality and Safety Commissioner undertakes any quality review. In this context, home care services are those services delivered under a Home Care Package, the Commonwealth Home Support Programme, or a flexible care service where restorative care is provided in a home care setting.³⁴¹ The Commissioner must ensure that a quality review of a home care service is conducted at least once every three years.³⁴²

Quality reviews must include site visits of the premises of the provider and may include a site visit of the premises where the service is provided.³⁴³ The assessors assess the quality of care against the Aged Care Quality Standards. They must meet with the provider. Unlike residential care accreditation assessments, home care service assessors are only required to meet with the person receiving care, or their representative, if a request has been made by, or on behalf of, that person. Otherwise, the assessor is dependent on the service for information from people receiving care.³⁴⁴ After the audit, the assessment team must prepare a quality audit report and the Commissioner then produces a performance report.³⁴⁵

The Commissioner conducts quality reviews of NATSIFACP services in accordance with the Quality and Safety Commission Rules and the NATSIFACP Quality Framework.³⁴⁶

In between accreditation or quality review cycles, representatives of the Aged Care Quality and Safety Commissioner—regulatory officials—may make an assessment contact with a provider.³⁴⁷ Any form of contact between a regulatory official and an aged care provider, other than a site audit, review audit or quality audit, is an assessment contact. Assessment contacts may or may not include a site visit and may be announced or unannounced.³⁴⁸

Following an assessment contact, the regulatory official must prepare an assessment contact report and the Commissioner must produce a performance report giving the provider written notice of any areas for improvement by reference to the Aged Care Quality Standards.³⁴⁹

For NATSIFACP services, the Aged Care Quality and Safety Commissioner must monitor a service in accordance with the Quality Framework. The NATSIFACP Quality Review Guidelines allow for an assessment contact outside of the quality review process. Site visits to NATSIFACP services require 14 days' notice.³⁵⁰

If the provider has provided notification of a change in circumstances that materially affects its suitability to be a provider of aged care services, or if the Aged Care Quality and Safety Commissioner has reasonable grounds to believe that a provider might not be complying with the Aged Care Quality Standards, the Commissioner may arrange for a review audit to occur at the provider's premises.³⁵¹

On receiving a review audit report, the Commissioner has 28 days to provide a performance report to the provider and a further 7 days to decide whether to revoke the accreditation of the service. A decision to revoke accreditation must be published on the Aged Care Quality and Safety Commission's website. Alternatively, the Commissioner may vary the service's period of accreditation.³⁵²

Consequences of non-compliance

Since 1 January 2020, the Aged Care Quality and Safety Commissioner has had the power to impose sanctions on an approved provider that has not complied, or is not complying, with its aged care responsibilities.³⁵³ Previously, and for much of our inquiry, the Secretary of the Australian Department of Health held that power.

In deciding whether to impose sanctions, the Commissioner must consider the seriousness of the non-compliance, whether it has occurred before, and whether it threatens the health, welfare or other interests of people receiving care. The latter must be the Commissioner's paramount consideration and applies to people receiving care at the time or in the future.³⁵⁴

There are a range of sanctions that may be imposed on an approved provider, including:

- revoking, suspending or restricting an approved provider's approval
- restricting the payment of a subsidy to people receiving care prior to receiving notice of the sanction
- revoking, suspending or prohibiting the allocation of places to the approved provider
- varying conditions on the allocation of places
- revoking, suspending or prohibiting permission for an approved provider to provide extra services that they charge the care recipient for
- prohibiting charging for accommodation payments, contributions or bonds
- requiring repayment of grants to the Australian Department of Health or refund of money to a person receiving care.³⁵⁵

Unless there is an immediate and severe risk to the safety, health or wellbeing of people receiving care, the Aged Care Quality and Safety Commissioner must give notice of the intention to impose a sanction. The approved provider can make submissions in response. Having considered any submissions made in accordance with the notice, the Commissioner may require the approved provider to give an undertaking to remedy the non-compliance or impose sanctions.³⁵⁶ The decision to impose sanctions can be reviewed. In the first instance, the review of the decision is undertaken by an internal decision reviewer as a delegate of the Commissioner. Applications may be made to the Administrative Appeals Tribunal for review of a reconsideration decision of an internal decision reviewer.³⁵⁷

1.7.5 Complaints handling

The Aged Care Quality and Safety Commission handles complaints about the responsibilities of approved providers of aged care services under the Aged Care Act or the Aged Care Principles, or the responsibilities of service providers of Australian Government-funded aged care services under the funding agreement that relates to the service.³⁵⁸

The Commissioner can, amongst other things, investigate a complaint or undertake a conciliation or mediation process between the complainant and the provider.³⁵⁹

The Commissioner has the power to issue directions to an approved provider if satisfied that the provider is not meeting its responsibilities. The directions can require the approved provider to take specified action.³⁶⁰

The Aged Care Quality and Safety Commissioner may decide to close a complaint the Commissioner determines is better dealt with by another person or body, such as the Australian Health Practitioner Regulation Agency, or where a coronial inquiry is underway.³⁶¹

1.8 Conclusion

In recent decades, the aged care system in Australia has evolved and has been changed in a myriad ways. During the course of our inquiry, as new initiatives and policies were announced by the Australian Government, the system has changed further. Some changes to the system have been large, some incremental, but all have contributed to the piecemeal development of the aged care system.

Here, we have described the fundamental elements of the current aged care system. In the rest of this volume, we explain why the aged care system needs fundamental reform. We also examine the interface between the aged care system and other systems, particularly the health and disability sectors. In Volume 3 of this report, we make recommendations for a new aged care system that puts older people first.

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2. Problems of Access

2.1 Introduction

It should be easy for older people to access the aged care they need. Having easy access means a person can get the information, support or care they need, when they need it. It also includes getting aged care appropriate to a person's individual needs, including care that is culturally appropriate and safe. Ease of access is not a feature of the current aged care system. At best, the effect of failing to provide easy access to aged care services is that people may not know where to turn for help. They may have to make decisions which are difficult emotionally, financially and practically, without the benefit of accurate and timely information and support. At worst, people do not receive the care they need, when they need it. These outcomes are unacceptable.

Problems of access have been raised throughout the life of this Royal Commission. In this chapter, we highlight what we see as the problems of access in the aged care system. First, we highlight the key problems with accessing different parts of the aged care system. Second, we highlight the particular difficulties specific groups have in accessing the aged care they need. Third, we look at where access issues are dependent on other systems and programs, such as health care or disability services. Together, these issues demonstrate the breadth of circumstances in which access may be a problem for older people who need aged care services.

2.2 Accessing aged care

The aged care system is difficult to access and navigate. People accessing the aged care system have reported the experience as time-consuming, overwhelming, frightening and intimidating.¹

2.2.1 Problems entering and navigating the system

The time of first contact with the aged care system is often stressful for older people and their loved ones. The availability of helpful and comprehensive information is critical to ensuring older people get timely access to the care they need and to empowering them to make choices about their care. The current aged care system does not do this well.

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Problems entering and navigating Australia's aged care system are not new. In its 2011 inquiry report, *Caring for Older Australians*, the Productivity Commission noted that older people 'face a complex and confusing array of entry points into the aged care system and multiple sources of information about ageing and how they can best manage their own ageing'.² The Productivity Commission recommended the establishment of a single gateway through which people could obtain information about, and access to, aged care services, with local infrastructure and face-to-face support.³

The Australian Government announced, in its response to the Productivity Commission's report, that My Aged Care would be established in 2013. The Government agreed that My Aged Care needed to be responsive to local needs. However, the Government considered that beyond the new website and call centre, it was 'premature' to establish new local physical infrastructure. It argued there was 'potential for the Department of Human Services (Medicare and Centrelink offices) to contribute to facilitating access to the Gateway'.⁴ About eight years after the establishment of My Aged Care, there is still no government 'shopfront' or physical infrastructure at the local level. A 2019 national study showed that carers need to access information from four or more sources to navigate the system successfully.⁵

In the Interim Report, Commissioners Tracey and Briggs outlined numerous problems with My Aged Care.⁶ At that time the evidence showed that information on the My Aged Care website was inconsistent, incomplete, lacked sufficient information about the quality of services, and had limited functionality.⁷ There has been similar variability with the information provided through the call centre.⁸ Ms Rita Kersnovske gave evidence about her experience seeking help from the My Aged Care call centre after she had a fall:

And they just quoted me numbers. They—they said 'You've been assessed' and quoted me numbers...And, you know, I got really upset on the phone call and just—I actually ended the call by saying, 'I will just sit here and starve to death.' And I just got no help—no help whatever from My Aged Care.⁹

The Australian Government has made a number of changes to My Aged Care since our inquiry commenced.¹⁰ Key changes include: improved readability; the capacity to search providers by location; a self-service online registration and screening system; a client dashboard or summary page with a journey tracker; automatic email notifications at key stages as a person accesses care; and the introduction of an e-Referral system which allows general practitioners to send referrals to My Aged Care directly from their practice management systems to request an aged care assessment.¹¹ We welcome these recent changes, but some problems remain.

We are particularly concerned that it remains difficult for people to make informed decisions about aged care services. No one who needs aged care supports and services should ever feel the way Ms Marie Dowling felt after months of trying to navigate the system:

Look, I felt, really, absolutely at a loss and unable—being unable initially to find help, it was so stressful. And I really felt—sorry, I've got a word and it will come in a minute—depersonalised, worthless, unable of course to organise my own care, and I really felt demoralised by the entire process.¹²

Dr Lyn Phillipson, a researcher and Dementia Fellow at the University of Wollongong, reported that ‘the government, whilst it had intended to introduce choice, hadn’t really established the preconditions for what we understand people need to exercise choice, which is accessible information’.¹³ There is no way for people seeking services to know, from My Aged Care, whether a service will meet their specific needs. While a service may state that it caters for particular communities and cultural groups on the My Aged Care website, or that they are specialists in the provision of care to ‘particular diversity groups’, there is no process to ensure the accuracy of those claims.¹⁴

There is also very limited information available about the quality of services provided. Only two measures are available: Aged Care Quality Standards ratings and, since June 2020, Service Compliance ratings have been published for all residential care services.¹⁵ However, these ratings offer few details about the performance of services and providers. While they identify services that have not met minimum standards, they do not differentiate between services that barely meet those minimum standards and those that have achieved excellence. Information about the quality of care is essential for older people making important life decisions such as who they let into their homes to deliver personal care or which residential aged care facility they will move to. Information about the quality of care is essential for older people making important life decisions such as who they let into their homes to deliver personal care or which residential aged care facility they will move to.

There is no other information available directly from My Aged Care that could help people meaningfully compare different services and providers. There is no consumer experience information.¹⁶ Important information about the nature, number and disposition of complaints and the number of reportable assaults that would alert older people to service problems is not accessible at either the provider or service level. Mr Glenn Rees AM, Chairman of Alzheimer’s Disease International, testified that lack of information like this makes it very difficult for people to make informed decisions:

it seems to me sad that consumers don’t know in a timely way which services are under investigation in a serious way. It seems to me bad that you can’t go to a website and see what the psychotropic levels of medication administration are. You can’t go to a website and look at the skills and staffing mix...and get reassurance about the extent to which the staff are trained. They may have palliative care skills or other things. I think for the consumer it is very, very difficult to know where to go.¹⁷

This is basic information about the quality and safety of care. It is not good enough that older people are having to make decisions about care without access to this information.

Access issues related to sources of information about aged care are compounded for people from diverse backgrounds and with diverse life experiences. For many, language and literacy barriers are an issue. People who are more socially disadvantaged than the general population, or who are located in regional, rural and remote areas, may not have ready access to technology and the internet.¹⁸ Mistrust and fear of government and organisations can be an issue, and socially isolating circumstances may leave people without the support and assistance required to overcome difficulties accessing and navigating the system.¹⁹

Throughout our inquiry, we have heard that irrespective of education levels, means, background or circumstances, it is very difficult for most people to navigate all aspects of the aged care system. The My Aged Care entry system lacks local, face-to-face assistance, including coordination to help plan and manage people's care.²⁰ Mrs Catharina Nieuwenhoven, a community liaison officer with a Home Care Package, explained that older people in her Dutch community in Adelaide often do not know how to access aged care services and do not always realise what services they can receive when they are allocated a package.²¹

The Australian Government is trialling different models of an aged care system navigator to assist people to understand and engage with the aged care system.²² The findings of an interim report of the evaluation of the system navigator trials, undertaken by Australian Healthcare Associates for the Australian Department of Health, were that 'many older people—particularly those who face additional barriers or are vulnerable—require face-to-face engagement, with repeated interactions over time'.²³

Aged care is a personal experience, and there needs to be personalised information and support for people seeking to access and use aged care services. The current aged care system does not deliver this.

2.2.2 Accessing home care

There are several access issues within the two programs for care at home, the Home Care Packages Program and the Commonwealth Home Support Programme.

Too many older people are not getting the Home Care Package they need at the time and level they need it. Many people cannot access a package even when they are approved for one because the supply of packages is capped by the Australian Government. In 2018–19, the waiting times between being assessed as eligible for services to being assigned a package ranged from seven months for a Level 1 package to 34 months for a Level 4 package.²⁴ This is simply too long for older people to wait for care, as many die or have to enter residential care while waiting.²⁵

Since the Royal Commission commenced, the Australian Government has released a number of additional packages, but as at 30 June 2020, 102,081 older people were still waiting for a package at their approved level.²⁶

The waiting times are greatest for people requiring higher levels of care, yet the additional packages announced since February 2019 have predominantly been lower-level packages.²⁷ In the June 2020 quarter, only 6400 of 39,000 new packages were Level 4 packages.²⁸ There were still almost 16,000 people waiting for a Level 4 package.²⁹ The number of people waiting for care is still too high and they are waiting for too long.

Too many older people are receiving lower levels of care than they are assessed as needing. Some 40,744 of the 102,081 people on the waiting list had been offered, although had not necessarily accepted, an interim package at a lower level than their assessed need.³⁰ People assessed as needing a Level 4 package of approximately \$52,000 a year

are often offered an interim Level 2 package of approximately \$15,750 a year.³¹ This is meant to tide them over until the National Prioritisation System allocates them a Level 4 package from the rationed pool of Home Care Packages. It is dependent on packages becoming available either through current package holders dying or commencing residential care, or on the Australian Government funding more packages.

Without access to home care services that meet their assessed needs, people risk and face declining function, preventable hospitalisation, carer burnout, premature entry to residential aged care, and death.³² The impact can be devastating, especially when an older person has high care and support needs.³³ One person making a public submission described the personal toll on her as a carer when her mother waited for a Home Care Package:

Over the next six months mum deteriorated as we waited for the Home Care Package, I did as much as I could. I hardly slept and spent most of my spare time with mum while my husband looked after our two children. My health suffered and I was barely coping.³⁴

Even when people are allocated a Home Care Package at their assessed level, they may not receive the actual level of care they need. We have heard that a considerable portion of an older person's Home Care Package allocation often goes to care management and administrative fees, rather than to its intended purpose of direct care.³⁵

A number of witnesses gave evidence about Home Care Package fees and charges. Ms Lynda Henderson explained that 35% of the fees charged to her friend Veda's Home Care Package was for 'administration costs' and 'case management'.³⁶ This amounted to approximately \$58,000 over three years.³⁷ Ms Raelene Ellis said that her mother's Level 4 Home Care Package provider charged 38% in administration fees, almost \$19,000 a year.³⁸ Mr Josef Rack said that his first home care provider charged 'about half' of the Government funding for his Home Care Package on fees.³⁹ He said that 'the management fee paid for access to physiotherapy, a coffee machine, a registered nurse and a bus. ...I never used any of these services'.⁴⁰ StewartBrown's analysis of collected home care data indicated that, across all package levels, care management and administration fees accounted for an average of 28% of the total package funding in 2018–19, increasing as the package level increases.⁴¹ That analysis also indicated that care management fees had increased as a proportion of all fees from 2017–18 to 2018–19 despite pricing transparency measures introduced by the Department of Health.⁴²

It is likely that the level of Home Care Package funding is insufficient to meet the care needs of many package holders. In 2018–19, the highest Home Care Package, Level 4, allowed an average of only eight hours and 45 minutes of service a week.⁴³ This includes care management, nursing care, personal care, cleaning and household tasks, and social support. On average, each package provides only three hours of personal care and less than 20 minutes of clinical care each week.⁴⁴

The total care hours provided across all Home Care Package levels has declined.⁴⁵ Over a decade ago, more than double this volume of care was possible from the funding provided, which has reduced significantly in real terms. In 2008, 16.2 hours, which included 14.1 hours of direct assistance, was offered to people with the equivalent

of a Level 4 package.⁴⁶ The March 2020 *StewartBrown Aged Care Financial Sector Report* indicated that the average weekly direct care hours a person received declined by 13% between March 2019 and March 2020.⁴⁷ This decrease in care is very concerning because packages are now delivering less care than intended by the Government and because older people who access aged care from home are increasingly frail and have high rates of comorbidities.⁴⁸ The aged care system is failing to deliver on their care needs.

Some older people do not receive the types of services they need because of funding limitations in the package levels, and the way the Home Care Package Program and the Commonwealth Home Support Programme interact.⁴⁹ One person in their submission described how the limited funding allowed ‘two hours of domestic assistance and two hours of “everything else” (gardening, window cleaning, transporting to appointments, physiotherapy, speech pathology, podiatry)’.⁵⁰ Dementia Australia explained how, due to limited funding, people tend to prioritise care services and house cleaning over other supports that have the potential to improve their wellbeing:

the majority of consumers will tend to choose home care services over counselling or social support because they do not have enough funding for both. The immediate need for, say, domestic support is prioritised over activities that have the potential to improve wellbeing in the long term.⁵¹

The Australian Government now allows some group social activities to be used by people with Home Care Packages that commenced after 1 July 2020, if the person was engaging in those activities before accepting the package.⁵² This is just one of many supports that people access, and that they must choose between when they are using a package. Assistive technologies and home modifications are other examples—as is access to respite, which is only available under a package in limited circumstances.⁵³

People using Home Care Packages or residential aged care do not have access to the broad array of supports under the Commonwealth Home Support Programme, unless they can pay ‘full cost recovery’ or the unsubsidised cost of the support charged by the provider.⁵⁴ While this may prevent ‘double dipping’, it means those with less ability to pay will always have less access to aged care.

Similar concerns about continued access to social supports as care needs increase were raised in connection with people using aged care at home and in a residential facility.⁵⁵ Personal and clinical care are not substitutes for other types of support people may need, such as social support, assistive technologies and home modifications, and respite care. Both care and other types of support are important to ensure an older person’s health and wellbeing. And people should be able to access both. In the current system, people too often have to choose between care and other supports. These are difficult choices which older people and their families should not be asked to make.

We are concerned that people may not be accessing key home modification and assistive technology needs under their Home Care Packages. Home modification and assistive technology do not play a significant role in the amounts charged against Level 1 packages, but become more significant from Level 2 packages. Overall, the most popular item purchased by volume was a washing machine (18%), closely followed by a television (17%)—while assistive beds featured very low on the list (1.3%).⁵⁶

This is very different to the former Community Aged Care Package program data captured in the 2008 Community Care Census. At that time, prior to consumer directed care, older people generally purchased or hired equipment from the provider; and older people most commonly used walking aids (48%), shower chairs (40%), and toilet modifications (23%). A similar trend was also found in the Extended Aged Care at Home program, where the most common item was shower chairs (68%), followed by continence aids (57%) and toilet modifications (56%).⁵⁷ While we understand the importance of older people making choices about their care, it is concerning that investment in home modification and assistive technology has declined so significantly under the Home Care Packages Program.

Aged care is not designed to replace State and Territory equipment programs. However, as COTA Australia has noted, the different eligibility requirements and budgets of these programs can mean that people receiving aged care may go without necessary assistive technologies. People may not be able to access their State program but their aged care funding does not cover the cost of the equipment as well as their care.⁵⁸ At the Mildura Hearing, Ms Nicole Dunn explained how her grandmother was not eligible to receive a personal alarm because Ms Dunn was living with her, even though she was working full-time.⁵⁹ In his 2017 Legislated Review, Mr David Tune AO PSM recommended that the different levels of government work together to increase access and increase focus on assistive technologies, noting the importance of these supports for staying at home:

One of the key issues for some groups of older people with a disability is timely and affordable access to aids and equipment, which may mean the difference between remaining independent or requiring ongoing aged care services.⁶⁰

Due to historical arrangements, each State and Territory has a different range of services available under the Commonwealth Home Support Programme. For example, Victoria has over double the number of people accessing allied health and personal care services as New South Wales. Queensland has more people accessing home modification and home maintenance services than any other State.⁶¹

South Australia has almost as many people accessing assistive technology as the rest of the States and Territories combined.⁶² Access to assistive technology is further complicated by related State and Territory assistive technology and home modification schemes. This has resulted in a complex patchwork of supports.⁶³ The evidence and information before us shows the importance of securing better assessment processes and broader eligibility for assistive technologies and home modifications.⁶⁴

Most older people want to remain living in their own homes, rather than moving to residential aged care.⁶⁵ However, in the current aged care system, older people often wait too long to get access to care at home. When they do get access to care, they may receive less care than they need or they may not have access to specific services they need. This must change.

2.2.3 Respite care

Too often, older people and their carers do not receive quality respite care when they need it. Respite care can provide a ‘circuit breaker’ for both an older person and their carer. When done well, it can provide an opportunity for an older person’s rehabilitation, reablement or medication review. Respite may offer short, regular breaks for a carer to attend to their own health needs or manage their household, or less frequent, longer periods that enable a carer to refresh or take a holiday.

For people with a Home Care Package, respite care tends to be allocated only if there are funds left over after other services are in place.⁶⁶ Dr Phillipson expressed her concern about how the current assessment process leaves carers waiting until they are desperate for assistance:

to leave the assessment of carers just at that level of is this in crisis? Is this carer kind of at breaking point? really does show a problem with the system if our goal is to be maintaining people to live well at home, and also to maintaining the wellbeing of carers as part of that situation.⁶⁷

The system relies on an informal carer self-identifying as a ‘carer’ and knowing where to go for support. It is also difficult for carers to access respite care for those that they care for and other support for themselves. We know that accessing support services early in the caring role is critical to support carer wellbeing and to increase the sustainability of the arrangement.⁶⁸ The Carer Gateway, administered by the Australian Department of Social Services, provides and connects carers to many services, including coaching, counselling, respite care, connecting with other carers, online skills courses and financial support. However, the Carer Gateway and My Aged Care are not joined up, and direct people and carers to separate intake and assessment processes.⁶⁹ Witnesses described the lack of communication between the two separate and disconnected systems as frustrating to navigate and a significant barrier to carer awareness and engagement.⁷⁰

Older people and their carers can be deterred from seeking respite care if they have had negative experiences. Some witnesses described poor quality services and service arrangements that did not meet older people’s needs, which contributed to their reluctance to use them again.⁷¹ Respite delivered in a residential care setting is subject to all the deficiencies we outline in our analysis of the nature and extent of substandard care (see Chapter 3 of this volume).

Poor quality respite care can create more problems than it solves. Mrs Lillian Reeves gave evidence that her husband, Mr Terance Reeves, became permanently incontinent during his stay in respite care and that ‘he never came back 100%’. She said Mr Reeves’s time in respite care caused increased stress for her and for their children.⁷² Commissioners Tracey and Briggs did not accept that the approved provider had caused Mr Reeves’ deconditioning, but found that the approved provider had provided substandard care that put the health, safety and wellbeing of Mr Reeves at serious risk.⁷³ Carers can lack trust in the respite providers—they do not think a facility is able to care for their loved one as well as they do.⁷⁴ This, combined with poor experiences, results in people not accessing these services when they need them.

We also heard about families who desperately needed respite but were unable to find any appropriate services. This is particularly the case for older people living with dementia and their carers. Ms Rosemary Cameron described her experience of seeking respite care for her husband, Mr Don Cameron, who had Lewy body dementia. She said that a respite provider required her to take Mr Cameron home as they could not manage his behaviour:

You know, I just remember feeling so extremely sad for Don, to be almost rejected when he needed help the most. And I think walking out of the facility with Don in one hand and his goods in the other, and I hopped in the car and I thought I can't rely on anybody. I just don't think there's anything out there, and I was so exhausted and I thought I'm failing him as well. And I thought if I can't look after him nobody else certainly is showing me they can do that too, and I just cried silently all the way home so Don couldn't see. And I just thought well maybe I just end it for both of us.⁷⁵

Respite care is not sufficiently flexible to meet the needs of older people and their carers. Cottage-based respite offers flexible overnight care in a home-like environment with a small number of people. Research suggests carers prefer this type of respite and that it has better outcomes for the person receiving care.⁷⁶ While this type of respite does currently exist, providers are very limited, particularly in regional areas.⁷⁷

Residential respite tends to be offered in prescribed timeframes that suit the provider rather than the person receiving care and their carer. When Ms Dorothy Holt wanted to travel for one week, an aged care provider told her that she could have four weeks of respite or nothing.⁷⁸ Ms Joan Rosenthal also recounted how difficult it was to plan in advance for her husband, Ian, to have a short respite stay. She saw the need for greater access to quality respite and improved information about the availability of respite options.⁷⁹ We have heard from representatives of aged care providers that they prefer people to spend a minimum of two weeks in respite care.⁸⁰ This is despite evidence that more flexible forms of respite, or a preventative, restorative approach such as short-term and regular cottage-based respite, can be more beneficial for carers and older people.⁸¹

High quality, accessible and flexible respite options are core services within an effective aged care system. For too many older people and their carers, the current aged care system does not meet these needs.

2.2.4 Allied health care in aged care

People receiving aged care have limited access to services from allied health professionals, including dietitians, exercise physiologists, mental health workers, occupational therapists, physiotherapists, podiatrists, psychologists, speech pathologists and specialist oral and dental health professionals.⁸² Allied Health Professions Australia stated that 'allied health service provision in aged care is predominantly not a matter of an aged care / health interface but an integral part of aged care'.⁸³ We agree.

Research demonstrates the benefits of allied health services for older people. For example:

- podiatry services are associated with a 36% reduction in the rate of falls in older people⁸⁴
- physiotherapy is effective at reducing older people's back pain and restoring their ability to move freely⁸⁵
- physiotherapy programs can improve functional independence and quality of life for people receiving palliative care at home⁸⁶
- music therapy can improve motor function for people with Parkinson's Disease⁸⁷
- occupational therapy and exercise can prevent or slow functional decline of older people with dementia living in the community.⁸⁸

Mrs Rosalie and Mr Rod Foreman's evidence demonstrates the impact that good allied health care can have. Mrs Foreman had a stroke. Her transfer notes from her rehabilitation service to the aged care provider said she would 'never walk again'.⁸⁹ Mr and Mrs Foreman engaged a physiotherapist privately to provide extra support and after a number of months Mrs Foreman was able to walk with support.⁹⁰

There are a number of exemplary multidisciplinary allied health services in aged care.⁹¹ However, multidisciplinary allied health care is not consistently provided in aged care as it should be. In some instances, it appears that very little allied health care is being provided. The Australian Government commissioned the StewartBrown 2018–19 survey on home care, which reported that only 2% of Home Care Package funding was spent on allied health during that period.⁹² Dr Nicholas Hartland PSM, First Assistant Secretary, In Home Aged Care Division, Australian Department of Health, said that, ideally, more people would access allied health (and nursing) services through their Home Care Packages.⁹³

Australian Department of Health 2018–19 data on the Commonwealth Home Support Programme indicated that, across Australia, 29% of people received services categorised as allied health and therapy services.⁹⁴ However, for each type of allied health and therapy service, the most common number of times a person received that type of service in a year was once, and more than half of them received fewer than five allied health services a year in total.⁹⁵ Nearly two-thirds of all allied health and therapy services were provided in Victoria (41%) or Queensland (22%), with rates of access in other States and Territories much lower.⁹⁶

Allied health care in residential aged care is also insufficient. We are concerned that, in practice, residential aged care providers are incentivised to provide only the types of allied health care that can generate additional funding under the Aged Care Funding Instrument.⁹⁷ If a person in residential care is receiving 'complex pain management and practice undertaken by an allied health professional or registered nurse', they are categorised as needing 'complex health care' under the Aged Care Funding Instrument and the provider receives additional funding. These pain management services are not evidence-based.⁹⁸ A number of allied health professionals, particularly physiotherapists, described their frustration at not being able to provide the allied health care they knew their

client needed because they were required, by the aged care provider, to provide a limited range of non-evidence-based pain management services to ensure retention of funding under the Aged Care Funding Instrument.⁹⁹

Professor Esther May spoke of her struggles to get access to allied health care for her mother in residential aged care:

So I have had to fight for her to get one podiatry assessment over the, what is it, six, seven, eight months that she's been within aged care. So there is no systematic way that that facility is able to draw upon allied health services. ...I think it's her right to have that but it has not been something that has been offered. It was not prioritised within her care plan that was developed by a clinical nurse, and there was no discussion with the family about what her needs were in relation to allied health services.¹⁰⁰

Some people receiving aged care fund their own allied health services, but many people cannot afford to do this. If they have a chronic disease, they may qualify for five Medicare-subsidised allied health services annually under the Chronic Disease Management program.¹⁰¹ This level of service provision is inadequate.¹⁰²

The lack of value placed on allied health services in aged care was apparent during the COVID-19 pandemic. It took a series of changes to the *Industry Code for Visiting Residential Aged Care Homes during COVID-19* to ensure allied health professionals could continue to visit facilities and provide care.¹⁰³ This was a time of increased need for people in residential aged care, due to isolation and reduced mobility. Yet we heard that there was reduced access to allied health services in some residential aged care facilities.¹⁰⁴ Allied health services should play a central role in providing care to older people.

2.3 Access for groups already at a greater disadvantage

People receiving aged care have diverse backgrounds and life experiences. Some groups of people have particular needs, which are too often not being met by the current aged care system.

The *Aged Care Act 1997* (Cth) identifies people with 'special needs', commonly referred to as the 'special needs provisions'. The current list identifies nine groups of people as having needs that warrant special consideration, including: Aboriginal and Torres Strait Islander people; people living in rural or remote areas; people from culturally and linguistically diverse backgrounds; veterans; people experiencing homeless or at risk of homelessness; care leavers; parents forcibly separated from their children; and lesbian, gay, bisexual, transgender and intersex people.¹⁰⁵

While people within the groups listed are referred to as having ‘special needs’ under the Aged Care Act, we refer to them as people with diverse backgrounds and life experiences. We believe this better captures the unique and complex experience of each person, and acknowledges that each person may identify with one or more of the groups listed in the Aged Care Act. This is aptly described in the Aged Care Diversity Framework, which states:

Older people with diverse needs, characteristics and life experiences can share the experience of being part of a group or multiple groups that may have experienced exclusion, discrimination and stigma during their lives. However, they are not a homogenous group. There are some similarities within groups in relation to the barriers and difficulties they may face in accessing the aged care system but additionally, each person may have specific social, cultural, linguistic, religious, spiritual, psychological, medical, and care needs.

In addition to common challenges, social differences often overlap as people identify with more than one characteristic, exacerbating already complex issues. There is no limit to the number of different characteristics a person holds and no two people’s lived experiences are the same.¹⁰⁶

We heard of numerous access issues experienced by people with diverse backgrounds and life experiences. In this section, we discuss the particular access problems for older people in regional, rural and remote areas, for older Aboriginal and Torres Strait Islander people, and for disadvantaged groups. While these groups, and individuals within these groups, have diverse experiences and needs, they each point to the need for an aged care system that genuinely can respond to them as people, understanding that a ‘one size fits all’ system is not enough.

2.3.1 Older people in regional, rural and remote areas

There are three reasons why we are particularly concerned about access to aged care services in regional, rural and remote areas (or areas outside major cities).¹⁰⁷ First, older people make up a greater share of the population in regional, rural and remote Australia than in major cities.¹⁰⁸ One study suggests that, over time, the level of frailty is expected to increase in regional, rural and remote Australia. From 2017 to 2027, the fastest projected growth of frail older people will be in regional, rural and remote areas, as well as the outer areas of major cities.¹⁰⁹

Second, people in regional, rural and remote areas experience multiple disadvantages, which can magnify the need for support in older age. These disadvantages include lower incomes, lower education levels, and poorer health outcomes, including higher rates of disease and injury.¹¹⁰ People in regional, rural and remote areas also have poorer access to primary health care, which increases pressure on the aged care system.¹¹¹

About 32% of people living with dementia live in regional, rural and remote Australia.¹¹² We heard evidence that residential aged care facilities in regional, rural and remote areas find it difficult to meet the needs of people living with dementia who display complex behaviour. The difficulties they face can include inadequate infrastructure and capital works, inadequate staff training, inability to carry out strategies in dementia care and management practice, and difficulties in accessing expert support.¹¹³

The third reason is that availability of aged care in regional, rural and remote areas is significantly lower than in major cities. We are also concerned that the availability of these scarce resources has worsened since 2014 in remote areas, as Table 1 shows.

Table 1: People receiving residential and community aged care / places per 1000 people in the aged care planning population by remoteness (at 30 June)¹¹⁴

REMOTENESS AREA	CARE TYPE	2014	2015	2016	2017	2018	2019	DECREASE/ INCREASE
Major cities	Residential aged care	83.8	82.2	80.8	79.6	79.4	79.2	5.5% decrease
	Community aged care	30.9	31.2	34.3		35.3	40.2	30.1% increase
	Total	114.7	113.4	115.1		114.7	119.4	4.1% increase
Inner regional and outer regional	Residential aged care	73.3	72.2	70.9	68.3	66.7	67.6	7.8% decrease
	Community aged care	25.8	25.6	28.4		33.1	36.4	41.1% increase
	Total	99.1	97.8	99.3		99.8	104.0	4.9% increase
Remote and very remote	Residential aged care	50.6	49.0	46.5	23.1	43.0	44.3	12.5% decrease
	Community aged care	33.4	31.9	30.9		24.2	29.1	12.9% decrease
	Total	84	80.9	77.4		67.2	73.4	12.6% decrease

Source: Productivity Commission, *Report on Government Services series*, Part F, 2015–2020.¹¹⁵

The Productivity Commission's *Report on Government Services* data, summarised in Table 1, shows that there are fewer residential aged care places per 1000 people in the aged care planning population (70 years or over) in regional, rural and remote areas than in major cities, with services particularly scarce in remote areas. For instance, in 2019 there were only 44.3 residential aged care places per 1000 people aged over 70 years in remote areas, but there were 79.2 places per 1000 people aged over 70 years in major cities. Since 2014, residential aged care services have been decreasing at a faster rate in remote Australia (12.5%) than in major cities (5.5%) and regional areas (7.8%).

Although data for inner regional and outer regional areas is combined in Table 1, there is a significant difference in access between these two location types. For example, there has been a disparity in the rates of growth of numbers of Home Care Packages in inner regional and outer regional areas. The numbers of Home Care Packages in outer regional areas have not kept track with overall growth in the home care program, and the proportion of Home Care Packages in outer regional areas declined significantly from 30 June 2016 to

30 June 2019.¹¹⁶ The disparity between access to aged care in outer regional and remote areas compared with other areas is demonstrated by another indicator of unmet need in residential aged care, which is the number of hospital patient days used by people who are eligible and waiting for residential aged care.¹¹⁷ In 2017–18, people living in outer regional (24.2), remote (38.7) and very remote (32.2) areas had much higher rates per 1000 hospital patient days used by those eligible and waiting for residential aged care compared with major cities (7.1) and inner regional areas (7.8) (see Table 2).

Table 2: Hospital patient days used by those eligible and waiting for residential aged care, rate per 1000 patient days, by remoteness

	2013–14	2014–15	2015–16	2016–17	2017–18	DECREASE/ INCREASE
Major cities	7.3	7.7	8.5	8.5	7.1	2.7% decrease
Inner regional	8.6	8.7	9.8	9.9	7.8	9.3% decrease
Outer regional	21.8	26.3	28.8	30.5	24.2	11.0% increase
Remote	30.4	29.1	47.2	35.2	38.7	27.3% increase
Very remote	31.3	13.8	22.0	36.4	32.2	2.9% increase

Source: Productivity Commission, 'Part F, Chapter 14 - Aged Care Services', *Report on Government Services 2020*, Table 14A.33

While the decrease in residential aged care places in major cities and regional areas from 2014 to 2019 is being offset by an increase in people receiving community-based aged care services, this is not happening in remote and very remote areas, and is not happening in outer regional areas proportionally with major cities and inner regional areas. We acknowledge that from 2018 to 2019, there was an increase of services in nearly all locations for both residential and community aged care services. The only exception was residential aged care in major cities, which had a less than 1% decrease. The increase for residential care appears to be the result of the 2018–19 Aged Care Allocation Round that prioritised regional, rural and remote areas. This is encouraging, but more is needed.

People living in rural and remote Australia often have to travel much further to access services. The Office of the Royal Commission analysed data from the Australian Department of Health to establish the distance people travel to access aged care services.¹¹⁸ The data indicates that the further a person lived from a major city, the more likely they were to have to travel long distances to access residential aged care.¹¹⁹

Ms Barbara McPhee AM, a carer for her mother in regional New South Wales, said that the ‘lack of respite care beds in our area created great stress for my sister and me’.¹²⁰

Ms McPhee explained that the two aged care facilities in the area each only had one respite room: ‘We had to book five months in advance for one or two-week stays but at certain times, such as Easter, we needed to book further ahead than that.’¹²¹

A number of witnesses described the scarcity of aged care services and the limited choice in regional, rural and remote locations.¹²²

There are low numbers of people with a Home Care Package in remote areas. Since Home Care Packages began being allocated to people rather than providers in 2017, access to home care services has reduced for people living in outer regional, remote and very remote communities as a proportion of the number of available Home Care Packages.¹²³ Mr Jaye Smith, First Assistant Secretary, Residential and Flexible Aged Care Division, Australian Department of Health, said the Department was concerned that remote and very remote areas had experienced the lowest relative growth in people on Home Care Packages between 31 March 2017 and 31 December 2018.¹²⁴ He said that the Department was also concerned that from 27 February 2017 to 31 December 2018, people living in these areas had a considerably lower ‘take-up’ of Home Care Packages for which they had been assessed as eligible.¹²⁵

Ms Jaclyn Attridge, Head of Home and Community Care Operations at the aged care provider Uniting NSW.ACT, said the impact of wait times for Home Care Package services are amplified in regional, rural and remote areas. She explained that if a person’s condition deteriorates while they wait for a package, they may need to move to residential aged care away from their community and support network.¹²⁶ Ms McPhee said that her mother was assessed for a higher-level Home Care Package in regional New South Wales, but that services did not follow:

we were told that packages were not available from local providers and she might have to wait two years. Fourteen months after she died someone rang me from My Aged Care (or the Department of Human Services) to say that a package had become available.¹²⁷

2.3.2 Aboriginal and Torres Strait Islander people

Aboriginal and Torres Strait Islander people experience access issues in the Australian aged care system. As we explain in more detail in Chapter 7 of Volume 3, we are concerned that Aboriginal and Torres Strait Islander people do not access aged care at a rate commensurate with their level of need. A combination of factors create barriers to Aboriginal and Torres Strait Islander people’s access to the aged care system. These arise from social and economic disadvantage, a lack of culturally safe care and the ongoing impacts of colonisation and prolonged discrimination.¹²⁸ Access issues are further compounded by Aboriginal and Torres Strait Islander people’s additional vulnerability arising from higher rates of disability, comorbidities, homelessness and dementia.¹²⁹

Entering and navigating aged care is difficult for many Aboriginal and Torres Strait Islander people. Mr Graham Aitken, a Yankunytjatjara descendent and Chief Executive Officer of Aboriginal Community Care SA, said that Aboriginal and Torres Strait Islander people do not understand aged care or where to start getting help with aged care.¹³⁰ We heard about the complexity of My Aged Care for Aboriginal and Torres Strait Islander people, with witnesses and submissions describing difficulties accessing and navigating the system.¹³¹

We were told about numerous assumptions built into My Aged Care which may impede Aboriginal and Torres Strait Islander people from gaining access. These assumptions include that people:

- reside in a fixed location, have access to mail delivery, a reliable phone, computer or the internet¹³²
- are sufficiently literate and computer literate¹³³
- have access to records and identification documents¹³⁴
- will trust strangers with sensitive information¹³⁵
- have 'lived experience of self-determination in choosing their own decisions in life'.¹³⁶

Mr Craig Barke, Chief Executive Officer of UnitingCare Queensland, noted that the complexities of My Aged Care can cause distress and confusion that may result in Aboriginal and Torres Strait Islander people disengaging and not accessing the services they need.¹³⁷

Many Aboriginal and Torres Strait Islander people experience marginalisation, discrimination, disadvantage and racism and, as a consequence, may not trust government and government systems. This further undermines the efficacy of My Aged Care.¹³⁸ Without trust, Aboriginal and Torres Strait Islander people may not engage with aged care providers.¹³⁹ Ms Moreen Lyons, a Jaadwa woman of the Wotjobaluk nations and Chief Executive Officer of aged care provider Aboriginal Community Elders Services Inc, described Aboriginal and Torres Strait Islander people accessing their services as 'wary' and wanting flexibility to test services before making a decision to move permanently into residential options.¹⁴⁰ Similarly, members of the Stolen Generations—Aboriginal and Torres Strait Islander people who as children were forcibly removed from their families and often institutionalised—may have a 'fear of being caged in'.¹⁴¹ This fear may affect whether people choose to access aged care services even when such services are needed. Aged care needs to be holistic and culturally safe.¹⁴²

To feel secure and obtain culturally safe services, many Aboriginal and Torres Strait Islander people prefer to receive services from Aboriginal and Torres Strait Islander people and from Aboriginal and Torres Strait Islander organisations.¹⁴³ There are not currently enough Aboriginal and Torres Strait Islander people, and other people with high levels of cultural competency, employed across all roles in aged care.¹⁴⁴

When Aboriginal and Torres Strait Islander people overcome the initial difficulties and do get to the point of assessment by the Regional Assessment Service or Aged Care Assessment Team, these assessments may not be culturally safe or sensitive to the complex trauma experienced by so many Aboriginal and Torres Strait Islander people. The assessments may also re-traumatise people or result in incorrect assessments because cultural sensitivities and a lack of trust inhibit the quality of information the assessors obtain.¹⁴⁵ For example, home care assessments are completed at, and based on, the person's functioning at home. This is not appropriate in many Aboriginal and Torres Strait Islander communities where it is not common practice 'for a stranger to be invited into the home'.¹⁴⁶ These experiences may deter other Aboriginal and Torres Strait Islander people from applying for aged care. Some providers noted that it can take a lot of joint, unfunded effort by a trusted organisation to get to a point where an assessment can occur.¹⁴⁷

Ms Noeleen Tunny, Acting Director Policy and Advocacy Unit at the Victorian Aboriginal Community Controlled Health Organisation, explained that those people who are trusted by, and connected to, the community provide vital workarounds for Aboriginal and Torres Strait Islander people who need to deal with My Aged Care. She also said My Aged Care has 'proved disastrous for Aboriginal people'.¹⁴⁸

Regardless of the region of Australia that Aboriginal and Torres Strait Islander people reside in, they experience limited or no choice of specialised service providers. Even in major cities, where there are many mainstream services available, those services may not be culturally safe.¹⁴⁹ It follows that if there appear to be few services that are suitable for Aboriginal and Torres Strait Islander people's needs, then they have little reason to apply for aged care services.

Many Aboriginal and Torres Strait Islander people want to stay on, or near, Country when they age and may choose not to access services if they are unable to stay connected to Country.¹⁵⁰ For Aboriginal and Torres Strait Islander people, there may be external influences that impact on their access to aged care services, including cultural practices, distances between services and communities, environmental conditions, economic barriers and insecure or overcrowded housing.¹⁵¹ These obstacles may be magnified for Aboriginal and Torres Strait Islander people living in geographically remote settings.¹⁵² Aboriginal and Torres Strait Islander people need better, more consistent access to aged care.

2.3.3 Other disadvantaged groups with diverse needs

Many people who come from a range of diverse backgrounds and have had varied life experiences have problems accessing aged care services that meet their particular needs. This includes people from culturally and linguistically diverse backgrounds, veterans, people who are experiencing homelessness or are at risk of becoming homeless, care leavers, and lesbian, gay, bisexual, transgender and intersex people. The existing aged care system is not well equipped to provide care that is non-discriminatory, culturally safe and appropriate for people's identity and experience.

We heard about aged care providers that actively work to meet the needs of diverse groups.¹⁵³ However, we also heard about aged care providers that do not acknowledge the complexity of people's lives. These providers do not provide culturally safe care, that is, care that acknowledges, respects and values people's diverse needs.¹⁵⁴ Across the aged care system, staff members are poorly trained in culturally safe practices, with little understanding of the broad additional needs of people from diverse backgrounds.¹⁵⁵ Language and culture are often a source of difficulty for people receiving aged care.¹⁵⁶ Ms Mary Patetsos, Chairperson of the Federation of Ethnic Communities' Councils of Australia, said that the issues for people from culturally and linguistically diverse backgrounds receiving aged care include:

- (a) Limited or no opportunities to speak their own language on a daily basis;
- (b) Being subject to racial discrimination or harassment from staff or other consumers;
- (c) Specific conditions which limit cost-free access to interpreters;
- (d) Lack of essential in-language information to enable full participation;
- (e) Inability to maintain links with local cultural/social organisations;
- (f) Barriers to practising cultural, religious or end of life practices and traditions; and
- (g) Limited provision of cultural or traditional food preferences.¹⁵⁷

Mr George Akl described the importance of maintaining cultural practices for his father in residential aged care:

During my father's illness, having familiar cultural norms and food made a big impact on his mental health and stabilised his moods. Connection with culture had a significant impact on my father's quality of life outcomes.¹⁵⁸

Mr Akl said that in his experience there was little support for maintaining a connection to culture in aged care.¹⁵⁹ A lack of culturally safe care can mean that older people from diverse groups avoid or delay seeking aged care or, worse, are discriminated against through the process of seeking aged care.¹⁶⁰ For example, Ms Samantha Jewell, Executive Manager – Sales & Marketing at Lifeview Residential Care, recounted the humiliation, shame, and isolation a transgender woman experienced when accessing aged care prior to 'living as herself' in Lifeview.¹⁶¹

We heard that many aged care providers are not equipped to provide trauma-informed care.¹⁶² While many people have experienced trauma, which may be triggered or exacerbated in aged care, people from diverse backgrounds and life experiences are more likely to have experienced trauma.¹⁶³ This is also true for people with mental health conditions and people with disability.¹⁶⁴ Ms Janette McGuire, who was moved into a state-controlled child-welfare institution at the age of 14 years, emphasised the need for understanding and trauma-informed care within the community and by carers of survivors of trauma:

Forgotten Australians don't want much. We just want the government and the community to understand the trauma we suffered as children. This will inform people's ability to care for us when we again enter into a vulnerable time of our lives in old age. We continue to try to move on with our lives. But being a Forgotten Australian means the trauma is always with you. As we get older, our fears become worse. We are becoming more and more terrified of entering aged care.¹⁶⁵

Appropriate communication is necessary for effective assessment, quality of life and care, and safety. Ms Catharina Nieuwenhoven, who had good English proficiency, told us she found it hard to understand the entitlements in her Home Care Package agreement due to the language used.¹⁶⁶ Mr Angelos Angeli said his mother had little access to interpreters in aged care and so had little say in, or understanding of, the care being delivered. This resulted in social isolation.¹⁶⁷

Ms Jaklina Michael, Diversity Manager at Bolton Clarke, described the critical nature of an interpreter to a person's admission and/or assessment to enable effective communication and understand a person's needs. However, she said there is a waiting time to access interpreting services, with possible delays in services.¹⁶⁸ Ms Ruth Crawford, Manager of Kimberley Aged and Community Services, gave evidence that while interpreting services for culturally and linguistically diverse languages are free, that is not so for Aboriginal languages.¹⁶⁹ Dr Sarah Giles, Clinical Director at Danila Dilba Health Service, described this as a 'shameful inequity'. She said that the same funding should be available for Aboriginal languages as it is for other languages.¹⁷⁰ In response to Counsel Assisting's final submissions, the Australian Government advised us that a National Indigenous Interpreting Service is being progressed.¹⁷¹

People without secure housing can also face problems accessing aged care.

Ms Fiona York, Executive Officer at Housing for the Aged Action Group, said there is an assumption built into the aged care system that older people have secure housing to receive home care services, that this housing is owned by the person and, when the time comes to enter residential aged care, it can be sold to fund entry. These assumptions can create barriers to accessing aged care services for those who do not own a home or have stable or appropriate accommodation. Commonwealth Home Support Programme and Home Care Package services can also be difficult to access when a person has insecure or inappropriate accommodation. Ms York said that this can result from a person having no security of tenure, landlords being unwilling to allow home modifications, unaffordability of rent or a perception by the older person of not being able to afford services. It may also be difficult to keep receiving services where a provider deems a home inappropriate or unsafe for its staff.¹⁷²

In 2017, the Australian Government published the Aged Care Diversity Framework, and it has developed subsequent Action Plans. The Framework and Action Plans emerged from broad consultation with people receiving aged care, providers, peak bodies and the then Aged Care Quality Agency.¹⁷³ These are nuanced and encouraging documents. However, they are voluntary. The Framework has now been in place for a number of years. Its introduction has not been a panacea to solve problems in the care received by some people who have diverse needs.¹⁷⁴ It is clear more needs to be done to promote the uptake and proliferation of best practice.

2.4 Aged care and other systems

This chapter deals primarily with problems of access to aged care. However, when a person's access to quality care is dependent on their access to another government-subsidised system, problems may also arise. This is particularly the case where the aged care system interacts with the health care system and the National Disability Insurance Scheme.

2.4.1 Access to health care

People receiving aged care, particularly those living in residential aged care, do not consistently receive the health care they need. This is a result of a number of factors. People receiving aged care have increasing health care needs.¹⁷⁵ Their care needs are often not identified or are identified late.¹⁷⁶ Older, frail people often cannot travel to access health care services and yet health care providers, particularly specialists, are reluctant to provide their services in a person's place of residence.¹⁷⁷ Lack of adequate access to health care affects a person's health and wellbeing and puts pressure on the acute health care system.¹⁷⁸

People receiving aged care have poor access to all types of health care. We heard evidence about problems accessing general practitioners.¹⁷⁹ These problems include general practitioners not visiting aged care, not visiting enough, not visiting in a timely manner, and not spending enough time to provide the type of preventative and holistic care provided. When people move into residential care, they may need to change general practitioners because not all general practitioners visit residential aged care facilities.¹⁸⁰

Without timely access to general practitioners, people with high care needs can suffer. One anonymous submitter described the lack of a timely general practice visit and their mother's painful death:

As it was a Sunday we could not get in contact with her regular medical practitioner (GP) and instead requested that the Aged Care Facility call a doctor at 3.00pm.

We were told that a locum doctor was called and at irregular intervals between 4.00pm and 9.00pm we inquired as to the doctor's whereabouts....

At 9.30pm we could not bear to see mum suffering anymore and requested the aged care facility to call an ambulance. The ambulance arrived at approx. 9.40 and after examining mum determined that she would not make it to hospital and it was decided to ease her pain with morphine. She died shortly after 10.00pm.¹⁸¹

In a submission, a community health nurse outlined her concerns about access to medical care. She said, for example, that local general practitioners:

often refuse new patients as they have large patient lists and my clients are often reduced to walk in GP [general practitioner] practices where they do not get the necessary consistency of GP to provide the overarching management of their many chronic health conditions. What is worse is when my aged clients become housebound due to poor mobility, frailty, dementia, progressive neurological conditions causing physical disability or end of life care. Unless they

have been fortunate to have been seeing a local GP for many years—they will not be able to access consistent GP care at home. GP's will not take on a new client if they are not able to attend the local clinic and even if the clients have been visiting for a period of some years and are now unable to get into the clinic, many GP practices will still refuse, advising that the patients should now contact locum after hours home Dr services. Such after-hours medical services are not a viable option for aged people requiring chronic health management as the clients do not get the same Dr and there is no access to full medical notes. Clients and their families are not easily able to articulate their needs and there is no follow up medical care to evaluate any proposed treatment. After hours locums are useful for emergency care, such [as] a script for antibiotics if an ulcer has developed an infection—but not for management of chronic diseases, such as heart failure, diabetes, ischaemic heart disease and chronic obstructive pulmonary disease.¹⁸²

People in residential aged care find it difficult to access specialist health practitioners such as geriatricians, psychiatrists, cardiologists, and specialist palliative care practitioners.¹⁸³ The Australian Institute of Health and Welfare data shows that older people living in residential aged care have less access to specialist health care than their peers in the community, despite them having much higher levels of care needs. In 2016–17, only 32% of people living in residential aged care facilities received at least one medical specialist consultation, funded by the Medicare Benefits Schedule. During the same period, 74% of older people receiving home support and 65% of older people receiving aged care at home had at least one medical specialist consultation funded by the Medicare Benefits Schedule.¹⁸⁴

Mr Hamish MacLeod, an aged care resident, explained that even though he needed to see a number of specialists, none had ever come to the aged care facility in which he lived.¹⁸⁵ We also heard that people in residential aged care are sometimes denied access to the State and Territory public health services they need.¹⁸⁶ Ms Catherine Davis and Ms Shannon Ruddock spoke about the inability to access specialist palliative care in residential aged care. This resulted in their family members being unable to access adequate pain medication and experiencing considerable, and avoidable, pain and discomfort.¹⁸⁷

Given their high use of medicines, people receiving aged care services, particularly in residential aged care, have inadequate access to pharmacists and medication reviews. Data from the Australian Institute of Health and Welfare shows, for example, that the median number of different medicines taken by people receiving residential aged care in 2016–17 was 11.¹⁸⁸ When a person takes more than one medicine, there is an increased risk of medication side effects, including that one drug may reduce the effectiveness of another or that the combination of drugs may be dangerous.¹⁸⁹

In 2016–17, only 31% of people in residential aged care and 4% of people living in the community and accessing aged care had a medication management review by a pharmacist.¹⁹⁰ A report released by the Pharmaceutical Society of Australia in February 2020 states that over 95% of aged care residents have at least one problem with their medicines detected at the time of a medicines review and over half of residents are prescribed medicines that are considered potentially inappropriate in older people.¹⁹¹ There should be a much greater involvement of pharmacists in aged care, particularly residential aged care, to ensure that people do not have adverse events related to poor medication management.

People receiving aged care, particularly residential aged care, have poor access to mental health services, despite having high rates of mental illness. In 2018–19, about half of people living in residential aged care (49%) had a diagnosis of depression.¹⁹² The prevalence of depression among this group is much higher than the same age group living in the community, where the depression rate for people aged 75 years and over was 7% for men and 12% for women.¹⁹³ People receiving aged care also have the same broad range of mental health conditions as others in the community, including schizophrenia, bipolar disorder, obsessive compulsive disorders, psychotic disorders, autism spectrum disorder, and personality disorders.¹⁹⁴

Suicide rates in residential aged care are also high. A 2018 study by Briony Murphy and colleagues identified 141 suicide deaths in residential aged care in Australia between 2000 and 2013.¹⁹⁵

People may develop mental health conditions while accessing aged care or enter aged care with pre-existing conditions.¹⁹⁶ Many people receiving aged care experience a loss of identity.¹⁹⁷ Many of them experience loneliness and disengagement.¹⁹⁸ These early signs of ill health should be identified and addressed early through targeted, evidence-based interventions. This requires access to mental health services.

Submissions made to us by aged care providers, health professionals, peak bodies, people receiving aged care and their families have identified problems with the mental health services available to older people receiving aged care, particularly residential aged care.¹⁹⁹ This poor access to services can be due to a number of factors, including:

- a lack of understanding of mental health issues by aged care staff members, including personal care workers, nurses and management²⁰⁰
- assumptions by staff members and others that loneliness and sadness are the natural results of ageing²⁰¹
- a lack of mental health practitioners trained in older age mental health²⁰²
- explicit rules preventing people receiving residential aged care from accessing services available to people in the community²⁰³
- eligibility criteria based on an artificial distinction between mental health and dementia²⁰⁴
- limited public funding.²⁰⁵

The model of service provision that has emerged focuses on acute, severe or complex mental health problems at the expense of prevention, early intervention or treating milder forms of mental illness.²⁰⁶

People receiving aged care sometimes lack access to oral and dental health services, which is partly due to a lack of outreach services.²⁰⁷ Lack of access can also be a result of prohibitive costs.²⁰⁸ For example, Ms Beryl Hawkins, who waited two years before receiving a Level 3 Home Care Package, described how the cost of, and a lack of access to, public dental services affected her overall wellbeing and quality of life.²⁰⁹ We heard that less than

half of people who enter residential aged care receive an oral health assessment on entry into residential aged care and that a large number of residential aged care facilities do not have processes in place for dental professionals to visit residents.²¹⁰ Assessments should be undertaken by oral health professionals, who are trained to undertake this task.²¹¹ Dr Martin Dooland AM, a retired dentist and dental health administrator, said there is not sufficient funding for dental services, which means there is not an effective referral pathway for care:

medical practitioners who do visit nursing homes tell me that they look in the mouth at their peril because they might find something for which they have no referral pathway and they tend to go blind, in a sense, and not look for oral health issues. There does need to be a referral pathway funded sufficiently to manage the conditions that will be found by regular assessment. The same is true of the aged care sector. Registered nurses caring for their clients may well do all things we would wish them to do, but if there is no referral pathway of sufficient scale, it won't happen. It will wither on the vine and, eventually, that assessment process will fail because you're assessing things and finding things you can't do anything about.²¹²

People living in residential aged care have unequal or insufficient access to health services to meet their high health care needs. This is particularly concerning given that people living in residential care often experience high rates of complex health conditions. The health and aged care systems are not meeting the expectation that they will provide appropriate health care for older people.

2.4.2 Accessing care for people with disability

Some people living with disability cannot access the level of services they need. The introduction of the National Disability Insurance Scheme has led to positive changes for many people living with disability. However, eligibility is dependent on the nature of a person's disability, their date of birth, postcode or citizenship status.²¹³ There are two key problems. First, some older people receiving aged care cannot receive the services they need because they are not eligible for, or cannot use fully, entitlements under the National Disability Insurance Scheme. Second, more than 1000 younger people with a disability were admitted to residential aged care in the year to 30 September 2020, because they do not have access to the level of disability services they need.²¹⁴

Older people with a disability in aged care may miss out on the disability services they need. This is particularly the case if their disability was acquired after the age of 65 years, if they turned 65 years before the National Disability Insurance Scheme was established in their area, if they are not an Australian citizen, or if their disability does not meet the definition in the *National Disability Insurance Scheme Act 2013* (Cth).²¹⁵

There are inconsistencies between services available under the National Disability Insurance Scheme and those available in the aged care system, especially in terms of access to supported accommodation, aids and equipment. There is much higher funding available for people in the National Disability Insurance Scheme than through aged care. MS Australia observed that, compared with someone aged over 65 years with multiple sclerosis in the aged care system, a younger person with multiple sclerosis 'would be a whole lot better off' because they are in the National Disability Insurance Scheme.²¹⁶

There are also stark differences in the level of care available under each system. Spinal Cord Injuries Australia submitted that the value of a package of care available to someone following a spinal cord injury may be affected by the person's date of birth.²¹⁷ If the person is aged under 65 years, they may be eligible for the National Disability Insurance Scheme and have access to a tailored package. But if they are aged over 65 years, they may only have a capped Home Care Package. We note the evidence of Ms Lynda Henderson, who said that because of the phased rollout of the National Disability Insurance Scheme, the level of care available to her friend Veda was much lower in the aged care system than it would have otherwise been had she accessed the National Disability Insurance Scheme. She described this as 'cruel' and 'unfair'.²¹⁸ It is apparent that older people with a disability do not have equitable access to disability services.

Unlike other access issues discussed in this chapter, the problem of younger people in residential aged care is about people who should not need to access the aged care system at all. There were 4588 people under the age of 65 years living in residential aged care at 30 September 2020.²¹⁹ This included around about 800 people under the age of 55 years, 119 of whom were aged under 45 years.²²⁰ Younger people should not be living in residential aged care, save for very limited exceptional circumstances. The aged care system is not designed, staffed or managed to care for younger people.

The fact that younger people are in residential aged care is not a failure of the aged care system as such, but rather a failure of care systems more broadly. Aged care legislation is deliberately drafted to provide a safety net for people who cannot get services in other places. However, residential aged care has become a default for younger people in circumstances where a better option should be available. Every quarter, over 200 younger people enter residential aged care.²²¹

We acknowledge that since the publication of the Interim Report, the Australian Government has committed to stop the stream of younger people entering residential aged care.²²² However, until this recent change, many younger people who fell through the cracks of the disability system were left with little or no choice but to accept services in residential aged care.

A number of younger people who had lived, or were living, in residential aged care gave evidence about their experiences. They said that they did not want to live in residential aged care, that younger people should not be in residential aged care and that there should be alternate and appropriate accommodation for them.²²³ We agree.

Ms Kirby Littley, who lived in residential aged care in her twenties after an acquired brain injury, said:

I remember feeling like nobody wanted me and that is why I had to go into aged care.

Mum and Dad had attempted to get me into various rehabilitation centres...No one would take me.²²⁴

Residential aged care is not designed to cater for the needs of younger people.²²⁵ Younger people typically have different goals and ambitions to older people in residential aged care. Often these goals are to become more independent and to live in the community. Some witnesses described the negative impact on their mental health of being surrounded daily by people who are dying or nearing the end-of-life, as well as feelings of disconnection from their own generation.²²⁶ Mr James Nutt, who moved into aged care when he was aged 21 years, described the experience of mourning friends he had made in residential aged care:

you make a friend or two, but within a couple of weeks, a week, that would be it. They'd no longer—they would be dead. It's very soul destroying.²²⁷

Younger people who lived in residential aged care, and their families, described the profound loss of independence and lack of choice when living in residential aged care.²²⁸ In aged care, they did not have choice about when they woke up and what they got to do each day, when and what they ate, what they wore. Younger people said they experienced loneliness and social and physical isolation in aged care.²²⁹ They lacked socialisation and suitable leisure and recreation activities.²³⁰ Some younger people likened the aged care environment to living in prison.²³¹ Some said that aged care staff members infantilised younger people in residential aged care or treated them as though they had dementia or a cognitive impairment.²³² We acknowledge that these experiences of poor care— isolation, disrespect and neglect—are not fit for any person, older or younger. These experiences represent substandard care that is unacceptable regardless of age. More fundamentally, as we discuss elsewhere in this report, as a general proposition aged care is inherently unsuitable for younger people.

2.5 Conclusion

Too often, older people are not able to access the care they need. The aged care system remains difficult to enter and navigate, particularly for those people with communication difficulties. There are not enough Home Care Packages or respite services to meet demand. Allied health services are underused and undervalued across the aged care system. People from groups already at a greater disadvantage are at risk of missing out on care that meets their particular needs. It is also difficult to access a broad range of health services for many people receiving aged care, and older people with a disability do not have equitable access to the care they need.

One of the key measures of success for the future aged care system will be that every older person can access the care they need, of the appropriate type, when they need it.

Endnotes

- 1 See, for example, Exhibit 2-34, Adelaide Hearing 2, Statement of Marie Dowling, WIT.0077.0001.0001 at 0009 [21]; Exhibit 10-18, Melbourne Hearing 2, Statement of Heather Brown, WIT.0537.0001.0001 at 0002 [8]–[11]; Exhibit 1-63, Adelaide Hearing 1, Statement of Barrie Anderson, WIT.0030.0001.0001 at 0002 [14]; Name withheld, Public submission, AWF.001.00231 at 0001; Joanna Shaw, Public submission, AWF.001.01660 at 0001; Name withheld, Public submission, AWF.001.02253 at 0001.
- 2 Productivity Commission, *Caring for Older Australians*, 2011, Vol 1, p lxxxv (Exhibit 1-32, Adelaide Hearing 1, RCD.9999.0011.1031).
- 3 Productivity Commission, *Caring for Older Australians*, 2011, Vol 1, pp xxix–xxx (Exhibit 1-32, Adelaide Hearing 1, RCD.9999.0011.1031).
- 4 Australian Department of Health, *Australian Government Response to the Productivity Commission's Caring for Older Australians Report*, 2012, pp 15–17.
- 5 Transcript, Mildura Hearing, Lyn Phillipson, 30 July 2019 at T4025.31–39; T4027.19–23; Exhibit 7-1, Mildura Hearing, general tender bundle, tab 29, RCD.9999.0130.0001 at 0005.
- 6 Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, 2019, Vol 1, pp 123–140.
- 7 See, for example, Transcript, Adelaide Hearing 2, Raelene Ellis, 18 March 2019 at T696.1–9; Exhibit 2-15, Adelaide Hearing 2, Statement of Josef Rack, WIT.0068.0001.0001 at 0004 [28]; Transcript, Perth Hearing, Shannon Ruddock, 27 June 2019 at T2631.16–19.
- 8 Transcript, Adelaide Hearing 1, Maree McCabe, 19 February 2019 at T406.6–8; Transcript, Adelaide Hearing 2, Raelene Ellis, 18 March 2019 at T696.1–9.
- 9 Transcript, Adelaide Hearing 2, Rita Kersnovske, 21 March 2019, T1003.7N12.
- 10 Australian Department of Health, *Updates to My Aged Care*, 2020, <https://www.health.gov.au/initiatives-and-programs/my-aged-care/updates-to-my-aged-care#recent-updates>, viewed 4 January 2021.
- 11 Exhibit 17-1, Melbourne Hearing 4, general tender bundle, tab 29, CTH.1000.0004.0739 at 0777 [131]–0779 [141].
- 12 Transcript, Adelaide Hearing 2, Marie Dowling, 20 March 2019 at T908.1–4.
- 13 Transcript, Mildura Hearing, Lyn Phillipson, 30 July 2019 at T4026.11–14.
- 14 Exhibit 10-3, Melbourne Hearing 2, Statement of Samantha Edmonds, WIT.0396.0001.0001 at 0024 [110b]; Exhibit 10-5, Melbourne Hearing 2, Statement of Noeleen Tunny, WIT.0422.0001.0001 at 0012 [36].
- 15 Australian Department of Health, *Fact sheet – Service Compliance Ratings: Information for Residential aged care service providers*, 2020, pp 1–2.
- 16 Transcript, Adelaide Hearing 1, Ian Yates, 11 February 2019 at T51.4–16.
- 17 Transcript, Sydney Hearing 1, Glenn Rees, 13 May 2019 at T1547.1–7.
- 18 Exhibit 10-23, Melbourne Hearing 2, Statement of Elizabeth Drozd, WIT.0449.0001.0001 at 0007 [26]–0008 [27]; National Seniors Australia, *Dealing with diversity: Aged care services for new and emerging communities*, 2018, pp 5–6 (Exhibit 10-1, Melbourne Hearing 2, general tender bundle, tab 29, CTH.0001.1001.2291).
- 19 Transcript, Melbourne Hearing 2, Janette McGuire, 8 October 2019 at T5457.33–45; T5458.33–41; T5459.14–18; T5459.26–37; T5461.45–5462.6; Transcript, Melbourne Hearing 2, Heather Brown, 9 October 2019 at T5535.36–41; T5536.42–46; T5537.14–15; Exhibit 10-4, Melbourne Hearing 2, Statement of Mary Patetsos, WIT.0437.0001.0001 at 0017 [113]–[114]; Exhibit 10-23, Melbourne Hearing 2, Statement of Elizabeth Drozd, WIT.0449.0001.0001 at 0006 [25]; 0007 [26]–0008 [27]; Exhibit 4-9, Broome Hearing, Statement of Ruth Crawford, WIT.0185.0001.0001 at 0016 [90]–[90.6]; Transcript, Sydney Hearing 1, Glenn Rees, 13 May 2019 at T1550.13–21; Transcript, Adelaide Hearing 2, Marie Dowling, 20 March 2019 at T908.9–18.
- 20 See, for example, Transcript, Broome Hearing, Ruth Crawford, 18 June 2019 at T2112.19–2113.11; Transcript, Broome Hearing, Leon Flicker, 17 June 2019 at T2035.20–39; Exhibit 4-8, Broome Hearing, Statement of Graham Aitken, WIT.1134.0001.0001 at 0009 [71].
- 21 Exhibit 10-25, Melbourne Hearing 2, Statement of Catharina Nieuwenhoven, WIT.0515.0001.0001 at 0005 [37]–[39].
- 22 Australian Department of Health, *Aged Care System Navigator Measure*, 2020, <https://www.health.gov.au/initiatives-and-programs/aged-care-system-navigator-measure>, viewed 5 January 2021.
- 23 Australian Department of Health, *Evaluation of the Aged Care System Navigator Measure: Interim Report*, 2020, p 4.
- 24 Productivity Commission, *Report on Government Services 2020*, 2020, Part F, Section 14, Table 14A.26.
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3. The Nature and Extent of Substandard Care

3.1 Introduction

Our Terms of Reference require us to inquire into:

the quality of aged care services provided to Australians and the extent to which those services meet the needs of people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response.¹

To do this, we needed to understand people's experiences of aged care. Many older people and their loved ones have said that aged care has not met their needs and expectations: that it was substandard. Understanding the extent of substandard care across the aged care system has been an important part of our work. We have identified key areas where older people are receiving substandard care, and why this is so. This chapter sets out our conclusions on these issues.

At the beginning of this inquiry, Ms Glenys Beauchamp PSM, the then Secretary of the Australian Department of Health, said that based on the 'evidence and information available to the Department...serious instances of substandard care do not appear to be widespread or frequent' and that 'the aged care system broadly does meet the needs of older Australians'.² We disagree.

We heard from many people about substandard care—those who experienced it, family members or loved ones who witnessed it or heard about it, aged care workers, service providers, peak bodies, advocates and experts. We heard about substandard care during hearings and community forums. We also heard about it in public submissions.

The accounts of substandard care were often sad and confronting. They were often difficult to tell and difficult to hear and read. We acknowledge the courage people have shown in sharing their experiences with us. Their contributions have been essential to our inquiry and we are grateful.

The extent of substandard care in the current aged care system is deeply concerning and unacceptable by any measure. The current system is deficient in its ability to measure the quality of care. Based on the available data, Commissioner Briggs concludes that at least 1 in 3 people accessing aged care has experienced substandard care. Commissioner Pagone does not put a specific figure on the extent of substandard care. We both consider that the extent of substandard care is inexcusably high.

In this chapter, we first explain what we heard about substandard care from those who experienced or witnessed it. We then set out our conclusions on the extent of substandard care in the current aged care system. Our analysis of the nature and extent of substandard care informs our conclusions about the systemic problems within the Australian aged care system, which we discuss in Chapter 4 of this volume. Our recommendations for change are outlined in Volume 3.

3.2 What is substandard care?

The term ‘substandard care’ appears in our Terms of Reference, and has a commonly understood meaning as care which is inadequate or inferior. But it is not a term formally defined or used in aged care policy in Australia. So, there are inherent challenges in identifying and quantifying the extent of substandard care.

Both Ms Beauchamp and the Aged Care Quality and Safety Commissioner, Ms Janet Anderson PSM, said that ‘substandard care’ is not a term used in Australian aged care policy and regulatory settings.³ Ms Beauchamp said that the Australian Department of Health ‘understands “substandard care” to mean care provided by an approved provider which does not meet the quality standards’, which are set out in the *Quality of Care Principles 2014* (Cth) or ‘relevant quality standards’.⁴ Ms Anderson had a similar view.⁵

In our view, substandard care has a broader meaning than care that does not meet the requirements of the Australian legislative framework for aged care. Our Terms of Reference state that Australians ‘expect high standards of quality and safety from our aged care services’.⁶ The current Aged Care Quality Standards or the previous Aged Care Accreditation Standards do not set a sufficiently high bar.

For the purpose of the Service Provider Survey that Commissioners McGrath and Briggs initiated, substandard care was defined as:

- care (or complaints about care) which did not meet the relevant quality standards under the Quality of Care Principles and other obligations under the *Aged Care Act 1997* (Cth)
- care (or complaints about care) which, although meeting the relevant quality standards under the Quality of Care Principles and other obligations under the Aged Care Act, was not of a standard that would meet the high standards of quality and safety that the Australian community expects of aged care services.⁷

This was also the definition adopted by Commissioners Tracey and Briggs in the Interim Report.⁸ In applying this definition of substandard care:

- we do not consider that there needs to be a risk of harm to the health or safety of a person for care to be substandard
- we take substandard care to be something less than would be required for a finding under section 63N(3)(c) or (d) of the *Aged Care Quality and Safety Commission Act 2018* (Cth), that a provider’s conduct has threatened or would threaten the health, welfare or interests of people receiving care

- we have taken into account findings from the Caring Futures Institute survey which Commissioners Tracey and Briggs commissioned to look into people's views on aged care quality and funding.⁹

In Volume 3, Chapter 3, we define the concept of high quality aged care, taking into account the community's expectations. In summary, high quality aged care puts older people first. It is a standard of care that meets the particular needs, aspirations and preferences of people receiving aged care. To achieve this, it needs to:

- be delivered with compassion and respect for the individuality and dignity of the recipient of care
- be personal to the person receiving care and designed to respond to their expressed personal needs, aspirations, and their preferences regarding the manner by which their care is delivered
- be provided on the basis of a clinical assessment, and regular clinical review, of the older person's health and wellbeing, and that the clinical assessment will specify care designed to meet the individual needs of the person receiving care, such as risk of falls, pressure injuries, nutrition, mental health, cognitive impairment and end-of-life care
- enhance to the highest degree reasonably possible the physical and cognitive capacities and the mental health of the person
- support the person to participate in recreational activity and social activities and engagement.

3.3 What we heard about substandard care

Experiences of substandard care are varied. We have analysed the qualitative information and evidence from hearings, public submissions, community forums, the Service Provider Survey and our research program and have identified 15 common areas where substandard care occurs in the aged care system. These areas relate to both the routine care that people receive, such as oral and dental health, as well as more complex care required for people living with dementia and those requiring palliative and end-of-life care.

We also consider abuse in this discussion of substandard care because our Terms of Reference require us to inquire into 'the extent of substandard care being provided, *including mistreatment and all forms of abuse*' (emphasis added). In our view, abuse is an extreme example of substandard care and reaches into the realm of criminal behaviour. As the Australian Law Reform Commission noted in its report into elder abuse, *Elder Abuse—A National Legal Response*, mistreatment is more likely to be a cultural issue than a 'bad apple' problem and ensuring quality of care 'is perhaps the best safeguard against abuse and neglect'.¹⁰

Our analysis of areas of substandard care is not intended to be exhaustive. Many people have experienced care that did not meet their expectations in ways that are not included here.

The accounts we received at hearings and in public submissions rarely raised only one form of substandard care, and often highlighted the compounding impact of poor care. We know that poor care in one area can affect many others, creating more complex care needs. Dr Sandra Iuliano, Senior Research Fellow at the Department of Medicine, University of Melbourne, explained that malnutrition can lead to reduced muscle strength and increased frailty.¹¹ Ms Sharon Lawrence, an Accredited Practising Dietitian with the Dietitians Association of Australia, noted the link between poor nutrition and pressure injuries due to a lack of protein, resulting in loss of muscle mass, reduction in the body's ability to repair skin and a compromised immune system, which increases the risk of infection.¹² Dr Joan Ostaszewicz, Research Fellow at Deakin University in the Centre for Quality and Patient Safety Research, explained that pressure injuries can result from poor continence management due to incontinence-associated dermatitis.¹³

In presenting people's accounts, we recognise the inherent connection between a person's health and their quality of life. Clinical and personal care can enable better health, which will lead to an improved quality of life. Care that enables a better quality of life is associated with better health outcomes. We also recognise that even where people may receive adequate clinical care, this care may be delivered in such a way that lacks respect or empathy and does not meet their social and emotional needs.

In this chapter, we highlight accounts we received as well as expert evidence to reach general conclusions about particular types of substandard care. We do not make any findings about specific instances of substandard care. However, we have made findings about particular instances of substandard care in case studies and we draw on that work here. Case study findings are set out in Volume 4 of this report.

3.3.1 Abuse

In its report on elder abuse, the Australian Law Reform Commission highlighted the prevalence of abusive practices within the aged care system and criticised gaps in the regulatory and reporting systems that allowed these practices to persist.¹⁴

The abuse of older people in residential care is far from uncommon. In 2019–20, residential aged care services reported 5718 allegations of assault under the mandatory reporting requirements in section 63-1AA of the Aged Care Act.¹⁵ A study conducted by consultancy firm KPMG for the Australian Department of Health estimated that a further 27,000 to 39,000 assaults occurred that were exempt from mandatory reporting.¹⁶ We detail more about this data in our examination of the extent of substandard care later in this chapter.

Most of what we heard about abuse related to people living in residential aged care. However, the Hon Dr Kay Patterson AO, Age Discrimination Commissioner at the Australian Human Rights Commission, highlighted that abuse is also perpetrated against people receiving aged care in the home. She said attention must be given to how to protect people who receive services in their own homes, given there are no other staff members around to identify and report potential abuse.¹⁷ Several public submissions highlighted this issue.¹⁸

Our analysis of abuse below focuses on physical abuse, sexual abuse and restrictive practices. However, it is also important to acknowledge the impact of other forms of abuse. For example, Ms Gwenda Darling, an Aboriginal woman who received care at home, relayed her experience of being racially abused by a care worker:

I was called a 'boong' on a couple of occasions by the care worker who would come to my house...To me, calling a person a 'boong' is one of the most offensive things you can say to an Aboriginal person.¹⁹

Physical abuse

We heard of physical abuse that occurred at the hands of staff members, and of situations in which aged care providers did not protect residents from abuse by workers or other residents. Ms Noleen Hausler gave evidence about the experience of her father, Mr Clarence Hausler, who was living with dementia. Because Ms Hausler held suspicions about the care her father was receiving, she installed a hidden camera in his room. The footage revealed that her father was physically assaulted three times over 10 days. On one occasion, a personal care worker made aggressive physical contact with Mr Hausler's head. Another incident involved the same carer's use of unreasonable force while he was changing Mr Hausler's continence pad.²⁰ On a different occasion, an agency nurse, while feeding Mr Hausler, repositioned him by wrenching his right arm to pull him into an upright position. She then jerked his head sideways to put the pillow behind his head, then pushed his head back using the palm of her hand on his forehead to hyperextend his head.²¹ Commissioners Tracey and Briggs found that Mr Hausler was 'the subject of a series of degrading assaults'. They said:

beyond the indignity and criminality of the assaults committed against her father, Ms Hausler had to contend with an organisation determined to avoid accountability for its actions.²²

Ms Lisa Backhouse gave evidence that three months after her mother, Mrs Christine Weightman, had moved into a new facility, Ms Backhouse received a call to advise her that one of the carers had hit her mother. A few weeks later, another carer hit Mrs Weightman twice on her upper leg, with intent and force.²³

Public submissions described examples of physical abuse in residential aged care. One woman, whose father lived in residential aged care, wrote that the facility did not take seriously her complaint about rough handling of her father.²⁴

We received submissions from people who, as students or employees in residential aged care, had witnessed abuse.²⁵ One work experience student gave the following account:

One of the staff was trying to undress a very frail lady who only weighed about 45kgs. Her night dress was literally being yanked off her. The lady was wincing in pain and was thrown around like a rag doll. Arms and legs were flying in all directions and she was picked up and literally thrown down on the bed. All the time she was yelled at. The lady was whimpering like a wounded animal.²⁶

Ms DF gave evidence about two incidents involving her mother, Mrs CA, who was living with dementia.²⁷ In the first incident, Mrs CA sustained a cut to her mouth after another resident struck her following an altercation over clothing. The second incident occurred when Mrs CA entered another resident's bedroom. It is unclear exactly what occurred because the residents were not under 'immediate supervision' at the time. Mrs CA's head and body made forceful contact with the floor, resulting in heavy bleeding from her head.²⁸ Both incidents involved residents living with dementia and living in a secure dementia section.

Ms Kathryn Nobes, a personal care worker, described an incident in which one resident killed another at the facility where she worked. She said she had been standing in a corridor with another care worker when she saw a resident come towards them 'holding a walking stick in his right hand like it was a club'. He had blood on his knees, face and hands.²⁹

We received many public submissions that raised concerns about a failure to protect residents from other residents. Submissions frequently referenced a lack of staff members available to prevent resident on resident abuse. One person told us:

Assault on my mother by another resident: My mother was hit twice by another resident quite harshly. The facility failed to isolate the issue when it first happened and therefore it happened twice. Both times occurred on Public Holidays when they had limited staff.³⁰

Another submission stated:

My father told me that when the man entered his room, he told the man to leave his room. The man then hit my father over his head several times with a plastic doll, resulting in a small cut to my father's forehead, bruising across the bridge of his nose and defensive bruising on his forearms. There were no staff around at the time the incident occurred.³¹

Sexual abuse

The accounts of sexual abuse that we heard about were deeply concerning.

Ms Lisa Corcoran, who moved into residential aged care when she was in her late 30s, gave evidence that she was sexually and physically assaulted while living in aged care.³²

'Elizabeth', a registered nurse, recounted an incident where a female resident living with dementia wandered into another resident's room and was sexually assaulted.³³

Ms Susan Walton, an assistant in nursing, gave evidence about a resident living with dementia who was 'wandering, sexually advancing towards ladies'.³⁴

A number of public submissions included accounts of sexual abuse of people by residential aged care staff members. The following account was provided by the wife of a man living in residential care:

My 71 year old husband is a resident in aged care because of advanced Parkinson's disease. On the night of December 31 2018 he was horrifically sexually abused by 2 night duty staff resulting in a very red, swollen and grazed penis. 1 nurse a female held him down while the other, a male masturbated him. He is frightened, withdrawn and very distressed.³⁵

One woman wrote to tell us that her mother was the victim of sexual assault in residential aged care:

she was repeatedly subjected to sexual assault by the night staff. She was so terrified of them that she would not tell me at first about what was happening. The men involved had threatened to kill her if she spoke about what they were doing. This was also happening to the woman in the room with her. Sexual assault in nursing homes is something that needs to be brought into open discussion.³⁶

A number of public submissions outlined incidents of sexual abuse between residents. One person who made a submission said a staff member had told her:

As she [staff member] moved closer, she saw that the male person, who she recognised as the man who occupies the room across the hallway, had his hand placed inside the incontinence pad and underwear that our mother was wearing.³⁷

Another person described an incident where his mother was sexually assaulted:

The latest was a sexual assault which occurred whilst she was in her room in her bed, perpetrated by one of the other residents who was able to wander freely into her room and assault her.³⁸

The use of restrictive practices

Restrictive practices have been identified as a problem in aged care in Australia for more than 20 years. Their use has been considered in several reviews. Many recommendations for reform have been made but not fully implemented.³⁹ Restrictive practices are activities or interventions, either physical or pharmacological, which restrict a person's free movement or ability to make decisions.⁴⁰ Where this occurs without clear justification and clinical indication, we consider this to be abuse. Not only do restrictive practices have questionable success in minimising changed behaviours, they can result in serious physical and psychological harm, potentially increasing health complications and, in some cases, can cause death.⁴¹ Their inappropriate use is substandard care. Physical restraint should be used only where it is absolutely necessary to protect a person from a serious and imminent risk of harm. The Australian Commission on Safety and Quality in Health Care recommends that prescribing antipsychotic medicines for older people as a form of restrictive practice should only occur as a last resort.⁴²

Aged care providers, as well as prescribers of medication, sometimes misuse restraints in place of other more resource-intensive interventions that would maintain the dignity and personal autonomy of residents.⁴³ For example, the approved provider of the Earle Haven aged care facility on the Gold Coast disclosed, when asked in June 2019, that 71% of its residents received psychotropic medication and 50% were physically restrained.⁴⁴ We discuss the extent of the use of physical restraint in our examination of the extent of substandard care later in this chapter.

Chemical restraint

Particular medicines may be prescribed for treating psychotic symptoms in residents of aged care. However, we heard that in many cases these medicines are used inappropriately to restrict a person's movements if they are experiencing changed behaviours because of dementia.⁴⁵ These medicines also restrict a person's ability to make decisions. The most common type of medicines that can have this effect are psychotropic medicines, which are capable of affecting the mind, emotions and behaviours of a person. These medicines include sedatives, antidepressants, antipsychotics, mood stabilisers and anti-anxiety agents. Antipsychotics and benzodiazepines are most commonly referred to in the context of 'chemical restraint' in residential aged care.⁴⁶

We heard many instances of antipsychotic drugs, such as risperidone, and a range of sedatives, being used to manage changed behaviours of people living with dementia. Mrs Barbara Spriggs gave evidence about the experience of her husband, Mr Robert Spriggs, at the Oakden Older Persons Mental Health Service. Mrs Spriggs said Mr Spriggs received medicine to sedate him and that other patients 'appeared sedated'. In Mrs Spriggs's view, 'this was done by staff to ease the management of residents'.⁴⁷ Ms Rosemary Cameron gave evidence about an incident involving her husband, Mr Don Cameron, who lived with Lewy body dementia, when he was in respite care:

I found him face down on the floor, out to it. And...he was so heavily sedated, they had left him in an upright chair in the lounge area and he had just fallen forward out. His face was quite bruised, and he was in a really bad way. And often when I would ask, 'Has he had any extra medication?' I would be told that they, no, they didn't think so, that he had just had a bad night, and he was very tired. But then when I would check closer and ask to see what the medications had been I would find that that was quite different, that he had, in fact, had extra.⁴⁸

Many family members told us about the effects of inappropriate medication use for their relatives. We received public submissions saying aged care residents had at times been over medicated.⁴⁹ One woman described the effects of increased medication on her mother:

What I do know for absolutely sure now is that mum, who three weeks ago waited in anticipation for family to arrive, spent every day talking, laughing, reminiscing and going on outings and being engaged with life, is now drugged to the eyeballs.⁵⁰

Another woman detailed the medication her father was prescribed when he was in respite care. She said that he was prescribed multiple medications, including risperidone, quetiapine, oxazepam, haloperidol and temazepam, despite him not having any psychotic symptoms. The aged care and medical staff members did not obtain informed consent from the family prior to prescribing and administering these medications. The woman said her father was so heavily 'sedated that he could hardly move', was confused and agitated, unsteady on his feet and non-interactive.⁵¹

Many other submissions suggested that medication was used as a strategy to manage workload and changed behaviour.⁵² One woman described her father being chemically restrained 'to manage the workload' while he was living in residential aged care in New South Wales. She called this 'appalling' and suggested that 'no one cares'.⁵³

An anonymous submission from a woman described the effects of chemical restraint, including the loss of her mother's independence:

For the first week mum was in the high care ward she was heavily sedated—I mean couldn't talk and couldn't keep her eyes open or head up! which was a shock as just the day before she was having very normal conversations and meeting with her friends out in the general area. When I questioned staff, they said she was unsettled so they gave her some drops on her tongue to keep her calm. Of course you believe them as they are the professionals with training to look after our elderly...Mum never recovered back to where she was the day before she went into the high care area, she couldn't walk unassisted, she couldn't talk or communicate in any way, couldn't eat.⁵⁴

Physical restraints

Witnesses at hearings described traumatic experiences of seeing loved ones physically restrained in residential aged care. Ms Michelle McCulla said that despite being assured that her father, Mr Terance Reeves, would only be restrained for short periods of time and in 'last resort' circumstances, he was routinely restrained.⁵⁵ A number of public submissions also detailed people's experiences with physical restraints.⁵⁶ One woman wrote that her husband was restrained for much longer periods of time than what she was led to believe would be the case when she gave consent for the use of a lap belt:

I sign permission for [name removed] to have a seatbelt on his wheelchair, expecting it to be used only when he is in transit. I am assured that it will not be left on him all day, but every time I go to see him, at different times every day, he is strapped down. It looks like the staff, at each new shift, just leave him as they find him. He is trussed tightly around his legs and body, the strap in the middle biting deeply into him. This makes it extremely difficult for me to take him to the bathroom, or for him to eat at table. He has no exercise, and his mobility is affected. He is constantly agitated, asking me and others to set him free.⁵⁷

The following submission from a friend of an aged care resident explained the distress experienced by the restrained person, as well as the reasoning a staff member used to justify the restraints:

While many of the staff seemed caring, one day I arrived to find [name removed] in a chair with a bar put down across it. She kept trying to get out and sliding down. She seemed distressed. She was effectively trapped in the chair and could not get out.

One of the staff came along while I was trying to work out what was happening and said that it was 'easier' to do this at change of shift, to stop [name removed] 'wandering'.⁵⁸

Conclusion: abuse and restrictive practices

Australians deserve an aged care system that protects older people from abuse and inappropriate restrictive practices. The evidence about abuse of vulnerable people in aged care has been some of the most difficult for us to hear. The aged care system must have safeguards built in to protect older people from abuse.

The inappropriate use of unsafe and inhumane restrictive practices in residential aged care has continued, despite multiple reviews and reports highlighting the problem. It must now be stopped.

3.3.2 Complex care

Many people living in residential aged care will have care needs that extend beyond assistance with day-to-day self-care. Complex care needs arise when people require support that is less predictable or requires more skilful care. This includes, for example, escalations in clinical conditions such as changed behaviour associated with dementia, chronic disease, pain management, or palliative care and end-of-life care.

An older person's complex care needs are likely to require input from health care specialists as well as members of their family and community. This input may be required in all or only some aspects of the assessment, planning, provision and review of care. We heard that residential aged care facilities often fail to deliver, facilitate or coordinate care to meet the complex care needs of residents. The most common areas of substandard complex care we heard about involve dementia and changed behaviours, mental health, and palliative care.

Dementia

Dementia is an umbrella term which describes symptoms associated with a group of major neurocognitive conditions or disorders of the brain. It results in deterioration in memory, thinking, behaviour, communication and the ability to perform day-to-day activities. Changed behaviours are a varied group of behaviours and symptoms that are common to many people as the severity of their dementia advances. Changed behaviours may include agitation or extreme restlessness, physical and verbal aggression, wandering, social and/or sexual disinhibition, delusions, apathy, depression, and/or anxiety. These actions and behaviours may be mild, moderate or severe in nature and are unique to each person.

Dementia care should be part of the core business of aged care services, and particularly residential aged care services. This is because over half of people living in residential aged care have a diagnosis of dementia.⁵⁹ Associate Professor Stephen Macfarlane, Head of Clinical Services at HammondCare, said he thought the proportion of people with dementia in residential care could be as high as 70%, given the prevalence of undiagnosed dementia.⁶⁰ Yet substandard dementia care was a persistent theme in our inquiry. We are deeply concerned that so many aged care providers do not seem to have the skills and capacity to care adequately for people with dementia.

Poor dementia care

Much of what we heard about substandard dementia care related to the ways in which staff members treated people living with dementia. In some cases, this involved the application of restrictive practices. Poor responses by staff members to changes in behaviour were exemplified by Ms McCulla's evidence about an incident she witnessed involving her father, Mr Reeves:

As I was walking him out I noticed his pants were wet, and that he was wet. This was the first time I had noticed he was in an incontinence pad. He was toileting himself the last time I had seen him. I told the nurse he is wet through and would need to be changed, and she took him away and she said, 'Okay, we'll sort that out'. So I went and sat outside in the courtyard with my girlfriend and waited. And then another nurse, different from the first two that I had seen that

day, called for me from a resident's window, I think, called me and said 'Can you please come inside and see this.' As I quickly jumped up and rushed inside and had to go out of the locked East Wing and into a corridor and into a bathroom, she said, 'Don't be upset by what you see', and by that stage I could hear dad yelling, saying, 'Stop it, stop it'.

I walked in and there would have been about six—six nurses hanging onto him. He had one on each leg, one on—holding both his arms, and this other nurse said to me, 'Maybe if he sees you he will settle down.' And another one was grabbing his pants and pulling them down. They were just all hanging off him. There was a lot of yelling and screaming and dad saw me and... he got an arm free and grabbed hold of my arm and he started saying 'No. No. Stop it.' It was very traumatic for him and for me. They sort of rushed, got it all finished, pulled his pants back up. When I turned around my girlfriend was standing in the doorway of the bathroom, and all the nurses left and dad grabbed my arm and said, 'How would you like it?' and my girlfriend said to him 'No, I wouldn't like it either.' And that was that.⁶¹

Public submissions also expressed concerns about staff treatment of people living with dementia.⁶² One woman described how she witnessed a nurse being rough with her father, who lived with dementia:

I witnessed a nurse's aggressive behavior of my Dad whilst she was trying to take his temperature in his ear to which he kept putting up his hand to brush away whatever it was that was getting in his ear, not unlike anyone brushing away an annoying fly. The nurse had tried a few times and got to a point where by she aggressively grabbed my Dad's hand and shoved it away whilst chastising him for his behavior. It bothered me to the point that I said to her 'Excuse me, that's a [bit] rough don't you think' to which she replied. 'It's okay, we know how to treat them here' to which I then bent down, looked her squarely in the face and replied, 'NOT LIKE THAT YOU DON'T'. I later made it known to a senior staff member in Dad's section only to find out weeks later that absolutely no report had been made whatsoever.⁶³

Staff members and other health practitioners detailed the difficulties they face in responding to aggression from people living with dementia. Many felt that they are not appropriately trained or supported. Ms Nobes recounted her experience of being assaulted by a resident living with dementia and raising it with her employer:

When I informed my In-Charge that I had been assaulted by a resident, the In-charge shrugged their shoulders and said 'That's dementia'. This has happened on different occasions; I think there's an overriding culture in aged care of simply shrugging it off.⁶⁴

We heard about some providers not addressing the unmet needs of people living with dementia, which can give rise to changed behaviour. Mrs Annunziata Santoro was diagnosed with dementia after she entered Assisi Aged Care. To help her mother adjust to life at Assisi Centre, Ms Anamaria Ng made a 'social story' for Mrs Santoro. It was a photograph album designed to help Mrs Santoro understand who she was and who the people around her were. Ms Ng found that going through the album with her mother helped to settle her. Ms Ng said that although she encouraged staff members to look at the album with her mother, particularly when her mother was upset, she never once saw them do so.⁶⁵ Commissioners Tracey and Briggs found that staff members 'did not make use of all available means to properly manage Mrs Santoro's agitation and other behaviour associated with dementia'.⁶⁶

Ms Tamar Krebs, Co-Chief Executive Officer of Groups Homes Australia, gave this evidence:

we had...a 74 year old gentleman who was living in residential aged care. And the facility called us and said he was displaying severe BPSD, behavioural and psychological symptoms of dementia, and that he was throwing furniture, he was scaling fences. ...when he moved in we identified that this was a tradesperson and he was used to waking up very early in the morning and doing physical activities.

And what was happening in the facility that he was living, he was sitting idle and playing bingo, and so he was becoming more aggressive. And so the environment and activities were, essentially, triggering him. And so we brought him a small bucket of paint and a small paint brush and we asked him to paint the fence of the home, in consultation, obviously, with the family and them agreeing. And he ended up doing physical work. Every day he would wake up really early in the morning, he would do the fence, he would do—we have a pool in that house, and so he would tend to the pool, do gardening.⁶⁷

Ms Kate Swaffer said that when her father-in-law, who was diagnosed with dementia, entered respite care he was not allowed to go outside, even though he had always been a very active man who wanted to continue to enjoy the outside world. Ms Swaffer, who herself lives with dementia, explained that her father-in-law's behaviour was misunderstood and he was labelled an 'absconder'.⁶⁸

Experts and academic witnesses described the aged care system as failing to manage changed behaviours associated with dementia. According to Associate Professor Macfarlane, 'In general terms, the more severe' the behavioural and psychological symptoms of dementia, 'the less likely the person living with dementia is receiving quality and safe care'.⁶⁹

Changes in behaviour are usually an expression of unmet need, including untreated pain, interaction with the physical environment and unmet psychological needs.⁷⁰ It is clear to us that environmental factors such as too much stimulation or lack of privacy or an institutionalised environment, commonplace problems in Australian residential aged care homes, have an exacerbating effect.⁷¹ Many residential facilities are not suited to providing care for people with dementia despite the prevalence of dementia in residential aged care.

Associate Professor Edward Strivens, President of the Australian and New Zealand Society for Geriatric Medicine, explained that the starting point for addressing changed behaviour should always be non-pharmacological management based around identification of the areas of unmet needs and enablement principles.⁷² The growing body of evidence and consensus about best practices indicates that, throughout all stages of dementia, people can respond favourably to exercise, eating well, and staying as independent and socially connected as possible, along with the provision of caring and supportive relationships and meaningful activities in safe and pleasant environments.⁷³

Conclusion: dementia care

Dementia care in the aged care system needs significant improvement. Staff often do not have the time or the skills to deliver the care that is needed. The response is often to rely on restrictive practices, which restrict a person's freedom and diminish their quality of life. Older people living with dementia deserve far better.

Mental health

We heard that the needs of older people with mental health conditions are not being adequately addressed across the aged care system. Professor Strivens said that about 10% of older people in Australia have symptoms of depression and anxiety, but that rises to up to 50% in residential aged care.⁷⁴ Mr Harry Lovelock, Director of Policy and Projects at Mental Health Australia, said that about half of all clinical cases of depression amongst people in residential aged care go undetected and untreated.⁷⁵ We refer to data relating to the prevalence of pharmacological interventions to treat mental health conditions in residential care in our examination of the extent of substandard care later in this chapter.

Promoting mental health in the aged care system

Caring for and ensuring older people's social and emotional wellbeing contributes to positive mental health and prevents mental illness. Physical wellness, and interventions to promote social and emotional wellbeing, such as opportunities for social engagement, can help prevent loneliness, boredom, depression and anxiety.⁷⁶

Various psychological interventions and therapies can be effective in treating mental health conditions in older people. Generally, these are provided through consultation with a psychologist.⁷⁷ Treatments include reminiscence, life review, life review therapy, cognitive behaviour treatment and behavioural activation.⁷⁸ Medicines can also be beneficial for some older people experiencing mental illness. However, treatment should be clinically indicated and there should not be an over-reliance on medicines. It is extremely important for older people to have access to medical professionals such as psychiatrists, who have a deep understanding of the complex interaction between physical and mental illness and of potential side effects of different medications, including psychotropic medication.⁷⁹ People living in residential age care should have access to the same mental health support as all members of the community.

Identifying and responding to mental health conditions

We heard a number of accounts describing problems associated with identifying and responding to mental health needs. Dr Alison Argo, clinical neuropsychologist, told us that without appropriately skilled staff, mental health conditions in older people living in the community and in residential aged care will continue to be under-identified.⁸⁰

Ms UX described her mother's struggles with mental illness. Ms UX's mother was admitted to an Older Person's Mental Health Unit on various occasions and had difficulty getting an accurate diagnosis and treatment for her condition. In 2010, Ms UX's mother moved into residential aged care.⁸¹ Ms UX told us:

the staff often seem slow to pick up on changes in Mum's moods or behaviour. It seems to me that there is an assumption that if a person has mental health issues, it is dementia and there is nothing staff can do other than make the person comfortable.⁸²

Ms UX explained that her family have 'had to play the role of care coordinator for Mum's access to ongoing mental health care', monitoring their mother's mood changes, notifying aged care staff and arranging for treatment from mental health professionals. Ms UX emphasised the importance of behavioural cues in monitoring and managing her mother's mental illness.⁸³

In public submissions, family members described difficulties in getting support and care for people in residential aged care with mental health needs.⁸⁴ A daughter described her mother's entry into residential aged care:

She entered the home as low care despite being blind and suffering from clinical depression. To have her re-assessed as high care was extremely difficult despite the fact that she was obviously incapable of looking after herself and low care was totally inadequate for her health and safety. ...It was obvious that the medical staff were treating her as a demented individual when she was of sound mind. A good reason to be clinically depressed!⁸⁵

Another family member, who also worked in aged care, said:

staff also need to be aware of those who are experiencing depression and who have become withdrawn and have the overwhelming desire to isolate themselves, and have sufficient training to be able to address issues such as this and provide encouragement and support to residents to attend and participate in social get togethers. My mother was in a severe depression, and she was left alone to deteriorate even further, to the extent she stopped eating and simply shut down, thus dying within several months of being placed into the Aged Care Centre. This was distressing to witness, and we all felt powerless to assist my mother.⁸⁶

Access to mental health treatment

We heard that it is often difficult for people living in residential aged care to access specialist mental health services, such as psychologists and psychiatrists. This can be particularly difficult for people living with dementia. We received evidence about a man who was turned away from a mental health service because he had dementia, but the aged care service where he lived was unable to care for his specific needs and ensure his safety.⁸⁷ Ms Cameron, whose evidence we discussed above, struggled to access good quality specialist mental health services for her husband who lived with Lewy body dementia.⁸⁸ Associate Professor Macfarlane told us that there was no consistency both between and within the States about which services are responsible for mental health treatment for people living with dementia.⁸⁹ He also said there are complexities for people who have pre-existing mental illness or acquired brain injuries:

If you've had somebody with a head injury, for example, who is in residential care and has disinhibited or regressive behaviours, aged persons mental health might reasonably take the view that that's not a mental illness. It's an organic brain syndrome following a head injury. And dementia support services may equally take the view that their specialist services and behavioural interventions that are targeted specifically towards the needs of people with dementia may well not be applicable to that client group either.

So large groups of people with psychiatric comorbidities where there's some debate about whether any given behaviour reflects dementia or the comorbidity may often fall between the gaps.⁹⁰

Public submissions also highlighted difficulties in accessing specialist support. Family members recounted poor experiences of care and described no service delivery or inadequate care for mental health needs due to lack of skills and poor communication. One submission from a family member described the difficulties she had in gaining a diagnosis and support for her father:

Mental health for the elderly are more than senility and dementia, trying to have my father assessed for Asperger's syndrome is proving impossible. I go through the correct channels, first his GP [general practitioner] who refers him to a Geriatric Memory clinic. Three times the clinic refused, then after a change of doctors we get an appointment with the new GP questioning 'why isn't your 91 year old father under a geriatrician?'⁹¹

We received submissions from health care professionals and aged care workers detailing the difficulties people in residential aged care face to access mental health services. One submission from a doctor working in aged care said:

For many elderly getting to community services such as allied health is not an option as they are frail and cannot easily get out and about. Anxiety and depression are common in the elderly population especially when you add in factors such as losing independence, not always recognising your environment, the death of a loved one or losing your home. Despite this there is no funding for psychology in facilities. ...Psychology services need to be accessible without costs to resident.⁹²

An aged care worker said psychological services should be more accessible for people in residential aged care:

The issue of psychologists providing services in residential aged care facilities under a Medicare mental health plan appears to be a grey area with confusing and contradictory information provided by Medicare which does not make logical sense.⁹³

Veterans' mental health

In 2019, the Department of Veterans' Affairs estimated that there were around 631,800 veterans in Australia, with almost 44% aged over 65 years.⁹⁴ Generally, the health care needs of older veterans are broadly consistent with the needs of older non-veterans.⁹⁵ However, we heard that veterans have particular mental health needs. Dr Duncan McKellar, psychogeriatrician and Head of Unit of the Older Persons' Mental Health Service in the Northern Adelaide Local Health Network, told us that veterans have a high prevalence of post-traumatic stress disorder symptoms.⁹⁶ Mr Nathan Klinge, Chief Executive Officer of RSL Care SA, explained that compared to conditions such as dementia, the aged care sector is less well informed and resourced to manage other mental health issues such as post-traumatic stress disorder.⁹⁷

Mr Brian Lynch, a Vietnam War veteran, gave evidence of his experience accessing aged care as a veteran with post-traumatic stress disorder. Mr Lynch told us that he had no recollection of living in residential care for about five years, and the documentation from his time in the facility showed he was heavily medicated.⁹⁸ When Mr Lynch moved to a different facility that knew how to care for veterans, Mr Lynch said he started to regain some of his memory and his cognitive condition improved.⁹⁹

Conclusion: mental health

Mental health conditions are not adequately identified or addressed in the aged care system. Older people should have access to the same mental health support as all members of the community, but they do not. The aged care system is often ineffective in addressing the complexities associated with older people's mental health, including mental health conditions in people with dementia and the mental health needs of veterans. Many staff working in aged care are not sufficiently skilled or trained to identify and support people living with mental health conditions. This results in care that falls below the high standard that Australians expect from aged care services. It should be addressed.

Palliative and end-of-life care

The majority of people who receive aged care services continue to do so for the remainder of their lives. Residential aged care is often a person's final place of residence before they die.¹⁰⁰ Palliative and end-of-life care, like dementia care, should be considered core business for aged care providers.¹⁰¹ However, throughout our inquiry we heard examples where the care provided to people in their last weeks and days of life was severely lacking and fell well short of community expectations.

Best practice end-of-life care

Palliative care is an approach to end-of-life care that aims to improve the quality of life of people who have an active, progressive, advanced disease, who have little or no prospect of cure, and who are expected to die.¹⁰² All people receiving aged care services should receive care that is informed by palliative care principles where appropriate. For people reaching the end-of-life with highly complex and persistent needs, specialist palliative teams, funded and provided by State and Territory Governments, need to provide support to aged care services. Specialist palliative care involves a multidisciplinary team with specialised skills, training and experience.¹⁰³ Not all people at end-of-life will need specialist palliative care, but all people deserve respectful, high quality palliative care, regardless of whether they are in the community, hospital or residential aged care.

Mr Joshua Cohen, a Palliative Care Nurse Practitioner, described some key elements of best practice palliative care in residential aged care, including having access to screening and assessment tools, timely prescribing, and access to palliative care equipment.¹⁰⁴

Dr Jane Fischer, Board Chair for Palliative Care Australia and palliative medical specialist, noted the importance of a responsive approach to the individual. She described good palliative care as 'holistic, person and family-centred care that is responsive to the clinical, physical, emotional, and psychological needs of a person and their family'. Dr Fischer emphasised that palliative care is not one-size-fits-all and must be tailored to each person's needs and preferences.¹⁰⁵

The evidence suggests that palliative care is not sufficiently embedded in residential aged care services.¹⁰⁶ Mr Cohen said that, in his experience, residential aged care staff members often mistakenly believe palliative care is only needed when death is imminent, and are not sufficiently trained, or present in sufficient numbers, to meet the needs of a person at the end-of-life.¹⁰⁷ There is also a lack of coverage of specialist palliative care services, and they may not always be available to people receiving aged care.¹⁰⁸

Palliative care plans and care

One of the most common issues throughout our inquiry involved a failure by providers to implement palliative care plans for residents. Ms Shannon Ruddock described the substandard palliative care received by her father, Mr Vincent Paranthoiene, at Alkira Gardens residential aged care in southern Sydney. Ms Ruddock explained that her father's pain management needs were not adequately met following his return from hospital.¹⁰⁹ Commissioners Tracey and Briggs found that Alkira Gardens 'lacked the physical and organisational capacity to provide Mr Paranthoiene with either adequate or quality palliative care'.¹¹⁰

Public submissions included accounts from people who said that they were unable to locate staff members, were uninformed and unaware of what was happening, and were not offered comfort or support. People described the added emotional burden of this lack of support during a time of grief and loss.¹¹¹ Mrs DJ said that on the evening her mother, Mrs DE, died, her laboured breathing could be heard from down the corridor. Mrs DJ and her sister spent half an hour seeking assistance from staff members. Two nurses, when finally located, offered little support or comfort and only administered medication when requested to do so. Mrs DJ recalled feeling that she had to 'beg' the staff to follow Mrs DE's palliative care plan:

That whole evening of Mum's passing was a farce and, honestly, an absolute disgrace. There was not enough staff. The staff who were there did not seem to know what was going on and we were in the dark the entire time.¹¹²

Ms Helen Valier described how she had difficulties in gaining access to and clarity about her late husband Mr Brian Harvey's palliative care plan in the final month of his life. Ms Valier was advised by a registered nurse in May 2019 that Mr Harvey was 'on a palliative care plan'. However, Ms Valier received no clarity about what was in the plan, who had devised it and whether she could access it.¹¹³ She said that Mr Harvey:

had an agonising death, which, on the information available to me and subsequently checked, was avoidable, inexcusable and unforgiveable. Brian, a very tactile, caring, loving individual, who was a big huggy kind of person, and he couldn't bear to be touched. So I couldn't hold him in my arms. I couldn't—I couldn't comfort him. I just had to watch him...in agony.¹¹⁴

Many public submissions described situations where people at the end-of-life in residential aged care did not have access to sufficient pain relief. Inadequate pain management was frequently associated with a failure to respect a person's dignity.¹¹⁵ One person said:

My mum passed away on the Wednesday (24 September 2014). She suffered pain, indignity, lack of compassion and basic care in the...nursing home. At counselling afterwards I was told that 'mum fell through the cracks'.¹¹⁶

A number of public submissions highlighted the lack of capacity of residential aged care to implement palliative care plans. This was usually attributed to a lack of time to spend with a resident who is actively dying or a lack of training in palliation.¹¹⁷

Support for family and friends

We heard about a lack of support for family and friends of people who were dying. Mrs Sandra Nisi described the final days of her father's life in a residential aged care facility. Three weeks before her father died, Mrs Nisi was told by a staff member over the phone that her father would be receiving palliative care. But care staff did not explain this term to her. Nor did care staff enact a palliative care plan. Mrs Nisi said she did not understand that her father was in the final stages of his life—no one took the time to explain this to her.¹¹⁸

In one public submission, a person described the experience of her brother dying in residential aged care, aged 52 years:

So instead of [being] with my brother and comforting my mother, my father was in the corridor of the facility trying to find a staff member to help them and my brother. He ended up saying 'can someone please help us, my son is dying'. It is sad that their last memories are of my brother struggling and looking in pain and them trying to get a staff member to assist. After he passed away, no one closed his eyes or did anything in the room other than open the doors. No staff member or manager came to the room to tell us what happens next. I had to go looking for staff to see what happened next.¹¹⁹

Access to specialist palliative care services

Dr Elizabeth Reymond, Deputy Director of Metro South Palliative Care Service, described the lack of access to specialist palliative care services. Dr Reymond explained that most residential aged care services do not have access to specialist palliative care teams. She said that this means that residents rely on their general practitioners for end-of-life care which, she said, 'is often a less than ideal arrangement'.¹²⁰

Mr Peter Jenkin, a palliative care nurse practitioner, said that 'there is not sufficient certainty as to the responsibilities for PC [palliative care] and EoL [end-of-life] care between health and aged care services'.¹²¹ Mr Jenkin said that he agreed with Palliative Care Australia's view that: 'there is a need for silos and system impediments to be minimised if equitable access to quality palliative care is to be realised'.¹²²

This issue was further highlighted in public submissions and evidence. One person described the challenges people faced when seeking these services for their loved one:

After many phone calls, emails and a lot of detective work, I accessed the only private palliative care unit on the entire [Gold Coast].¹²³

Another person's submission outlined the difficulty they had obtaining palliative care services at home for their husband:

For the inexperienced carer like myself, it is like negotiating a red tape nightmare. If my husband had been delivered proper nursing and medical care at home, then the outcome may have been different. He may have been able to die as he wished...at home, and not at a hospital facility.¹²⁴

In its response to the Service Provider Survey, Uniting NSW.ACT highlighted the variable nature of State and Territory specialist palliative care services:

There is a lack of reliable outreach palliative care from Local Hospital Districts (LHD) within NSW. Approaches vary by LHD, some do not support RAC [residential aged care] services at all, and some do not have any outreach services. This lack of consistency results in a 'post code lottery' of sorts for clients seeking palliative care support.¹²⁵

Dr David Panter, Chief Executive Officer of ECH Inc, told us:

we had a debate the other day with a public hospital provider because they told us that the person we were providing services to on a level 4 package in the home who was dying was ineligible for state-funded palliative care because they were on a home care package.¹²⁶

Conclusion: palliative and end-of-life care

It is clear to us that too few people accessing aged care receive the evidence-based, end-of-life care they need. People at the end of their lives should be treated with care and respect. Their pain must be minimised, their dignity maintained and their wishes respected. Their families should be supported and informed.

3.3.3 Routine care

As people get older, they may require assistance to enable them to care for themselves. The types of assistance needed vary for each individual and are commonly referred to as help with the 'activities of daily living'. The activities of daily living generally relate to moving, eating, using the toilet, personal hygiene, which includes bathing and showering, dressing, brushing hair and brushing teeth. They may also include a person receiving support to socialise or to take medicines or exercise.

The routine daily living care that older people receive should be predictable and reliable. They should be able to trust that each day they will be able to brush their teeth, eat nutritious and appetising meals, go to the toilet, and feel connected and mentally stimulated. Our inquiry has shown that the routine needs of older people, particularly in residential aged care, are often substandard in the following areas: skin care, mobility, nutrition, oral health, medication management and prescribing, continence and incontinence, infection control, social and emotional needs, and diversity and cultural needs.

Skin care

The most common form of substandard skin care we heard about related to the lack of prevention, and poor treatment, of pressure injuries. Pressure injuries—also known as decubitus ulcers, pressure sores, pressure ulcers or bedsores—are localised injuries to the skin or underlying tissue caused by pressure or friction.¹²⁷ Pressure injuries, while common in older people, are generally preventable with adequate care and intervention.¹²⁸ Despite this, we heard numerous accounts of people in residential aged care developing serious pressure injuries. In some cases, staff members had not identified them as injuries. In other cases where they had been identified, providers had not treated them well.¹²⁹ Failure

to treat wounds appropriately can have serious adverse consequences and can lead to amputation of a limb or death.¹³⁰ People living in residential aged care often do not receive adequate clinical care for wounds which arise from pressure injuries and other causes.¹³¹

Best practice skin care

As people age, their skin loses integrity and can become susceptible to tears and injury. In a statement on behalf of Wounds Australia, Associate Professor Geoffrey Sussman and Ms Hayley Ryan noted that a good skin care regime for older people revolves around protecting the skin from tears.¹³² When a proactive and preventative approach does not occur, wounds can quickly become life-threatening.

A number of experts emphasised that implementation of preventative measures is key to maintaining skin care, treating pressure injuries and proper wound management.¹³³ Associate Professor Sussman explained that good quality moisturisers can prevent skin tears.¹³⁴ Dr Iuliano highlighted the importance of good nutrition for skin care. She explained that without sufficient protein in the diet, skin cannot heal, weight loss results in less padding between pressure points and bone, and a compromised immune system leaves the body more susceptible to infection.¹³⁵

Associate Professor Sussman and Ms Ryan described the key features of pressure injury prevention programs as ‘risk assessment, skin assessment and protection, pressure redistribution, nutrition assessment and optimisation and patient education’. According to Associate Professor Sussman and Ms Ryan, these features can be used to develop an individualised plan to meet the needs of residents and to reduce the incidence of pressure injuries.¹³⁶

Identifying and preventing wounds

A number of witnesses and submissions from members of the public described circumstances where pressure injuries and wounds were not identified and worsened over time. In the Assisi Case Study, there was evidence about delayed treatment of a pressure injury on Mrs Santoro’s right heel. Facility staff members consulted a wound specialist two and a half months after the wound was first noticed and several weeks after it had begun to deteriorate seriously. By then, the injury was chronic and irreversible.¹³⁷ Ms Ng said that her mother suffered excruciating pain because of the way the wound had been dressed, and that she had no relief from the pain.¹³⁸ By the time Mrs Santoro died, the wound on her heel had not healed. Mrs Santoro’s doctor gave evidence that a bone infection associated with the wound on Mrs Santoro’s heel contributed to her death.¹³⁹

Some public submissions described times when residential aged care staff members did not detect pressure injuries. In some cases, people receiving care displayed signs of pain and discomfort which were noted by family members but dismissed by staff members.¹⁴⁰ In one submission, a woman had been complaining to care staff of pain for three weeks before her general practitioner identified a pressure injury.¹⁴¹

Adequate treatment

A number of witnesses and public submissions raised concerns about the adequacy of treatments for pressure injuries and wounds. An inability to access the services of wound specialists was an issue for some. Ms Johanna Aalberts-Henderson described the experience of her mother, Mrs Bertha Aalberts, at Avondrust Lodge. Mrs Aalberts had developed a serious wound on her lower right leg. Although Avondrust knew the wound was serious and would require high-level clinical care from competent nursing staff, it did not involve a wound consultant nurse for two weeks.¹⁴² Avondrust also failed to follow its own 'Wound Assessment and Management Plan' that required the wound dressing to be changed daily by an enrolled or registered nurse.¹⁴³

Ms Kristine Stevens described the experience of her mother, Nena, who developed a pressure injury while in residential care. Ms Stevens had believed that care staff members were adequately managing the wound.¹⁴⁴ She only became aware that the wound was seriously deteriorating when, approximately a year later, her mother moved to a new facility and was subsequently transferred to hospital. Ms Stevens said she was told by hospital staff members that her mother was suffering from a life-threatening pressure wound that was likely causing her great pain.¹⁴⁵

Some submissions described instances where aged care providers delivered inadequate clinical care, including failing to seek specialist wound management services. They also described horrific deterioration of injuries and excruciating pain.¹⁴⁶ As one submission outlined:

We watched my father pass away in 2016 from a Bed sore that was not attended to, after an operation—the huge [hole] in his back was distressing, it was too late the infection had spread into his bones diagnosis Osteomyelitis—it was a horrible, slow and painful death. It should not have happened if the carers and nurses attended to his needs in a professional manner.¹⁴⁷

Conclusion: skin care

These failures in skin care, particularly the identification, prevention and treatment of pressure injuries and wounds, are unacceptable. Pressure injuries are preventable. When identified and treated appropriately and in a timely manner, these wounds can heal. It takes time and skill to care for older people's skin and to protect them from developing injuries. We heard that staff members often do not have adequate knowledge and training to prevent pressure injuries and wounds from occurring, nor for treating them effectively when they do occur.¹⁴⁸ The consequences for people receiving aged care are painful, distressing and can have immense health implications, which sometimes lead to early death.

Mobility

Mobility is closely linked with people's health and their quality of life.¹⁴⁹ However, we heard numerous examples of aged care providers not supporting people to maintain and improve their mobility—including limited access to allied health professionals critical to promoting mobility, such as physiotherapists. In our view, aged care providers, and the aged care system more broadly, do not invest sufficiently in maintaining and improving people's mobility.

Mobility is defined as a person's ability to move, either independently or with assistive devices or transportation, within their home and in the broader community.¹⁵⁰ Reduced mobility affects people's sense of independence, their ability to undertake activities of daily living and to participate in social activities. Being able to walk is a critical factor in determining whether a person can remain at home or may need to live in residential aged care.

A failure to support and promote older people's mobility can have significant implications for their health. Poor mobility increases the risk of falls and fall-related injuries due to deconditioning and reduced muscle strength.¹⁵¹ People living in residential aged care are at particular risk of falling.¹⁵² Substandard care in a range of areas can increase this risk. For example, poor nutrition and weight loss can reduce a person's muscle mass and strength and make them more unsteady on their feet.¹⁵³ Certain medications and both physical and chemical restraint can also increase this risk.¹⁵⁴ The prevalence of falls among people who are receiving residential aged care compared with those that occur among people who are living in their own homes is discussed in our examination of the extent of substandard care later in this chapter.

Best practice in mobility support

Exercise and movement can have an important role in preventing or slowing decline and improving mobility. They can improve brain function and emotional wellbeing and reduce risks of other illness. This applies especially to those people who have multiple underlying health conditions and people living in residential aged care.¹⁵⁵ Allied health professionals can play a key role in ensuring older people are independent and mobile for as long as possible. Allied health services can support people to engage in social opportunities, maintain and improve function and improve quality of life. Allied health services, in combination with medical, nursing and support for activities of daily living, can maintain and enhance mobility in older people.¹⁵⁶

Supporting people's mobility

We received evidence that aged care providers often do not support older people to maintain their mobility. In many cases, people reported that staff members in residential aged care did not encourage residents to walk or to be as active as possible. Ms Diane Daniels said that her mother lost the ability to walk, became a 'two person assist' and lost her independence due to a lack of movement on returning to residential care after hospitalisation.¹⁵⁷ Ms Judith King said she believed staff members thought it was quicker and easier to put her husband in a wheelchair rather than let him walk:

He's a man who can walk, who enjoys walking, but he doesn't have the option to walk. ...When I saw them automatically coming in to put him into the wheelchair, the carers, I would speak to them and say, 'Neville is able to walk. Could you please walk him to the dining room.' Some would, some wouldn't. I think they had instructions that they had to have two people to walk him. And they were worried about falls. And this is me surmising, because no one actually told me that. So they were putting him into the wheelchair. He hasn't fallen when I'm walking him to the dining room.¹⁵⁸

Ms Lyndall Fowler, whose mother developed contractures in her legs while in care, said that a staff member told her that personal care workers cannot support residents to complete exercises:

I consulted an external physiotherapist about my mother's contractures and was told that simple guided exercise, assisting the movement of the knees, could slow the development of leg contractures. When I asked about potential for this to be done, a Team Leader at the facility told me that Care Workers are not trained to facilitate exercise and that this was a physiotherapist's role.¹⁵⁹

We also received public submissions about a lack of mobility support. One person told us about how her father was discouraged from being active:

Allan was labelled a 'falls risk' from the day he entered the residence and this meant that any independent movement was discouraged. He was walking on crutches when he entered care in December last year but was quickly discouraged from using them due to the risk of a fall. He progressed to a wheelie walker but was discouraged from using this without accompanying staff.¹⁶⁰

Another person noted the lack of exercise equipment in their father's residential facility:

Gerontology for decades now has emphasised the importance of exercise for the elderly.

Yet the facility provided no exercise equipment...This absence is a blatant failure to provide the basic requirements of health for institutionalised people.¹⁶¹

Minimising the risk of falling

Aged care providers often fail to minimise the risk of residents falling. When providers do try to minimise this risk, their response can be ineffective or restrictive to the older person. Some witnesses have attributed falls to a lack of staff and supervision.

Ms Ruddock said that when her father, Mr Paranthoiene, was a resident at Alkira Gardens, she received regular phone calls about him falling when he tried to get out of bed.

Ms Ruddock explained that he had a bed alarm, but this did not stop the falls.¹⁶²

Ms Eresha Dassanayake said that her mother had a number of falls while living in residential aged care. Ms Dassanayake believed these falls occurred due to a lack of staff, as one fall occurred when her mother was unable to get assistance to go to the toilet.¹⁶³

Ms FA said that her father had a number of unwitnessed falls in residential aged care.¹⁶⁴

Other witnesses also described unwitnessed falls, which they attributed to a lack of care staff.¹⁶⁵ Ms Kristine Stevens told us how her mother deteriorated following a series of falls:

Well, she was unsteady on her feet so she was sort of placed in a chair and because residents are often placed in chairs and then put in the corner of the room and left unattended they often try to get out of the chair because—in my mum's case she wasn't used to not being able to walk so she experienced a series of falls and the last of those falls resulted in a fairly severe gash to the back of her head and that's the one that really I believe was the last straw, basically, in terms of her being able to communicate and participate.¹⁶⁶

Public submissions described similar experiences. Many described unwitnessed falls in residential aged care.¹⁶⁷ One person told us that pain and fear from previous falls impaired their father's mobility.¹⁶⁸ Others described the lack of staff assistance to encourage and assist mobility, which resulted in falls.¹⁶⁹ Another put it like this:

The Home promised access to physiotherapy to help maintain her independence but the reality was that, apart from an initial assessment, Mum spent most of her days sitting in her chair, as there were not enough available therapists for ongoing maintenance. Instead of staff assisting Mum to mobilise independently, they transferred her 'because it was quicker' and very soon the mobility she did have started to deteriorate. She had TEN falls in less than 3 months at this care home and she was deemed unsafe to walk—even supervised walking to the dining room was prohibited—despite the fact that my sister and I had no problems transferring and walking her. I believe the falls related to inexperienced staff, with poor transfer skills and the fact that she was not provided with sufficient support to maintain her mobility.¹⁷⁰

Access to allied health services

A number of witnesses and public submissions described the limited access people living in residential aged care have to allied health services, particularly physiotherapy. In some cases, residential aged care providers simply did not provide such access. In others, access was limited.

Ms Ng explained that she thought that her mother would receive physiotherapy in residential aged care. However, she was told that physiotherapy was only provided as a pain management option for residents suffering chronic pain.¹⁷¹ Family members of people in residential aged care gave evidence that access to physiotherapists was not a standard service. It was often left to family members to arrange private services.¹⁷²

We heard that even when physiotherapy assistants are employed in residential aged care, the services are often not accessible to residents with cognitive impairment. Ms FA said:

When Dad was finally assessed by a physiotherapist at Facility 1 I was told there would be limited point in Dad having physio, as at this stage of his Alzheimer's he could not follow instructions well enough to make any worthwhile progress. Dad was now bedbound and had to be hoisted into a 'bed chair' to get him out of bed.

Within three months of being admitted to residential aged care, our Dad had gone from being an active and able-bodied man, to being bedridden and unable to even feed himself.¹⁷³

Conclusion: mobility

Too many older people do not receive the assistance they need to promote and maintain their mobility. Walking is an important element of good health and wellbeing for most people. Some aged care providers consider older people's mobility as an imposition or a risk, rather than something that should be encouraged and supported. Others are missing falls, sometimes because of a lack of staff. A lack of support to maintain or restore mobility can also lead to premature entry to residential aged care. Allied health professionals, who could help prevent falls or help recovery after a fall, are too rarely used to improve and maintain mobility.

Nutrition

Diet, nutrition and food are critical to the health and wellbeing of older people. Food must meet the body's needs to maintain organs and body systems, to repair injury, to fight off or recover from illness or infection and to maximise physical and cognitive capacity. People with higher levels of frailty require greater levels of protein and other nutrients to reduce the rate of decline.¹⁷⁴ Food is also important to provide enjoyment through taste and smell.¹⁷⁵ It stimulates memories.¹⁷⁶ Too often we heard that residential aged care providers fail to meet the nutritional needs of people and that poor quality and unappetising food was provided.¹⁷⁷

The consequences of poor nutrition are significant and often irreversible for older people. As noted above, malnutrition is associated with an increased incidence of falls and fractures and increased time for pressure injuries to heal.¹⁷⁸ Weight loss in older people can increase the risk of infection, impair the body's ability to repair wounds, decrease muscle mass and affect the ability to sit and to eat, as well as increase the risk of pneumonia. In extreme cases, it can result in multiple organ failure.¹⁷⁹

The Dietitians Association of Australia estimated that 8% of older people living in the community and between 22% and 50% of older people living in residential care are malnourished.¹⁸⁰ We discuss data about poor nutrition in our analysis of the extent of substandard care later in this chapter.

The quality of food

A number of witnesses and public submissions raised the quality of food as a key concern. Ms Dassanayake told us about her mother's experience of food in residential aged care:

until about, say, six months ago, dinner, it was normal to have party pies, sausage rolls, and just sausages. Mashed potatoes is the norm, and as the first witness said, I don't think there's anything in there except a whole lot of potato and I'm not sure even if there's milk in there, so it's not very appetising.¹⁸¹

Many public submissions described poor quality food and a lack of nutritional value in the food older people received in residential aged care.¹⁸² According to one submission, the meals contained 'nothing nutritious at all, very few vegetables which were all over cooked and very small meals'.¹⁸³ Submissions described texture-modified meals as unappealing, inedible and 'like dog food'.¹⁸⁴ Some people told us they took food to a person living in residential aged care to supplement what the facility provided or because the food provided was of poor quality or unappealing.¹⁸⁵

Aged care workers gave their perspective on the impact food can have on residents. Ms Patti Houston, a personal care worker, put it like this:

Imagine having to eat your meals (modified diet) at the same times every day. Imagine sitting every meal time in a community dining room with people you do not know or may not even like. ...I challenge you to have someone puree your meal and spoon feed it to you.¹⁸⁶

Ms Gaye Whitford, a residential aged care coordinator, described the importance of food preparation for residents:

Unfortunately our kitchen was closed a few years ago, so we get all of our meals delivered from the hospital. We fought that move very hard; a kitchen is about more than just producing food. A kitchen promotes atmosphere and energy with sounds and smells and movement. For many of our residents, they have extraordinary practical skills. Some of our women used to live on farms and cook for shearers and workers. They know how to make a great cream puff. I think a kitchen can be used to promote person centred care, and it is disappointing that ours has gone.¹⁸⁷

Mr Timothy Deverell and Mr Nicholas Hall, chefs who worked in aged care food services, said that residents' satisfaction, or lack thereof, in the food they provide greatly impacts on their own job satisfaction.¹⁸⁸ According to Mr Deverell:

the whole resident's day is structured around their meal periods. It's the one thing that they get to look forward to every day. ...So their happiness and getting a decent meal is huge. It's very important to them.¹⁸⁹

We recognise that in some cases food cannot be provided in its normal state because a person may have difficulty swallowing. We have received evidence that this may affect up to 50% of people living in residential aged care.¹⁹⁰ Associate Professor Lynette Goldberg, from the Wicking Dementia Research and Education Centre at the University of Tasmania, said that neurological changes associated with dementia can affect an individual's interest in eating and drinking and the physical ability to use eating utensils and lift food to the mouth. She said that people with dementia may need food de-texturised and their drinks thickened to help them swallow safely.¹⁹¹ However, these foods are often not appetising. The thickened fluids feel different in the mouth, and flavour and appearance can be altered. All this decreases the likelihood of people consuming them.¹⁹²

Ms Maggie Beer AM, who established the Maggie Beer Foundation 'to provide the pleasure of a good food life for all, regardless of age or health restrictions', said there is a systemic issue in relation to the quality and 'appetite appeal' of the foods provided in residential aged care.¹⁹³ She said that the Maggie Beer Foundation receives complaints from residents, relatives of residents, chefs, cooks and nurses, expressing concern about the quality of food that is served in residential aged care.¹⁹⁴

Mr Robert Hunt and Ms Lawrence from the Dietitians Association of Australia gave evidence that nutrition should be overseen by an accredited practising dietitian.¹⁹⁵ In their view, dietitians in residential facilities should not merely respond to consequences of inadequate nutrition. Rather, a dietitian can ensure:

not only the accurate and timely assessment of nutritional need, but also oversee the provision of high quality, nutritious meals, drinks and snacks, ensure prompt efficient delivery of these to each and every resident and, through onsite education, engage all staff to share the responsibility for achieving nutrition care.¹⁹⁶

The quality of food provided to older people living in residential facilities is limited by the budgets allocated to kitchens. Witnesses gave evidence about a study showing that the average food budget in residential aged care is \$6.08 per resident per day.¹⁹⁷ Ms Beer said that quality food can be provided for \$10–\$14 per resident per day.¹⁹⁸ Facilities with higher

food budgets can purchase better quality ingredients and therefore provide residents with quality meals and larger portion sizes.

Assistance with eating

We also heard that the lack of training, knowledge and qualifications of staff, and the lack of staff and their high workload, contribute to the substandard food and nutrition for people in aged care.¹⁹⁹ The most common issue related to food raised by witnesses and in submissions was a lack of assistance to eat and drink. Ms DI and Ms DJ gave evidence about their mother, Mrs DE, who was a resident of Bupa Aged Care Willoughby. Mrs DE needed full assistance with her meals.²⁰⁰ But Ms DI said that on most occasions when she visited her mother, who she described as bed-bound, there was a tray of food beside the bed that was usually untouched and cold.²⁰¹ Commissioners Tracey and Briggs found that the care provided to Mrs DE to meet her nutritional needs, as observed by her daughters, was substandard.²⁰²

Ms Aalberts-Henderson described her concerns about the quality and the quantity of meals her mother received at Avondrust Lodge. She said her mother had her arm in plaster and did not receive assistance to eat, and was given breakfast at 11am and then did not receive lunch because she ‘wasn’t hungry at lunchtime’.²⁰³ Ms Jo-Ann Lovegrove said that her father, who lived in residential aged care in Darwin, required help to eat: ‘They think he’s full, and they’ll take the meal away. He’s not. He’s just very slow.’²⁰⁴

We received public submissions that described instances of staff members disposing of partially eaten or untouched meals provided to people who required, but did not receive, assistance to eat.²⁰⁵ Many said people lost weight after entering residential aged care.²⁰⁶ Some believed this was due to residents not receiving adequate assistance during meal times.²⁰⁷ In some submissions, family members said that without family intervention people living in residential aged care would starve or go hungry.²⁰⁸

Conclusion: nutrition

The quality of food that people in residential aged care receive is often substandard. It is unacceptable that food is unappetising and does not meet the nutritional needs of older people. The lack of assistance provided to people who need help to eat their meals is unacceptable. Food can be a source of enjoyment and happiness, and it is critical to overall health and wellbeing. Meals should be a time to look forward to, not a process people are rushed through as quickly as possible.

Oral health

As people become physically frail or develop cognitive impairment or multi-morbidity (the prevalence of multiple health conditions), their risk of oral health problems — mainly tooth decay, gum disease and tooth loss — increases.²⁰⁹ Poor oral health can lead to a number of other health problems. While the need for high quality oral and dental health care for older people is essential, we heard consistently that oral and dental health care is not treated as a priority for people living in residential aged care. Daily oral health care is often not undertaken and access to oral and dental health practitioners is limited.

Oral and dental health care ranges from daily tasks such as teeth brushing and cleaning and assisting people with dentures, to preventative dental care conducted by an oral or dental health professional, to treatment services for disease or teeth and gum damage. Under the Quality of Care Principles, residential aged care providers are required to provide assistance with personal hygiene for all residents. This includes basic oral and dental care, although this is not explicitly stated. Providers are also required to provide assistance for residents to obtain dental health services.²¹⁰

Poor oral health can have far reaching consequences. Professor Strivens said that there is a strong link between oral health and general health and wellbeing. He said that poor oral health can lead to pain, preventing the ability to eat normal food or swallow medication.²¹¹ It can also lead to malnutrition because people cannot eat properly. Other associated health conditions, such as cardiovascular disease, may arise.²¹²

Ms Adrienne Lewis of the South Australian Dental Service described the effects that poor oral health can have on an older person's quality of life, including their ability to eat and enjoy their meals, as well as their appearance and their interaction with others. Ms Lewis explained that a simple check of oral health can have a profound effect on health generally and the quality of life for an older person.²¹³

Dr Janet Wallace, Associate Professor in Oral Health, University of Newcastle, told us that the best way to manage oral health in residential aged care is to have qualified oral health practitioners—dental hygienists, dental therapists, and oral health therapists—provide leadership, training and daily support to staff, residents and family members.²¹⁴ Dr Kerrie Punshon, President of the Australian Society of Special Care in Dentistry, explained that for older people living in the community, clinical protocols recommend high quality daily home care and frequent dental checks, every three to six months.²¹⁵ Ms Nicole Stormon, an oral health therapist and Vice President of the Australian Dental and Oral Health Therapists' Association Inc, said that 'complete oral health care for older Australians' requires both prevention and treatment, with funding to support both.²¹⁶

Preventative oral and dental health care

We heard that a lack of preventative oral health care and accessible oral and dental care are common across residential aged care.²¹⁷ Ms DM and Ms DL gave evidence about care received by their mother, Mrs CO. Ms DM said the dentist found her mother's gums had eroded significantly and her teeth were rotting:

According to the dentist, the problem was simple. The carers at Brian King Gardens were not taking her denture plate out each night. They were also not cleaning it. The dentist told DL that this was obvious because of where the sores and abscesses were in Mum's mouth—these wouldn't have occurred if the dentures were being taken out at night.²¹⁸

Commissioners Tracey and Briggs found that that Mrs CO's oral and dental care fell well short of the appropriate standard.²¹⁹

Ms Kristine Stevens said she was concerned that without her advocacy, her parents' oral and dental care needs would have been overlooked in residential aged care because of insufficient staff:

my father indicated that he had a toothache at one stage and so I arranged to take both my parents to the dentist, and then I asked the dentist to write a report...to take back to the facility, which indicated that they had very poor oral hygiene. So that's another thing that's overlooked because there's a lack of staffing levels. You know, there's inadequate staffing levels to look after high needs people.²²⁰

We received public submissions describing inadequate oral and dental health care in residential aged care, which was often attributed to staffing levels, heavy workloads and inadequate staff training.²²¹ Ms Prue Kelly detailed a 'number of issues' with her mother's provider, including lack of attention to personal hygiene:

I am concerned my mother is not getting personal and oral hygiene on, at least, [a] daily basis as she often has strong body odours and her teeth are lined with food.²²²

Another person described providing oral care for a family member because they did not believe staff members were doing so.²²³

We also received submissions from aged care workers. One worker told us that low staffing levels meant that many activities of daily living, including dental hygiene, shaving or hair washing, may be missed.²²⁴ Another submission from an aged care worker said:

I don't know a single staff member who brushes resident's teeth or dentures besides myself. Our residents have teeth literally falling out and nothing is done to try to slow the decay. I do not believe prompting is even attempted for residents who refuse staff help but could brush their own teeth.²²⁵

Access to oral and dental health care

People in residential aged care often lack access to oral and dental health services. We heard that in some areas dentists rarely visit residential aged care services and that residents rely on family or carers to arrange dental appointments and organise transportation.²²⁶ Not all residents have families with the capacity to take on these tasks. This creates inequality in accessing health care. Ms Rhonda McIntosh illustrated this point when remembering an incident experienced by her father:

the facility rang me and said that...in the morning the care staff had noticed that he had some blood in his mouth and somebody looked in his mouth and saw that he had a decayed tooth, and they suggested to me that I needed to take him to a dentist, which I subsequently did. I asked them, what would happen if I was unable to take him? And they said that in the past they had volunteers that used to do that but they don't do that anymore. So it was up to me to take him to the dentist which was difficult because at that time he was in a wheelchair, so we had to call a disabled taxi to get him there.²²⁷

Some public submissions described challenges of organising oral and dental health care for family members in residential aged care.²²⁸ One woman said that her mother could no longer access specialist services because she had limited mobility.²²⁹ An aged care worker explained in a submission:

Dental care is pretty much non-existent in every facility I have worked at unless family can transport to the dentist. We NEED mobile dental clinics set up to cater for frail people and those people in wheelchairs. Without good dental care we have worse health outcomes for those who already have multiple co morbidities and unnecessary pain and discomfort.²³⁰

While our hearings largely focused on the oral health issues that people face in residential aged care settings, people who are receiving aged care in their own homes may also struggle to access appropriate oral and dental care. Ms Beryl Hawkins described her difficulty in accessing affordable dental treatment while receiving a Home Care Package, with a two-year wait list for dentures through the public dental system.²³¹ The Australian Dental Association told us in their submission that there is:

relatively little evidence available in relation to the quality of oral and dental health care provided by home care providers. However, available evidence suggests that substandard oral health care provision is likely to be common in aged home care as a result of the same systemic factors found to operate in residential aged care.²³²

Conclusion: oral health

Oral and dental care for people in residential aged care needs to improve significantly. Much of what we heard about the factors that contribute to failures in oral and dental health care focused on staff time and training, as well as a lack of access to oral and dental health professionals.²³³ Older people are often reliant on care staff to maintain their oral health. They should be assisted to ensure their teeth are brushed or their dentures removed and cleaned twice daily, as is common practice for us all. Staff often lack the training and time to meet the oral and dental needs of people living in residential aged care.

Older people should also have equitable access to oral and dental health professionals, regardless of whether they live in the community or in residential care. These expectations are often not being met.

Medication management and prescribing

With people living longer and the increasing prevalence of multi-morbidity, older people are more likely to be taking medicines and, in some cases, more likely to be taking multiple medicines daily. Generally, people in residential aged care take a median of 11 medicines.²³⁴ Often, older people need assistance to take medicines correctly, whether they live in their own home or in residential aged care. Medicines have beneficial effects and can improve health and wellbeing. However, some medicines have harmful unintended consequences, including increasing the risk of falls, urinary incontinence, antimicrobial resistance, weight loss, and impacts on diabetes management.²³⁵ We heard numerous instances of inappropriate management of medication regimens.

Between January and March 2020, the most frequent complaints made to the Aged Care Quality and Safety Commission were about medication management.²³⁶ Much of what we heard about the failures in medication management were due to inadequate staffing levels and skills.²³⁷ We review additional data about use of medicines by people living in residential aged care compared with those living in the community in our analysis of the extent of substandard care later in this chapter.

Best practice medication management

Dr Janet Sluggett, a consultant pharmacist and a National Health and Medical Research Fellow at the Centre for Medicine Use and Safety at Monash University, said that best practice medication and prescription management involves a multidisciplinary approach across registered nurses, general practitioners and pharmacists.²³⁸ She said it is essential to review residents' medicines, consider input from other health professionals providing care, and consider the person's health status and goals of care to determine whether all prescribed medicines are appropriate.²³⁹ In the 2016–17 financial year, only one-third of people receiving residential aged care had a Residential Medication Management Review, which is a comprehensive assessment of a resident's medication management needs conducted by an accredited pharmacist in collaboration with the resident's general practitioner.²⁴⁰

In May 2019, Professor Brendan Murphy, then Chief Medical Officer for the Australian Government, gave evidence that the Australian Government was considering embedding pharmacists in residential aged care to help improve medication management issues and that a recent trial had indicated positive results.²⁴¹ A trial to embed part-time pharmacists in all residential aged care facilities in the Australian Capital Territory was announced in the 2019–20 Budget and will proceed in 2021–22.²⁴²

Administering medicines

We heard about aged care staff members failing to administer medicines correctly or administering medicines but failing to ensure residents swallow them. We heard of failures to administer medicines at the correct time or in the correct dose, and of residents being administered incorrect medicines.

Ms DI and Ms DJ gave evidence that their mother, Mrs DE, was transferred to hospital less than 36 hours after moving into Bupa Aged Care Willoughby, where unchewed food and medicines were found in her mouth.²⁴³ Commissioners Tracey and Briggs found that the care provided to Mrs DE to ensure she had cleared her mouth was substandard.²⁴⁴ Bupa Aged Care accepted that this could have led to harm, loss or damage to Mrs DE.²⁴⁵

We received a number of submissions from members of the public describing residents receiving medicines unsupervised, and in some cases, as a consequence, medicines being found on the floor in residents' rooms.²⁴⁶ For example:

His medication would be left with him and they would expect him to take it unsupervised but due to his poor eye sight and motor skills, tablets were often dropped and not taken. As well as this, some of the tablet he believed he did not need and at times we believe he may not have taken any of them. We commonly found these tablets on the floor when visited and informed staff.²⁴⁷

Ms Sarah Holland-Batt gave evidence about her father, who had Parkinson's disease and lived in residential aged care. Ms Holland-Batt explained that her father's general practitioner had emphasised the importance of her father receiving his medicines at exact intervals to avoid the increasing of symptoms, including difficulties with coordination, balance and gait.²⁴⁸ Ms Holland-Batt said that her father did not receive medicines at correct times. She described the persistent discussions she and her mother had with staff members to ensure her father was given Madopar, a medicine to increase mobility and reduce Parkinsonian symptoms, at exact intervals. Ms Holland-Batt said that when she noticed that staff members were not administering the medicine in accordance with the general practitioner's directions, they would give excuses such as the error being a result of agency staff members or that staff members were busy with other residents.²⁴⁹

A number of public submissions described similar errors or omissions in the administering of medicines.²⁵⁰ A former aged care employee described their observation of a staff member:

I observed a Cert III AIN [assistant in nursing] who had completed an online medication competency give a resident blood pressure medication without checking her blood pressure first. The blood pressure was already low and the patient collapsed on the way to the toilet and fractured her hip. I asked if he knew what he was giving, and he replied it's in the webster pack so she must need it.²⁵¹

Conversely, there are instances when residents should be free to self-administer medicines.²⁵² Ms Darryl Melchhart described her lack of autonomy with medication management while living in residential aged care in Victoria. Ms Melchhart gave evidence about a glyceryl trinitrate spray that she self-administers for her angina. She said that if she is unable to administer this medicine when she needs it, there is a risk of hospitalisation or death. Ms Melchhart described an incident in late 2018 or early 2019 when staff members took this medicine away from her.²⁵³

Prescribing and dispensing

We heard evidence about concerns with the prescription of medicines by health professionals. This often took the form of unnecessary prescribing of a medicine, and failures to consider issues about polypharmacy—the use of nine or more medicines. Many of these issues were explored in the context of psychotropic medicine and restraint. Here we focus on general prescribing issues.

Ms Holland-Batt gave evidence about an incident in 2016 when a general practitioner prescribed her father with a medication to assist with nausea. This medication was contraindicated—medicines that should not be prescribed to an individual due to existing circumstances—with his Parkinson's medication.²⁵⁴

We also received public submissions describing situations where medication was used when other interventions would have been more appropriate.²⁵⁵ A number described circumstances where they felt residents were overmedicated. For example:

Mum has been over medicated with narcotic medications. These medications were prescribed to provide pain relief for her arthritis that occasionally flares up. Nursing staff were unable to provide alternative non-opioid analgesics such as paracetamol as they felt obliged to provide whatever pain medication was prescribed, without any indication or second thought whether she actually required them. In one case that we documented, mum complained of a stiff neck and was given Endone.²⁵⁶

The Brian King Gardens Case Study included evidence about general practitioners prescribing outside of guidelines and failing to consider polypharmacy. Mrs CO's general practitioner prescribed Mrs CO 45mg of the anti-depressant mirtazapine due to agitation, distress and signs of depression. This was contrary to professional guidelines and advice that mirtazapine is not appropriate or effective for people with dementia and depression.²⁵⁷ Following this prescription, nursing staff informed Mrs CO's general practitioner that Mrs CO was 'increasingly drowsy', although by the time the general practitioner attended she was 'responsive and talking'.²⁵⁸ According to her daughter, Ms DM, on one occasion Mrs CO was 'out of it'.²⁵⁹

We also received evidence about the process of dispensing medicines. This is usually completed by a community pharmacist. The traditional model of community pharmacy involves the opportunity for a face-to-face discussion with the patient or family member. Where a patient lives in residential aged care, community pharmacists often dispense medicines into a dose administration aid such as a blister pack. They then supply the blister pack to the aged care provider. In this scenario, pharmacists often have very limited clinical information provided to them about the residents for whom they are dispensing medicines, and may never actually meet those residents.²⁶⁰ Dr Sluggett warned that there is no system in place to flag important information—for example, if a medicine is associated with an increased risk of falls.²⁶¹ Dr Juanita Westbury (now Breen), a registered pharmacist and senior lecturer in dementia care at the University of Tasmania, said that as a community pharmacist, she has identified incidents where residents of aged care have been prescribed high doses and medicines that have negative interactions with other prescribed medicines.²⁶²

Ms Judith King, a witness from the Hobart Hearing, said that a particular medicine her husband was prescribed after a heart attack for a blood clot deteriorates after being removed from its foil seal and becomes ineffective. Despite the manufacturer's instructions stating this, the medication continued to be dispensed outside its foil packaging and in Webster packs under the direction of the Clinical Care Coordinator because it was, Ms King said, 'easier for the nursing staff'.²⁶³

Public submissions also highlighted problems with dispensing medicines. Some submitters told us that pharmacies sometimes dispensed incorrect medicines.²⁶⁴

Conclusion: medication management and prescribing

Much of what we heard about the problems in medication management was as a consequence of inadequate staffing levels and skills, and inadequate supervision by pharmacists. Medicines are overused and prescribed unnecessarily, when alternative interventions can often improve older people's quality of life.

Continence and incontinence

Urinary incontinence and faecal incontinence are conditions that are defined by an accidental or involuntary loss of control of the bladder and bowel respectively.²⁶⁵ It is an intensely personal and often stigmatising condition that requires time and the right skills to manage appropriately. The evidence indicates that far from appropriately managing the condition or promoting continence, some residential aged care providers unintentionally contribute to incontinence. They do not provide sufficient resources or allow enough time for staff members to assist people to go to the toilet. Incontinence products are overused in aged care, often as a substitute toilet.²⁶⁶

Urinary incontinence is divided into subtypes: stress incontinence, urge incontinence, overflow incontinence (also known as urinary retention with overflow), mixed incontinence and socially engineered incontinence (also known as functional incontinence or disability incontinence).²⁶⁷ These subtypes are dependent on what is causing the incontinence. Stress incontinence is associated with coughing or sneezing and is caused by a loss of function of the pelvic floor muscles. Urge incontinence occurs when a person does not get to the toilet in time and the urge to void cannot be overruled or suppressed. Mixed incontinence involves a mix of causes. Socially engineered incontinence is when a person cannot get to the toilet because of a lack of assistance or because the environment is not conducive to the easy use of a toilet. Where a person is living in residential aged care, socially engineered incontinence should not occur.²⁶⁸ Medication has been shown to cause and exacerbate stress, urge, and overflow incontinence.²⁶⁹ It can also reduce a person's ability to manage their continence by, for example, preventing a person from getting out of bed.²⁷⁰

High quality continence care is critical because 71% of people in residential aged care have experienced urinary or faecal incontinence, or both.²⁷¹ Incontinence has negative effects on people's lives, including increasing the risk of depression and reduced quality of life.²⁷² It can undermine a person's dignity and wellbeing as well as increase the likelihood of pressure injuries and infections.²⁷³ Poor continence care can lead to urinary tract infections, incontinence-associated dermatitis, constipation and faecal impaction.²⁷⁴ Incontinence is also associated with an increased risk of falls, if a person cannot wait for assistance to go to the toilet.²⁷⁵ Incontinent episodes also increase the risk of falls because they create slipping hazards.²⁷⁶

Promoting continence

Dr Ostaszkiwicz explained that good continence management and promotion of continence includes evidence-based assessments to identify individual continence care needs and to identify and treat reversible causes of incontinence.²⁷⁷ Good continence care, according to Associate Professor Michael Murray, National President of the Continence Foundation of Australia, 'should be based on people's preferences and needs, with their dignity maintained and choice optimised'.²⁷⁸

Dr Ostaszkiewicz explained that current guidelines emphasise multidisciplinary screening and assessment to identify and treat potentially reversible causes, followed by conservative interventions—such as pelvic floor muscle training, lifestyle changes, incontinence aids—and/or pharmacological treatments. In her opinion, continence care in residential aged care facilities is not best practice.²⁷⁹

Assistance with using the toilet

A number of witnesses and public submissions identified issues with a lack of assistance given to aged care residents wanting to use the toilet. Nursing staff and personal care workers, as well as older people and their family and friends, told us in submissions that often facilities were too understaffed or staff too overworked to assist older people to go to the toilet.²⁸⁰ We received multiple submissions describing occasions where a person pressed their call bell or requested to go to the bathroom, but had to wait for such a long time that they experienced incontinence.²⁸¹ Several members of the public making submissions said that the wait for assistance to go to the bathroom could be up to 40 minutes.²⁸²

We heard evidence about older people being told to urinate or defecate in incontinence aids because care staff did not have time to assist them. Dr Ostaszkiewicz said that incontinence aids are often used as a substitute for helping people get to and use the toilet—or as the pragmatic solution to time pressures associated with helping people use the toilet.²⁸³ Ms Aalberts-Henderson, whose mother was in residential aged care, said:

You know, we teach children to be continent. It's part of growing up. Mum was put into an adult diaper and one nurse said, 'Just poo in your pants' which was just so undignified for my very dignified mother, and in a way putting a continent [person] into diapers infantilises them. For what purpose? It's inhumane, and of course they didn't want to stand her up, because they couldn't. It seemed it became a problem, a staffing issue. Did they have the staff that were tall enough or willing enough to bring in even a commode or even walk her to the bathroom? It wasn't going to happen. And she said to me one night she used the diaper and I said, 'Mum, why didn't you ring the bell?' and she said, 'I did ring the bell, but nobody came'.²⁸⁴

Ms King told us that it was rare for her husband, Neville, to be incontinent when she cared for him at home.²⁸⁵ She said that this changed when Mr King entered residential aged care:

When he first got there and he had the pull-up pants, he was told not to worry about the toilet, because he was wearing pull-ups. And it was alarming. And it was said in such a casual way, that that was just normal practice. ...

It was really bothering Neville. You know, nobody would choose to be incontinent because they can't get to the bathroom. And to have that ability taken from you when you're aware, it's horrible. It's just one of the many things that crushed people when they go into care processes.²⁸⁶

Many public submissions similarly described situations where people requested help to use the toilet, but were denied this assistance and told to use an incontinence pad instead of a toilet.²⁸⁷

Rationing and changing incontinence aids

A number of witnesses and public submissions referred to inadequate supplies of incontinence pads. Ms Melchhart gave evidence that she found it 'a constant battle' to get enough incontinence pads from her aged care provider.²⁸⁸ According to Ms Melchhart, one of her friends at the facility told her that they did not participate in a happy hour because they did not have access to incontinence pads.²⁸⁹ Ms Melchhart said, 'I have observed this is a continuing battle for my friends in the facility who don't have someone to advocate for them. As a result, they have to sit in wet pads'.²⁹⁰

A number of people making submissions said that some residential aged care providers limit the number of incontinence aids to three or four per person per day.²⁹¹ A former registered nurse who worked in residential aged care made the point that incontinence pads 'were never meant to be a substitute for toileting...I have witnessed a carer remove the faeces from a soiled pad only to then put the soiled pad back on the resident'.²⁹²

Several former aged care workers said that incontinence pads were sometimes kept in locked cupboards.²⁹³ Some described situations when staff members had to fill out paperwork to justify the use of an additional pad. For example:

continence pads were now limited to 3 per day, and the pad storeroom was kept locked so we couldn't access the supply for more. We were told pads needed to be 3/4 full before they should be changed. Imagine, a heavily incontinent person having to tolerate a big fat heavy pad for 8 hours! And faecally incontinent residents? We had to beg for extra pads and sign a form explaining why we needed the extra pad, which was stored under lock and key. And if the pad supply ran low before end of month, then we had 50kg residents in XXL pads!²⁹⁴

Many witnesses and public submissions raised issues about changing incontinence aids, often in connection with rationing. Ms Lisa Backhouse described visiting her mother in hospital after a fall in residential aged care. Hospital staff members showed her an incontinence aid that her mother had been wearing for an extended period of time before the transfer:

Mum was surprisingly calm on my arrival, but the nursing staff were not. They had just finished changing her into a hospital robe and replacing her incontinence aid. There were hushed voices from behind the curtain and a discreet cautious sharing of information; tentative, in breach perhaps of some unspoken policy, but the furrowed brows and low tones illustrated the gravity of concern. The incontinence aid was removed from the waste with the explanation, 'I'm so sorry but I need to show you this, it's important that you are aware.'

I stood for a moment, gaping at the item which clearly had been in use for an unacceptably extended period of time. An item that, in its current condition, breached all levels of basic hygiene and human standards. The ambulance officers had noted the strong odour on entry to mum's room in their paperwork.²⁹⁵

Some people who made submissions described the negative impact being left in incontinence aids had on residents' dignity, as well as their health and wellbeing.²⁹⁶ One submission detailed the lack of care and dignity provided to his wife when she entered residential aged care:

Kathy had been left in her wheelchair until 5pm while staff organised a different bed and mattress, this meant she was in her chair for over 9 hours. ...By the time that Kathy was put into bed Martha advised that her wheelchair was 'putrid'. She had been left in the same incontinence aid that I had put on her before taking her to the facility and she was very obviously in pain. There was no care and no dignity.²⁹⁷

Conclusion: continence and incontinence

Continence and incontinence care in residential aged care often do not afford respect and dignity to older people. Staff do not have the time needed to assist residents to go to the toilet in a timely manner. Too often there is a routine use of incontinence aids to manage workload. Where people are reliant on incontinence aids, they may not have a sufficient supply. Not only does this risk adverse health outcomes, including creating or exacerbating incontinence, it impacts on older people's dignity, quality of life and wellbeing.

Infection prevention and control

Infection control should be a central feature of care for aged care providers. In residential aged care, an infection outbreak has the potential to cause serious illness and death among vulnerable older people. Influenza and gastroenteritis are common infectious illnesses that occur in residential aged care. Influenza, commonly known as the flu, is a contagious disease of the respiratory tract caused by a virus.²⁹⁸ Gastroenteritis, sometimes referred to as gastro, is a highly infectious illness triggered by the infection and inflammation of the digestive system.²⁹⁹ In 2017–18, 45% of aged care services reported at least one potential influenza outbreak and 31% reported at least one gastroenteritis outbreak.³⁰⁰ Influenza and gastroenteritis outbreaks can be life threatening for older people, particularly those receiving aged care. Between January and July 2020, 28 of the 36 deaths associated with influenza in Australia were older people.³⁰¹

On 11 March 2020, coronavirus disease (COVID-19) was declared a pandemic by the World Health Organization.³⁰² COVID-19 is caused by the severe acute respiratory syndrome coronavirus 2 and is highly infectious. People aged over 80 years are most at risk of death from COVID-19, followed by people aged between 60–79 years. As at 9 December 2020, there were 685 people living in residential aged care in Australia who had died due to COVID-19. At that time, there had been 2049 infections among people living in residential aged care.³⁰³ The independent review into the outbreak at Anglicare Sydney's Newmarch House facility found that 'imperfect' infection prevention and control practices led to transmission of the virus to staff members and other residents.³⁰⁴ Seventeen deaths 'were directly attributed to COVID-19' at Newmarch House.³⁰⁵ This is but one example. In our special report, *Aged care and COVID-19*, we noted that some measures the Australian Government had taken with respect to supporting the aged care sector were insufficient to ensure preparedness of the sector for dealing with an outbreak of a pandemic infection.³⁰⁶

Best practice

According to the World Health Organization, infection prevention and control is a ‘practical, evidence-based approach preventing patients and health workers from being harmed by avoidable infections’.³⁰⁷ Standard 3 of the Aged Care Quality Standards requires service providers to minimise ‘infection-related risks’. Aged care providers are expected to achieve this in two ways: through infection control and reducing the risk of antibiotic resistance. They are expected to ‘assess the risk of, and take steps to prevent, detect and control the spread of infections’ and minimise infection-related risks by implementing ‘standard and transmission-based precautions to prevent and control infection’.³⁰⁸

Preventing and managing outbreaks

While we did not hear substantial evidence about influenza or gastroenteritis outbreaks in residential aged care in our hearings, Ms Virginia Clarke gave evidence about her late father’s experience as a resident at Newmarch House:

The only time my family ever had issues at Newmarch House before the COVID-19 pandemic was when there were lockdowns for things like the flu and gastro. I used to get an email from Newmarch House to say they would be going into lockdown, and we knew that we wouldn’t be able to visit Dad or take him out. My family wouldn’t get a lot of time to act after the notification, but we could drop things off for Dad during these lockdowns, like his washing, by leaving them outside the door. The staff would then drop them off to Dad. I would receive another email from Newmarch House when the lockdown was lifted, and that would be the extent of the communication.

These lockdowns were short—the longest was around two weeks. I thought that Dad was always okay during them, because my family could still talk to him over the phone. I thought he seemed happy during these lockdowns because he knew the reason for why they were happening, and he would still be getting his meals on time. Provided Dad had his usual routine, I know he would be fine during lockdowns.³⁰⁹

We received some public submissions that raised concerns, however, about how residential aged care facilities manage influenza and gastroenteritis. Some submissions raised concerns about staff training in infection control and hygiene, as well as limited access to gloves, wipes and personal protective equipment.³¹⁰ Others told us that during winter, influenza outbreaks ‘rapidly spread through nursing homes’ and staff shortages can result.³¹¹

Some submissions described the lack of concern for older people who exhibited ‘flu-like symptoms’:

Recently I requested for an RN [registered nurse] to view my father after several days of him deteriorating with flu like symptoms. Note here that several days had passed and no one had noticed he was sick, coughing and sneezing around the facility...³¹²

Another said:

Staff were supportive and respectful of her decisions and she died at the facility. Unfortunately not peacefully as she wanted but gasping [for] every breath due to an Influenza A virus introduced to the facility by a returning resident from a public hospital—it took 5 days to confirm that this returning patient did indeed have the virus.³¹³

One person expressed concern about aged care staff members who were unwell still being required to attend work and care for residents.³¹⁴ Another said:

The staff are rewarded for not having any 'sick days' off, whereby they are given a bonus by management, if you have a sick day, you do not receive the bonus. This is against public policy for immunocompromised people, where by if you have a cold or flu, you should not present to an aged care facility, as this could harm the residents and even result in death. There are posters everywhere for this in the facility but at the end of the day, management is putting profit over care of residents.³¹⁵

How facilities respond to outbreaks of infection can impact the quality of care they provide. Some facilities introduce lockdown measures, which can be detrimental to the health and wellbeing of residents. One person described her mother as dying 'from neglect' during a lockdown period:

My mother, suffering dementia, and was unable to eat or drink for herself. My father lived directly behind the care home ... They had been inseparable since marriage.

He fed and gave her water 3 times a day, every day. The staff just did not do it. The care home was private at a large cost. What were we paying for? Unsure.

The care home enforced a shutdown due to internal infections prevention for 2 weeks. Dad, WWII injured veteran, was not allowed in. Mum died from neglect inside the two weeks. (and not from an infection!)³¹⁶

Ms UY gave evidence of the mental health impacts that COVID-19 restrictions had on her father. Her father died in residential aged care in June 2020. He did not have COVID-19. Ms UY told us that due to her father's diagnosis with motor neurone disease, he was not able to speak. She said that touch was vital to him: 'contact by hands and hugs became important ways to communicate'.³¹⁷ Ms UY described the decline in her father's mental and physical health during COVID-19 isolation—she said he became unhappy, seemed to lose his purpose and sense of life, and was physically getting sicker.³¹⁸ Ms UY told us:

I believe Dad gave up wanting to live because his family support and connection was disconnected. As an Italian man, he had lost what he called his 'blood support'. Without this, he did not have meaning. This is not what my family had signed up for, however I felt as though we were all trapped by rules and the fear of catching the virus.³¹⁹

Ms Merle Mitchell AM, who lives in residential aged care in Victoria, anticipated that mental health issues would arise following the lockdown and ban on visitors in aged care. She said that mental health needed to be considered more by aged care providers during lockdown and isolation periods:

I think mental health needs to be much more deeply addressed at this time. I have thought 'you're looking after my physical health, but what are you doing about my mental health?'³²⁰

Ms Mitchell told us that she noticed deterioration in other residents, particularly those living with dementia. She also commented on the lack of access to health professionals, particularly physiotherapists. Ms Mitchell acknowledged the success of her facility in keeping the virus out, but asked 'at what cost?'³²¹

Many public submissions echoed the concerns about the impact COVID-19 restrictions had on older people's mental health.³²² Some people said that their loved ones in aged care, particularly those living with dementia, were confused and struggled to understand what was going on.³²³ One person's submission said: 'If COVID19 doesn't kill my Dad the isolation will'.³²⁴

Public submissions suggested a number of areas for improvement in infection control and management in aged care, including employing staff members with infectious disease expertise and training.³²⁵ Other evidence and information highlighted the importance of having a clinical governance framework that included infection control and the importance of clinical governance expertise at the board or management level.³²⁶ Several witnesses agreed that access to accredited infection control and prevention specialists could assist the aged care sector.³²⁷

Our special report on aged care and COVID-19 identified four areas for immediate action and made six recommendations to the Australian Government, including for immediate measures to address problems in infection control. We recommended, amongst other things, that residential aged care homes should have one or more trained infection control officer as a condition of accreditation.³²⁸ On 30 November 2020, the Australian Government announced that it had allocated additional funding for infection control and that by 1 December 2020, all residential aged care facilities must have an infection prevention control lead staff member.³²⁹

Conclusion: infection prevention and control

Without adequate infection prevention and control strategies, vulnerable older people are at increased risk of serious illness and death. There should be a proactive approach to preventing infections in aged care. When infection prevention and control measures are implemented, aged care providers should consider the impacts these measures can have on residents' health and quality of life.

Social and emotional needs

We have heard about care that did not meet people's social and emotional needs. We heard numerous examples throughout our inquiry about care that was dehumanising or that failed to recognise individual needs or to support people to make meaningful choices. We also heard numerous examples of what we call small oversights, such as a cup of tea placed just out of reach or a request not acknowledged.

In isolation, these 'oversights' may not be considered significant instances of substandard care. But when repeated over time, they can be more than just unkind, they can amount to neglect. They can have significant implications for a person's health and wellbeing. A failure to meet people's social and emotional needs can lead to poor mental health, which can reduce motivation to eat and maintain mobility. In severe cases, the failure to meet a person's social and emotional needs constitutes abuse.

A person's social and emotional needs refer to the circumstances that are required for them to feel connected to others and happy. As people age, their social and emotional needs can change. This may be especially true for people experiencing cognitive decline, an increase in care needs, or a move to permanent residential care. As Mr Jason Burton, Head of Dementia Practice and Innovation at Alzheimer's WA, explained, care environments often lead to a diminished sense of personhood where people 'give up on life and deteriorate very quickly'.³³⁰

Supporting social and emotional needs in aged care

Meeting people's individual social and emotional needs in an aged care context can be achieved through an approach to care delivery that acknowledges the individual ways that people respond to ageing. An important part of meeting individual needs involves maintaining and protecting people's sense of self and their right to make meaningful choices.³³¹ Care should be delivered in a way that is 'respectful of, and responsive to the preferences, needs and values of those receiving care and those who care for them'.³³² Mr Bryan Lipmann, Chief Executive Officer at Wintringham Aged Care, described the value of encouraging genuine relationships between staff and residents in aged care.³³³

We commissioned the National Ageing Research Institute to conduct a study about the extent to which people's social and emotional needs are met in residential aged care in terms of measurable quality of life factors. While most residents surveyed reported high satisfaction with their quality of life, there was a significant share (17%) of residents who rated their life satisfaction as 'low'.³³⁴ Further analysis of these results is in the discussion of the extent of substandard care later in this chapter. Some aged care services in Australia do not meet the individual social and emotional needs of older people. This is often a result of overworked and under-skilled staff.

Choice and control

We heard that when people enter residential care they can lack opportunities and support to make meaningful choices about their lives. Their right to take risks and exercise control over their lives can be overridden because 'safe care' is prioritised.

Mr Bernard Cooney summed up his experience of residential aged care towards the end of his life: 'Not much empathy is needed to appreciate that it is hard to retain a sense of personal dignity when, little by little, individual autonomy is lost.'³³⁵ Ms Melchhart described feeling that her wishes about privacy are mostly disregarded.³³⁶ Ms Emma-Kaitlin Murphy, a registered nurse, spoke about a married couple who lived in the same residential facility but in different wings:

He's allocated one hour twice a day to see his wife and he will come and ask us many times a day to come and see her, and often due to time constraints we have to let him know that he has already seen her twice today, he has to wait until tomorrow or it's not his time yet. Or sometimes staff might be busy and he might only be able to see her once a day.³³⁷

An aged care worker said this in a public submission:

All residents were put into bed in the evening by 7pm, without any choice or decision in relation to what they wanted. There was 2 to a bed room with the smallest wardrobe and a small bedside table with curtains to divide the room, it did not present a home environment or even a personalized space for the residents to make [their] own.³³⁸

A younger woman living in residential aged care told us that the lack of individualised personal care resulted in a loss of identity. She said:

I was no longer Kate, I was room number 15.³³⁹

Connections between staff and people receiving care

A lack of connection between staff members and people receiving care, including people being ignored or not communicated with, also emerged as a common experience. Ms Mitchell said that given the structure of the aged care system ‘staff cannot implement compassionate person-centred care’.³⁴⁰ She gave the example of staff members harassing people to finish their food. She said that some people who struggle to eat quickly will say they are finished so as not to be a problem. A public submission also highlighted mealtimes as a missed opportunity for staff to connect with residents:

Many staff have no connection to the person they are feeding. I have seen staff standing next to a resident who is sitting down low in a chair and feeding them with a spoon Much like when you go to a petrol station and stand near your car when filling up with petrol. There was no eye contact to see if the resident was enjoying the meal or ready for the next spoon of food and no communication to see if they were still hungry or wanted a drink of water between mouthfuls. Just silence and the [shovelling] of food as quickly as possible into the resident's mouth...³⁴¹

One man said that his mother's 90th birthday highlighted to him a significant lack of personalised care and attention:

the sudden increase of visitors by relatives & friends visibly improved her mood and cognitive awareness. Symptoms of her vascular dementia seemed to evaporate as she became more lucid and happy. This was further evidence to us that Mary is not experiencing any level of stimulating engagement from the [facility name removed] environment.

Sadly, [facility name removed] staff were also totally unaware of her 90th birthday—such a significant milestone and totally unacknowledged until family members alerted them to her special day.³⁴²

Mr Cooney gave an example of the sense of helplessness that can arise from staff members completing tasks with carelessness or a lack of thought for the needs of each person:

Each day, cups of coffee are brought to my room at the appropriate time by a kitchen staff member. The cup is then placed on a trolley or small table. I cannot move my chair to reach for it and even if I could do so I would be unable to hold the cup or drink without assistance. It does not seem to me to be unreasonable to expect, given that my physical condition is well known to the facility's administrators, that this assistance would be automatically provided. That does not happen and I find myself disinclined to press my buzzer for a cup of coffee, when it is difficult enough to secure a response at times when I am experiencing severe discomfort and require staff members to readjust my position. The coffee will usually remain on the trolley or table until the cup is removed or I am assisted to drink by a visitor.³⁴³

Ms DI described the night her mother died in residential care. She said staff members were ‘too busy’ to provide any support or comfort for her:

they seemed to rush in and out of the room. They seemed to be very busy and run off their feet. ...[name removed] said to me later, ‘We’re so busy tonight. There’s too many issues. We’re so understaffed.’³⁴⁴

Ms Murphy explained that time constraints are a significant barrier to providing holistic care:

Unfortunately, I often do not have time to provide additional personal or emotional care to those who seek it. I simply do not believe it’s possible for anyone to provide safe, holistic, person-centred care to upwards of 30 people within the time constraints. Let alone ensuring every resident feels they are much more than a task to complete in a workplace.³⁴⁵

Ms Bethia Wilson AM, Wilson and Webster Consultancy Services and a former Victorian Health Services Commissioner, explained the importance of creating a supportive culture for both staff and residents in aged care:

Lack of friendliness and kindness could be driven by poor staffing management practices. If staff are not treated with kindness, that is with flexibility and concern about their professional and personal well-being, then this tends to flow on to how they treat the residents.³⁴⁶

We also heard about older people in residential care who have been verbally disrespected by staff members, as well as being left unattended during times of distress. Ms Sarah Holland-Batt described her father’s experience in residential care. A staff member told Ms Holland-Batt’s mother that one of the carers had been deliberately victimising her husband by isolating him for hours, knowing that he needed to go to the toilet.³⁴⁷

We received many public submissions from people who gave accounts of staff members who were rude and generally unpleasant.³⁴⁸ One woman told us:

On a multitude of occasions, I have overheard interactions between staff members and mum. They’re rude, abrupt, shouting, abusive, and generally unpleasant. Until, that is, they become aware of my presence and their entire disposition changes.³⁴⁹

Much of what we heard about failures to meet people’s social and emotional needs related to the time that staff had to provide care. We heard that a high workload results in a busy, task-orientated workplace in residential aged care. People have told us that staff rushing about completing task after task leaves little time or value to be placed on the activities that facilitate genuine caring and trusting relationships.³⁵⁰ The aged care system should be able to deliver compassionate and kind care built on respectful relationships.

Isolation, boredom and lack of meaningful activities

When people enter residential care, they often lack the support and opportunity to engage in meaningful activities and stay connected to the broader community. This can result in isolation, boredom and lack of engagement.

Ms Janette McGuire, a Forgotten Australian who spent two weeks in a short-term aged care facility, said:

The facility would have silly games like bingo and things. Some people might have liked it, but it wasn't right for me. It was patronising. We are people with minds and brains. I tried to get used to the way I was treated at the facility. I don't think I could ever get used to it.³⁵¹

A number of people told us in submissions that there is a lack of meaningful and varied activities on offer to people living in residential care. A woman described the impact of a lack of choice in activities on her mother:

There is no stimulation as the residents in the Memory Support Unit just sit in the lounge in front of a television and stare. It makes me very sad to see my mother's dignity being destroyed...The carers do not have the time to listen to Mum and try to understand what she is asking and the more she is hurried the more she gets confused.³⁵²

Another person making a submission said:

I know mum's depression could be fixed with a cat. Or a dog. ...my sister does take her dog to visit occasionally (which the staff support). Essentially to improve mum's wellbeing she needs to build a relationship with an animal, a cat at the end of her bed. ...Mum doesn't leave her room, a lot of the activities are linked to the common areas, like the virtual reality room (that is never open, and you need to book an appointment).³⁵³

People receiving aged care are not always supported to remain socially connected to the broader community. Staying actively involved in the community is an important component of helping people live at home for as long as possible.³⁵⁴ And whether a person is receiving aged care at home, or in a residential setting, social connection is a key part of a fulfilled and meaningful life. Mr Robert Fitzgerald AM, the NSW Ageing and Disability Commissioner, when talking about 'community inclusiveness' said:

COVID has demonstrated, beyond any shadow of a doubt, that a society doesn't function well when that's gone. And in the case of older people, those community connectedness, the neighbourhood connectedness, is very important.³⁵⁵

Ms Elizabeth Drozd, Chief Executive Officer of Australian Multicultural Community Services Incorporated, gave evidence about the needs of people with culturally and linguistically diverse backgrounds. She said:

Community connection, time together, speaking a common language with peers, maintaining relationships and a sense of purpose at a time described as much more valuable than cleaning or visiting services.³⁵⁶

Without adequate support, remaining engaged in the community can be difficult for some older people. Increased frailty, loss of mobility or bereavement can make people particularly vulnerable to social isolation. Some people may find that their existing networks fall away as it becomes more challenging to maintain hobbies and social circles.³⁵⁷ Professor Henry Brodaty AO, a psychogeriatrician, physician, psychiatrist and Scientia Professor of Ageing and Mental Health at the University of New South Wales, said:

We see that residents are very lonely in nursing homes. I had a PhD student who, her thesis was on social relationships in nursing home. The median number of relationships that a person in a nursing home had was one. That means 50 per cent had zero, and most of the relationships are with the staff.³⁵⁸

The risk of isolation is more significant for people without family and friends to visit. Mr Kevin Littley, who spoke about his daughter's experience as a younger person in residential aged care, said:

So, yes, she was pretty much—very lonely. If it wasn't for Carol and myself and her sister, she wouldn't have had any visitors and any outside contact because she was pretty much in her room.³⁵⁹

The COVID-19 pandemic and the restrictions put on visitation highlighted the importance of social connection in residential care. Ms Julie Kelly, a psychologist, said that 'loneliness has had a real impact on their [residents'] mood and, especially, on depression'.³⁶⁰

A lack of community connectedness can be even more of an issue in home care. Professor Johanna Westbrook, a Professor of Health Informatics and Patient Safety, said that social isolation and loneliness pose one of the biggest challenges to providing high quality care in a person's home.³⁶¹ People can be very isolated in their home, and those in need of social support can fall through the cracks and be 'left to fend for themselves'.³⁶² Sometimes the only social contact a person has is with a service provider.³⁶³ Ms Beryl Hawkins, a recipient of home care, said:

I don't have many visitors, really—I used to, but my life has changed completely.

I think that there is a whole generation of people who are 80, 90 and 100 years old, sitting with their eyes closed, waiting to die.³⁶⁴

Reflecting on what could have been done to help her and others, she said:

What I love most of all is when someone walks into my unit and says 'would you like a cup of tea?'...I think that if you could get volunteers that would come to you with a dog or a child and take you down to the park for half an hour, that sort of thing could help.³⁶⁵

Social connection and engagement in the community is a vital part of high quality aged care. But the current aged care system is leaving too many older people isolated and disconnected.

Conclusion: social and emotional needs

The lack of care and support for people's social and emotional needs is a consequence of a number of problems in the current aged care system. Staff do not have the time or skills to provide individualised care to people in residential aged care. The task-based focus of work in residential aged care does not sufficiently allow consideration for the person who is being cared for, their wants or social and emotional needs. There is an inadequate focus on helping people receiving aged care services stay connected to the broader community. The personhood of people receiving aged care is too often disregarded. This, too, must change.

Diversity and cultural needs

The aged care system often struggles to provide appropriate care to people with diverse needs. There can be a lack of understanding and respect for people's culture, background and life experiences and how this can impact on how they want to receive care. Care that does not acknowledge and respect different life experiences is substandard. We discuss the problems people with diverse needs face in accessing the aged care system in Chapter 2 of this volume. Many of these same issues—poor communication, a lack of culturally safe care and trauma informed care—also affect the quality of care provided to people once they are in care. There is some overlap in our discussion in these chapters but it is important to identify these problems as affecting both access to, and the quality of, care people receive.

In our hearings, we heard evidence from people with culturally and linguistically diverse backgrounds, people who identify as part of the LGBTI communities, care leavers, Aboriginal and Torres Strait Islander people living in urban areas and in rural and remote communities, people who are or are at risk of becoming homeless, and veterans.

Best practice

Given the breadth and diversity of people's needs, there is no one-size-fits-all aged care model. Some aged care providers meet the needs of people with diverse backgrounds. They may provide strong communication and translation services, employ bilingual staff and have mechanisms for communicating with people with limited English or who are nonverbal.³⁶⁶ Care should be non-discriminatory and culturally safe. We heard about the importance, to meet people's needs, of recognising their culture and background and making extra effort to acknowledge people as individuals. It is also important to have trained members from diverse groups among staff, as well as to train all staff about cultural safety.³⁶⁷

Aged care needs to be trauma-informed at all levels. Trauma-informed care is care that understands and recognises how trauma affects people's lives, service needs and the way they interact with services, and seeks to avoid re-traumatising people.³⁶⁸ It can be beneficial for providers to partner with peak bodies and advocacy groups who can share specialist knowledge to assist in the provision of good care in these cases and to prevent social isolation.³⁶⁹

Communication

Communication barriers may exist due to differences in language or the need for augmented communicative methods. Augmented communication may include hand, facial and body signals and simplified communication for people with cognitive impairment. Language is one of the major barriers for many Aboriginal and Torres Strait Islander communities and people from culturally and linguistically diverse backgrounds who have little or no English proficiency. We heard that communication barriers can make providing care more difficult and can also lead to social isolation, mental illness, discrimination, lack of cultural safety and abuse.

We heard that older people can lose the ability to retain language learnt later in their lives because of dementia-related disease.³⁷⁰ Mr George Akl described his late father's experience in residential aged care. Mr Akl's father was born in Egypt and his first language was Arabic, but he spoke fluent English. In 2016, Mr Akl's father was diagnosed with Lewy body dementia. His ability to speak English subsequently decreased considerably. According to Mr Akl, this inability to communicate exacerbated his father's symptoms of dementia.³⁷¹ Mr Akl raised the matter with the provider:

Not quite brushed to the side, the matter seemed to be beyond the scope of their system. Short of the volunteers and strategies like drawings that Dad could point to when his English becomes incomprehensible, there appeared to be no effective policy or resources relating to the complex communication issues for ESL [English as a Second Language] people.³⁷²

Mr Angelos Angeli described the home care services received by his mother, a Greek Cypriot who had a low level of English proficiency. He said his mother was socially isolated due to the communication barriers between her and the care staff.³⁷³

We received many public submissions highlighting failures of services to provide adequate measures of communication for people who have limited English.³⁷⁴ One person's submission said:

Her stroke has left her speaking Italian (her first language) she spoke and understood English very well now she is yelled at 'ENGLISH LUCY, I CAN'T UNDERSTAND YOU!' she is ashamed and embarrassed as she feels like they treat her like she is doing it on purpose or that she is somehow now an idiot gibbering to them.³⁷⁵

Ms Jaklina Michael, Diversity Manager at Bolton Clarke Aged Care Services, said that there are many situations when an interpreter is critical to understand the needs of a person from a culturally and linguistically diverse background.³⁷⁶

Culturally safe care

'Cultural safety' aims to ensure people of a different cultural background to the caregiver or provider can feel safe in their experience of care.³⁷⁷ One definition of cultural safety is:

an environment which is safe for people; where there is no assault, challenge or denial of their identity, of who they are and what they need. It is about shared respect, shared meaning, shared knowledge and experience, of learning together with dignity, and truly listening.³⁷⁸

While aged care services should meet the cultural safety needs of all older people, we heard numerous examples of failure to do so.³⁷⁹ Ms Moreen Lyons, then Chief Executive Officer at Aboriginal Community Elder Services, told us:

I've had residents come back, really distressed from quite blunt interactions with culturally-insensitive providers...Understanding the ceremonies are vital, or—people will not feel settled and cared for appropriately, if those things are not in place and not understood. And a part of that is having Aboriginal employees working at the service.³⁸⁰

Some public submissions addressed concerns about cultural safety for Aboriginal and Torres Strait Islander people in aged care:

Far too often elderly women are receiving 'women's business' care performed by young male carers who often can't speak enough English to understand let alone understand the elderly Indigenous resident or their cultural requirements.³⁸¹

A submission from an aged care worker described an Aboriginal person who lived in a residential aged care facility 'where there were no programs for him, no therapy, and stuck in the room constantly. Dignity and respect should be priorities for residents'.³⁸²

Ms Anne Tudor described her and her partner Ms Edie Mayhew's experience, as a lesbian couple, with home care. Ms Tudor's partner, Ms Mayhew, was diagnosed with younger onset dementia in 2010 and, in May 2015, accepted a Home Care Package. Ms Tudor described what she felt was a lack of acknowledgement of their relationship from the home care provider, including a lack of careful consideration about the carers they provided.³⁸³ She also told us that some workers made her and Ms Mayhew feel uncomfortable:

There were some carers that were sent to our home that I did not feel comfortable around. Edie is spontaneous, when she wants to physically hug me or tell me how much she loves me, she should feel free to do that, especially in her own home. ...Several workers who came to our home dampened Edie's spontaneity and this frustrated me as she withdrew into herself. Our whole lives had to fit around the availability of [home care program] staff and over the years we faced disappointment after disappointment with them.³⁸⁴

Ms Tudor said that while this experience was not an example of 'shocking overt discrimination', it illustrated a lack of effort to ensure their needs as members of the LGBTI community were acknowledged and met.³⁸⁵

Ms Samantha Jewell, Executive Manager of Sales & Marketing at Lifeview Residential Aged Care, gave an example of lack of cultural safety and discrimination towards a transgender woman when she was receiving home care:

A lot of the staff that would come and care for her would say, 'But you're a male, you're not a female' and that was quite disturbing to her. A lot of her paperwork used to come in her former male name even though she had changed her name quite a few years ago; there was no recognition of that.³⁸⁶

Conclusion: diversity and cultural needs

The aged care system is often unable to care appropriately for older people with diverse needs. There can be a lack of understanding and respect for people's culture, background and life experiences and how this can impact on how they want to receive care. As a result, some older people in aged care are not supported to make meaningful choices that reflect their individual backgrounds, beliefs and needs. This is unacceptable. The aged care system should be equally welcoming and supportive of everyone needing care.

3.3.4 Conclusion: nature of substandard care

In this part of the chapter we have identified the nature of substandard aged care. We outlined the experiences of people in care, and those of their families and friends. We have also captured the experiences of staff, students, and health professionals who were likewise concerned about the quality of care people were receiving. Substandard care can take the form of deliberate acts of harm and forms of abuse—physical, sexual or through inappropriate restrictive practices. It can also occur in complex and routine areas of care—from dementia care to the daily food and nutrition provided to people.

In this chapter, we have sought to give voice to those in the aged care system. Their experiences have common themes: staff who are overworked, rushed and generally under pressure; a lack of clinical skills and failures to identify care needs; staff responding and reacting to crises, rather than promoting wellbeing and maintaining function; patronising attitudes and lack of respect; restrictions on resources, including appropriate aids, equipment and nutritious food; poor care planning and communication; and poor leadership and management.

The experiences recounted in this chapter are those of individual people—they are instances of substandard care. But they are reflective of so many others. We received a vast number of submissions and heard numerous people at forums tell similar stories. People have told us that, far too often, substandard care is a problem across the aged care system and that older people are suffering as a result. In the next section, we identify what the available data can tell us about the extent and distribution of this substandard care.

3.4 Extent of substandard care in the aged care sector | Commissioner Pagone

Our Terms of Reference require us to inquire into the extent to which aged care services meet the needs of people accessing them and the extent to which substandard care is being provided.³⁸⁷

We received a lot of evidence and many public submissions. We commissioned research and commissioned our own analysis to try to understand the extent of substandard care. Further, many moving personal accounts of poor care were described at community forums. It is clear to us from all this effort the extent of substandard aged care is too high and is unacceptable.

While we differ in our approach about ascertaining the extent of substandard care, I agree with Commissioner Briggs's description of the processes we have used to inquire into the issues and her summation of the research findings in parts 3.5 and 3.6.6 of this chapter. Accordingly, I will not repeat that content other than to provide context for my own remarks.

Commissioner Briggs has sought to express numerically the extent of substandard aged care but I am not able to conclude from the material that the extent of substandard care can be expressed numerically in a way that is meaningful to me, and which represents adequately the evidence and extensive materials I have seen. A National Ageing Research Institute report, for example, concluded that more than 30% of respondents to a survey indicated that some aspect of the quality of their care and services was failing them, but such a finding may imply more than it establishes.³⁸⁸ The experience of a survey population of 391 needs to be treated with caution. It also cannot be understood to mean that about one in three people across the entire sector was experiencing the same level of substandard care for the entirety of their time. Questions of quality, time and reliability of a sample are all relevant to the extent of substandard care and all are apt to be obscured by expressing the care as a number.

The fact is that each case we heard of substandard care was a case that should not have happened. Service providers should not tolerate any degree of substandard aged care, especially to those who may be frail, vulnerable or dependent. There is, in my view, no threshold under which the community should tolerate substandard aged care. Even if 5% of people receiving aged care endured substandard care, that would still be unacceptable.

I do not believe it is currently possible to ascertain the precise extent of substandard care in aged care. For the reasons set out by Commissioner Briggs, I consider that the data is not always complete, reliable or capable of verification. Each dataset produces a different measure of the level of substandard care. The administrative data Commissioner Briggs summarises was not collected for the purpose of ascertaining the extent of substandard care. The absence of a shared understanding of what constitutes ‘substandard care’ is another barrier to accurate quantification. While all of the research demonstrates an unacceptable level of substandard care in the system, it does not produce a consistent explanation of the extent of substandard care.

The National Ageing Research Institute, in partnership with Ipsos and the Social Policy Research Centre of the University of New South Wales, undertook two surveys of 391 residential aged care residents and 1223 people receiving home care or respite care, or their proxies.³⁸⁹ The surveys show that 33% of people who received residential care, 44% of people who accessed home care, 51% of people who received community respite care, and 46% of people who received residential respite believed that one or more of their care needs, across a number of areas, were sometimes, rarely or never met.³⁹⁰ Analysis of this data by Flinders University suggests these figures may be understated—that is, more people’s needs were only sometimes met—if the adequacy of complaints handling is taken into account for home care and residential care.³⁹¹ This research and analysis points to a significant issue, but in my view it does not provide an adequate basis to determine objectively the extent of substandard care.

Complaints data shows that the number of complaints made about residential aged care and home care increased significantly between 2014–15 and 2019–20. Those increases exceeded what would be expected from the increase in the numbers of people receiving care. In 2019–20, there were an average of 2.59 formal complaints made to the Aged Care Quality and Safety Commission per 100 people receiving permanent residential aged care.³⁹² On the basis of the findings in the National Ageing Research Institute research to

which I referred above, I doubt the complaints data accurately represents the extent of substandard aged care. I agree with Commissioner Briggs that there are several reasons for this, one of which is fear of reprisal.

Accreditation data provides a high-level point-in-time view of the potential extent of substandard care across the aged care sector. Approximately one in five audits in 2018–19 concluded that the residential aged care service failed to meet at least one expected outcome under the former aged care Accreditation Standards.³⁹³ Similarly, about one in five quality reviews of home care providers in 2018–19 concluded that the provider failed to meet at least one home care outcome.³⁹⁴ Of course, a provider that has met all accreditation requirements may still be providing substandard care that has not been identified by the regulator.

In 2019–20, following the introduction of the new Aged Care Quality Standards, there was a significant increase in the proportion of residential site audits that concluded that providers did not meet accreditation requirements.³⁹⁵ During this time, two in five residential audits identified that at least one requirement was not met. Similarly, during the same period, over two in five quality reviews or quality audits of home care services identified that at least one requirement was not met.³⁹⁶ Accreditation data shows non-compliance by aged care providers with expected standards. It is likely to be indicative of substandard care. However, it is not a comprehensive and reliable measure of substandard care because it is conceivable that a provider that fails to meet a standard is not providing substandard care.³⁹⁷

The service provider survey that Commissioners McGrath and Briggs conducted demonstrated that there is no shared view among aged care providers of what ‘substandard care’ is.³⁹⁸ For example, one provider reported that a resident’s friend being unhappy with the way he was informed of the resident’s death was an incident of substandard care. Other providers applied a more restrictive definition, capturing far fewer incidents of self-identified substandard care.³⁹⁹

Even so, residential aged care providers reported a total of 272,546 incidents of substandard care for the five-year period to June 2018. For the 2017–18 financial year, residential aged care providers reported an average of 260 occasions of substandard care per 1000 people receiving permanent residential care.⁴⁰⁰

Similar issues arise in relation to using public submissions to this inquiry to gauge the extent of substandard care. We received 9282 general public submissions that were within our Terms of Reference.⁴⁰¹ A total of 42% of the online public submissions within our Terms of Reference were marked as relating to substandard or unsafe care. This likely understates the true proportion, because 32% of the online public submissions that referred to abuse or neglect were not marked by their submitters as relating to substandard care. I regard abuse or neglect as clear examples of substandard care. There were other submissions that described circumstances that I would generally consider to be substandard care, such as the use of restraints (39%).

In 2019–20, residential aged care facilities reported 5718 allegations of assault.⁴⁰² During this time, 244,363 people received permanent residential care. This means that the incidence of reports of suspected or alleged assaults was 2.3%.⁴⁰³ The average number of service providers that reported allegations of assault increased over the past six years; so, too, have the number of reports per provider. In 2014–15, 45% of residential aged care services reported an allegation of assault, a figure that increased to 64% in 2019–20.⁴⁰⁴ Over the same period, the number of reports per service increased from 0.98 to 2.10.

The number of allegations of sexual assault has increased over the past six years in line with overall assaults. There were 426 allegations of sexual assault in 2014–15, which increased to 851 reports in 2019–20.⁴⁰⁵

As concerning as these figures are, they significantly understate the true extent of alleged assaults in residential aged care because resident-on-resident alleged assaults are generally not reportable. A 2019 report by KPMG analysed assault data submitted by 178 residential aged care services. Its analysis found that resident-on-resident alleged assaults were significantly more prevalent than suggested by publicly available figures.⁴⁰⁶ The estimate was that 26,960 to 38,898 physical or sexual assaults per year were occurring that were exempt from reporting across Australia.⁴⁰⁷ When these estimates are added to the existing assault allegations for the 2018–19 financial year, the incidence of assaults increases from 2.16 to 13–18 per 100 residents.⁴⁰⁸ Alarming, the report indicated that as many as 1730 additional reports of sexual assault may result if a broader definition of reportable assault was applied.⁴⁰⁹ Again, the data shows a significant problem, but it does not provide an adequate basis to ascertain the extent of substandard care principally because the reports are of unproven allegations which are rarely investigated.

It is evident from this short summary of the evidence and material before us that there is too much substandard aged care: the problem is clear. It is necessary to introduce lasting reform to ensure substandard care is no longer a feature of aged care in Australia.

3.5 Extent of substandard care in the aged care system | Commissioner Briggs

Our Terms of Reference require us to inquire into the extent to which aged care services meet the needs of people accessing them and the extent to which substandard care is being provided. This was a difficult task, but it is something that I have considered for over two years. The evidence on substandard care that Commissioner Tracey and I heard about in the hearings from May to August 2019 has been particularly striking to me. My conclusions are also informed by the nature and number of distressing stories I heard at community forums around the country—these have left an indelible impression.

The sheer number of submissions and evidence about negative experiences of aged care, and the consistency of their accounts tell us that too often aged care services are not meeting the needs of people. They also tell us that too often there is substandard care across the aged care sector. It is clear this substandard care is widespread. It is harder to quantify the extent of this substandard care.

To answer this question of how often aged care is substandard, Commissioner Pagone and I have considered a number of existing data sources, including Australian Government administrative data. The Victorian Government holds more extensive data about its public sector residential aged care facilities and we considered this as a valuable source of supplementary data. We have also conducted our own research projects or commissioned others to do so. Earlier in this chapter, we referred to some of this data when it was relevant to the specific area of care we were discussing. Here, I focus on the system-wide data and what it can tell us more generally about substandard care.

Analysing this data has been a complex and resource-intensive task, but an important one. There are a number of challenges in analysing this data. The data is variable and inconsistent, does not share a definition of substandard or high quality care, focuses on different aspects of care, was often gathered for an unrelated administrative purpose, and is, in some instances, of poor quality. We also found that there is not a shared understanding of substandard care across the aged care system. In addition, quality data is not routinely collected in a way that makes it easy to determine whether people are receiving substandard or high quality care.

We received sufficient evidence, however, to be assured that some people receive high quality aged care, albeit that the quality of care is variable across the aged care sector—with the type of aged care service provided, organisation type, and size of provider all likely to affect the quality of care.

Viewed as a whole, however, the data tells a story of unacceptably high levels of substandard care.

A number of very disturbing themes are apparent from my analysis:

- It is likely that at least 1 in 3, or over 30%, of people in aged care have experienced substandard care.
- In some areas of care, the data is clearer about the extent of substandard care, including:
 - the incidence of assaults may be as high as 13–18% in residential aged care
 - there is a clear overuse of physical restraint in residential aged care
 - in residential aged care, some 47% of people have concerns about staff, including understaffing, unanswered call bells, high rates of staff turnover, and agency staff not knowing the residents and their needs
 - in home care, one-third of people have concerns about staff, including continuity of staff and staff not being adequately trained
 - similarly, in residential respite care and the Commonwealth Home Support Program respite care, about 30% of people have concerns about staff, including understaffing, continuity, unanswered call bells, training and communication.
- Substandard care has become normalised in some parts of the aged care system, such that people have low expectations of the quality of their care.

In subsections 3.5.1–3.5.5 and section 3.6, I explain the basis for my conclusion that substandard care has been experienced by one-third of all older people in aged care. I present a large number of statistics relating to substandard care. It is important to remember that behind the statistics are real people—people who did not receive the care that they needed, and whose health and wellbeing may have suffered as a result. Irrespective of the precise proportion of people who are affected, the extent of substandard care in Australia’s aged care system is inexcusable. Swift and deliberate action is needed to fix this situation for the current generation of older people and for future generations.

3.5.1 Administrative data and research

In reaching my conclusions on the extent of substandard care, I have considered a number of data sources.

Through the life of our inquiry, a substantial amount of administrative data was obtained from government bodies and we supplemented this with publicly available data. This has included:

- Aged Care Complaints Data—quantitative data on the number of complaints submitted to the Australian Government about aged care services, 1 July 2014 to 30 June 2020
- Aged Care Accreditation Data—quantitative data on the number of times accreditation activities were carried out and the outcomes of these activities and on whether service providers were unable to meet specific accreditation standards during two separate periods, 1 July 2014 to 30 June 2019 and 1 July 2019 to 30 June 2020
- Aged care compliance data—quantitative data on the number of times aged care services were sanctioned or issued a notice of non-compliance, 1 July 2014 to 30 June 2020
- Compulsory Reporting data on assaults and unexplained absences—quantitative data on the number of times residential aged care facilities reported allegations of assault, and missing residents, 1 July 2014 to 30 June 2020
- National Aged Care Mandatory Quality Indicator Program data—quantitative data on the number of times residential aged care services had residents who had experienced a pressure injury, significant or consecutive weight loss or physical restraint, 1 July 2019 to 30 June 2020
- Consumer Experience Report Data—qualitative interviews about people’s experiences of aged care based on responses to 10 questions, 1 May 2017 to 17 July 2019
- Victorian Public Sector Residential Aged Care Service Quality Indicator Data—quantitative data on the number of times residential aged care services had residents who had experienced a pressure injury, significant or consecutive weight loss, or physical restraint, 1 October 2006 to 30 June 2020.

- State and Territory Health departments—quantitative data on hospital admissions and emergency department presentations for people aged 65 years or over, 1 July 2013 to 30 June 2019
- Medicare and Pharmaceutical Benefits Scheme data—quantitative data on the proportion of the population that accessed mental health services and mental health prescriptions, 1 July 2018 to 30 June 2019

To supplement this material, we generated our own data. At the commencement of this inquiry, Commissioner McGrath and I invited all approved Australian aged care service providers to take part in a Service Provider Survey.⁴¹⁰ As part of the survey, providers were asked to report on occasions of substandard care and complaints about substandard care over the five-year period from 1 July 2013 to 30 June 2018.

I have also considered qualitative data on the public submissions people made to us. Of the 10,197 submissions we received (excluding submissions in response to Counsel Assisting's final submissions), 9282 (90.6%) were within our Terms of Reference. Submitters themselves could code their online submissions (which made up 48% of all submissions) as relating to one or all of the Terms of Reference. The staff of the Office of the Royal Commission performed additional coding to ensure that online submissions and those received through other channels were within our Terms of Reference and could be categorised into different areas of care (although many submissions discussed more than one area of care).

The following approach was taken to analysing the data:

- identifying year-on-year trends and points of comparison where available
- taking account of changes to data collection practices, such as when the accreditation and compliance data changed according to the changes in the Aged Care Quality Standards
- exploring factors that led to service providers receiving high numbers of complaints, or being subject to high levels of regulatory or other activity
- categorising the data by organisation type (for-profit / not-for-profit / government), size (small, medium and large) and location (regional / remote / metropolitan).

To supplement this analysis, significant mixed methods research were commissioned. The National Ageing Research Institute, in partnership with Ipsos and the Social Policy Research Centre of the University of New South Wales, was engaged to undertake two large surveys of residential aged care residents and people receiving home care or respite care, or their proxies. These surveys explored the prevalence of aspects of substandard care and reasons that incidents of substandard care go unreported; people's satisfaction with their care; and people's views on their quality of life. The first survey was of people receiving residential aged care in January–March 2020 and the second was of people receiving home and respite care in 16 April 2020–4 June 2020.⁴¹¹

Both research projects adopted rigorous methodologies, including using validated survey tools, a large sample size, and representative samples with good response rates. These studies confirmed the other evidence and data I have considered. They showed that 33% of people who received residential care, 44% of people who accessed home care, 51% of people who received community respite care, and 46% of people who received residential respite believed that one or more of their care needs, across a number of areas, were sometimes, rarely or never met.⁴¹² Analysis of this data by Flinders University indicates these figures worsen—that is, more people’s needs were only sometimes met—when the adequacy of complaints handling was taken into account for home care and residential care.⁴¹³ I discuss these results in more detail below.

The University of Queensland was commissioned to conduct an analysis in 2020 of the costs of delivering quality of care in residential aged care. The study considered clinical health outcomes of residents, process accreditation standards, regulatory compliance data and sanctions, and service experience indicators.⁴¹⁴ The study divided residential aged care services into three different bands based on available linked administrative data—higher quality, middle quality and lower quality.⁴¹⁵ This study also used rigorous research methods. It provides a tool to compare trends between providers, including different types of providers. It suggests that government and not-for-profit providers perform better than private providers, as do small providers compared to larger providers.⁴¹⁶ Again, I discuss this research in detail below.

The commissioned research is published on the website for the Royal Commission.

3.5.2 Poor quality data

Defining and measuring substandard care is challenging. While Commissioner Pagone and I have obtained and made use of research and administrative data to gain an understanding of the extent of substandard care in the sector, this has taken a large amount of effort and resources.

There will naturally be limitations to what administrative datasets can reveal. They were not designed for the purpose of measuring substandard care. Administrative datasets are created when governments complete functional tasks. These tasks may involve making payments to people or service providers, processing complaints and reports, or performing accreditation activities. The collection of data is often a secondary benefit. This means that these datasets are not usually validated or standardised.

In my analysis, I identified issues with both the collection and validation of the data in administrative datasets. Some relied on self-reporting by members of the public or having members of the public respond to non-validated surveys or questions. This means that issues such as English language proficiency, technology savviness, and knowledge of how to navigate the aged care system can affect responses. Complaints data and Consumer Experience Report data may not be representative of the extent of problems within the aged care sector. I cannot underestimate the effect that fear of reporting might have on respondents, specifically for those who might be worried that providers would treat them poorly, following a report.

There are also problems with data that relied on self-reporting by service providers. Responses to the Service Provider Survey were highly variable. We observed similar trends in data on national aged care quality indicators, assaults and unexplained absences, which showed subjectivity in what providers understood to be reportable incidents. Some providers clearly took much too restricted a view of what ought to be reported. With assault data, we also recognise that vulnerable older people may face significant barriers to reporting an assault to their provider, especially if it was at the hands of a staff member.

Cultural representation in data collection is another point of concern. The Residential Care Survey had an under-representation of culturally and linguistically diverse residents and Aboriginal and Torres Strait Islander people. Their views on quality of life and satisfaction with their care might have been different from the general experience represented in the survey results.

A final comment on the limitations of datasets relates to the availability of data for aged care services that operate in the home and community, or through flexible programs. We know that the Australian Department of Health and the Aged Care Quality and Safety Commission are taking some steps to address this, although they are at an early stage of development. In 2019, the Aged Care Quality and Safety Commission pilot-tested Consumer Experience Interviews and Reports in home care settings. We also know that the Department of Health is exploring options for a Serious Incident Response Scheme within home care.⁴¹⁷

The research we have commissioned provides a good indication of the extent of substandard care. But the system needs to be able to identify substandard care on an ongoing basis. The process we have undertaken to measure the extent of substandard care reinforces our view that the poor quality of data in the Australian aged care system is systemic.

3.5.3 Extent of high quality care

Some people report having positive experiences of aged care. We have received many examples of good practice throughout our inquiry and they should be celebrated. We recount some of these in the introduction to this volume.

Of the public submissions we received that were within our Terms of Reference, less than 2% (174) were positive about aged care and 11% (983) described a mix of positive and negative experiences. Of these submissions, 56% were written by older people, or their family and friends. I acknowledge that people who were happy with aged care services may have been less likely to engage with us. It is important to recognise excellent work being done by many individuals and providers within a difficult system.

The National Ageing Research Institute surveys, which I discuss in more detail below, highlighted that some people were happy with all aspects of their care. These surveys found that 28% of people who received residential care, 27% of people who accessed residential respite, 23% of people who accessed a Home Care Package, and 14% people who accessed Commonwealth Home Support Programme respite services said they

‘always’ received care that met their needs across all areas of care within the survey.⁴¹⁸ However, when data about the adequacy of complaints handling was taken into account, the number of people whose care needs were always met was lower.⁴¹⁹

The Australian Department of Health has cited the Consumer Experience Reports to support its view that people living in residential aged care are satisfied with their care.⁴²⁰ The Consumer Experience Report data (2017–19) does suggest that people’s experiences in residential aged care are generally positive, although these reports may not be representative. The approach to coding these reports is such that if a respondent said ‘most of the time’ or ‘always’, this was considered a positive response. In our view, feeling safe or respected ‘most of the time’ is not good enough.⁴²¹ The former Secretary of the Australian Department of Health, Ms Beauchamp, agreed that for some aspects of quality care ‘most of the time’ or less than 100% is not at all an acceptable result.⁴²² For example, for the question ‘do you feel safe here’, 17% responded ‘most of the time’ and 81% responded ‘always’.⁴²³ Similarly, 24% responded ‘most of the time’ when asked if staff treat them with respect and 28% answered ‘yes’ when asked if staff meet their health care needs.⁴²⁴

I also hold concerns about the quality of these interviews. In addition to factors such as service size, English proficiency and who responded to the survey (resident or proxy), a significant limitation to this dataset is the potential impact of what is known as ‘social desirability bias’—where survey respondents choose responses that are socially acceptable rather than the response that accurately reflects their experience. This may have influenced the residents’ willingness to report negative experiences in residential facilities, specifically for residents who might feel disempowered or afraid of retaliatory action if they report negative experiences. For these reasons we are pleased that since 9 December 2019 the Aged Care Quality and Safety Commission is exploring options for Consumer Experience Interviews to become part of ongoing monitoring rather than part of site audits.⁴²⁵ We expect that these surveys in the future will address the concerns we have raised.

The National Ageing Research Interview surveys and the Consumer Experience Reports suggest that some people have a high degree of satisfaction with the quality of aged care. But it is also true that many people do not and that these surveys may underestimate the proportion of dissatisfaction due to comparatively low expectations of care and reluctance to raise issues.

3.5.4 Extent of substandard care

At least 1 in 3 people accessing aged care services have experienced substandard care.

There are a number of data sources that I have used to inform my understanding of the extent of substandard care. In the Interim Report, Commissioner Tracey and I outlined expert evidence on the extent of substandard care.⁴²⁶ This included evidence that 22–50% of people in residential aged care were malnourished;⁴²⁷ 75–81% were incontinent;⁴²⁸ pressure injuries occur in a third of the most frail residents towards the end of their lives;⁴²⁹ and 61% were regularly taking psychotropic agents—with 41% prescribed antidepressants, 22% antipsychotics and 22% benzodiazepines.⁴³⁰ Building on this, I have examined a number of additional data sources below.

Experiences of people in care

The National Ageing Research Institute surveys of people receiving aged care are the most direct measure of substandard care available to us. These surveys asked people receiving aged care or their proxies about different areas of quality care, including whether they were treated with respect and dignity, being supported to make one's own decisions about care and services, receiving care from appropriately skilled staff, receiving supports for daily living that met their health and wellbeing needs, and being supported in their social relationships and connection.

The National Ageing Research Institute surveys of older people receiving care suggested that 1 in 3 people using residential care (33%), over 2 in 5 people using home care (44%) and residential respite care (46%), and over 1 in 2 people using community respite care (51%) believed that one or more of their care needs, across a number of areas, were sometimes, rarely or never met (see Table 1).⁴³¹ These areas of care covered dignity and choice, being involved in making one's own decisions about care and services, having appropriately skilled staff providing care, receiving appropriate personal and clinical care for their health and wellbeing, and being supported in their social relationships and connections. These areas of care align with the elements of our definition of high quality care.

The people surveyed by the National Ageing Research Institute may also experience occasions of good or high quality care, but they experience substandard care more often than is acceptable. As the authors of the report noted, this is 'a significant minority whose needs are not met to a considerable extent'.⁴³² They summarised their results in relation to residential aged care in the following terms:

If it is believed that RACFS [Residential Aged Care Facilities] should meet the needs of each resident all of the time, then nearly 75% of residents feel that some aspect of the quality of their care and service is failing them in one or more areas. If it is instead believed that RACFs should only be required to meet the needs of each resident most of the time, then around 33% of residents feel that some aspect of the quality of their care and service is failing them.

The authors made similar observations in relation to home care, Commonwealth Home Support Programme respite services and residential respite care, although with even higher levels of care needs not being met.⁴³³

On a conservative reading of these results, at least 1 in 3 people in residential care, and more people receiving other types of care, receive care that does not meet their needs too often. In short, too many people are receiving substandard care too often and too few people are receiving high quality care often enough.

Table 1: Percentage of clients who felt their care needs were met across six domains of quality care, in a survey of people receiving aged care⁴³⁴

Care type	% of clients answering in all areas#		
	'always' in all areas	at least 'mostly' in all areas (but excluding 'always' in all areas)	'sometimes' or less in any area
Home Care Package clients	23.4	32.5	44.1
Commonwealth Home Support Programme respite clients	14.1	35.2	50.7
Residential respite clients	26.9	27.4	45.7
Residential care clients	27.6	39.0	33.4

Source: National Ageing Research Institute, *Inside the system: aged care residents' perspectives*, 2020.

Excludes responses to the complaints related domains in the survey and excludes 'don't know' answers.

Results of the quality of care questionnaire in residential aged care showed that 7% of residents felt they were only sometimes, rarely or never treated with respect and dignity. A total of 13% said they only sometimes, rarely or never received the support to make their own decisions about the care and services they received and 16% said they only sometimes, rarely or never received care and support from appropriately skilled and trained staff. A total of 8% said they only sometimes, rarely or never received the support and services they felt were important for their health and wellbeing and 17% said they only sometimes, rarely or never felt supported in maintaining their social relationships and community connections.⁴³⁵

Two-thirds of the surveyed residents identified at least one main concern with the care that they received. Of all surveyed residents, the two most common concerns related to staff (47%) and services and fees (40%).⁴³⁶ Concerns about staff included understaffing, high turnover, and staff members not answering call bells. Concerns about services and fees related to poor food and catering, feelings of loneliness and boredom, and the quality of laundry services. Just over one-quarter of residents (26%) had concerns related to their medical and health care.⁴³⁷ These included falls and fall prevention, medication management and access to medical professionals (including general practitioners and dentists). Almost one-quarter of residents (24%) expressed concerns about dignity and respect, and 18% had concerns about being given choice.⁴³⁸ These concerns included feeling forced to be dependent on staff or wear continence pads, being treated like a child or shouted at by staff members, not having specific care needs thought about or listened to, and lack of choice about timing of meals, personal care and lifestyle activities.⁴³⁹

From the home care component of the home and respite care survey, 6% of the respondents said that they were sometimes, rarely or never treated with respect. Responses for other care areas were less positive, with 31% of respondents saying that they were only sometimes, rarely or never supported to maintain their social relationships and connections with the community. About 15% of respondents said that they were sometimes, rarely or never supported to make their own decisions about care and services. Close to 13% of respondents said that they sometimes, rarely or never received care and support from aged care staff with appropriate skills or training.⁴⁴⁰

Three-fifths of the home care respondents identified at least one main concern.⁴⁴¹ The most common concerns related to finance and administration (45%) and staff (33%). Concerns about finance and administration included value for money, service coordination and rostering, and transparency around fees and charges. Concerns about staff included continuity, training, poor communication, punctuality and cancellations, and staff attitude. Concerns about choice were raised by 27% of respondents, covering lack of clarity about entitlements, inability to negotiate costs or choose who provides care, and lack of activities to choose from. A further 21% raised concerns about services including domestic assistance and transport, and 16% raised concerns about personal or medical care, including mobility and falls prevention and access to other health professionals (for example, allied health).⁴⁴²

For respondents who accessed residential respite services or Commonwealth Home Support Programme respite services, 10% and 4% respectively said they were sometimes, rarely or never treated with respect. Of particular concern, 25% of people who accessed residential respite and 24% of people who accessed Commonwealth Home Support Programme respite services said they were sometimes, rarely or never supported to make their own decisions about care and services. A total of 28% of people who accessed residential respite and 30% of people who accessed Commonwealth Home Support Programme respite services said they were only sometimes, rarely or never supported to maintain their social relationships and connections with the community.

About two-thirds of people who accessed residential respite identified at least one main concern.⁴⁴³ The most common concerns related to services and fees (39%) and staff (31%). Concerns about fees and services included feeling lonely or bored, food catering and dining experiences and availability of interesting lifestyle activities. Concerns about staff included understaffing, call bells not being answered, communication issues and adequacy of training. A total of 29% raised concerns about medical and health care including medication management, and access to and quality of allied health. A total of 28% raised concerns about choice, including lifestyle activities and choices about personal care. A total of 27% raised concerns about respect and dignity including not being allowed to do certain things, needs and wishes not being considered and being treated like a child. A further 25% raised concerns about their room, 19% raised concerns about the facility, and 18% raised concerns about personal care.⁴⁴⁴

Similarly, about two-thirds of people who accessed Commonwealth Home Support Programme respite services identified at least one main concern.⁴⁴⁵ The most common concerns related to finance and administration (47%) and staff (31%). Concerns about finance and administration included value for money, service coordination and rostering and transparency about fees and charges. Concerns about staff included continuity, training, punctuality and cancellations and communication. Concerns about services were raised by 30% of respondents, including loneliness and boredom, transport, and being connected with the community. A further 29% raised concerns about choice, including not being about to choose when and how services are provided, lack of activities to choose from, and lack of clarity about entitlements. A total of 24% raised concerns about the respite facility, 11% raised concerns about personal or medical care, and 10% raised concerns about dignity and respect.⁴⁴⁶

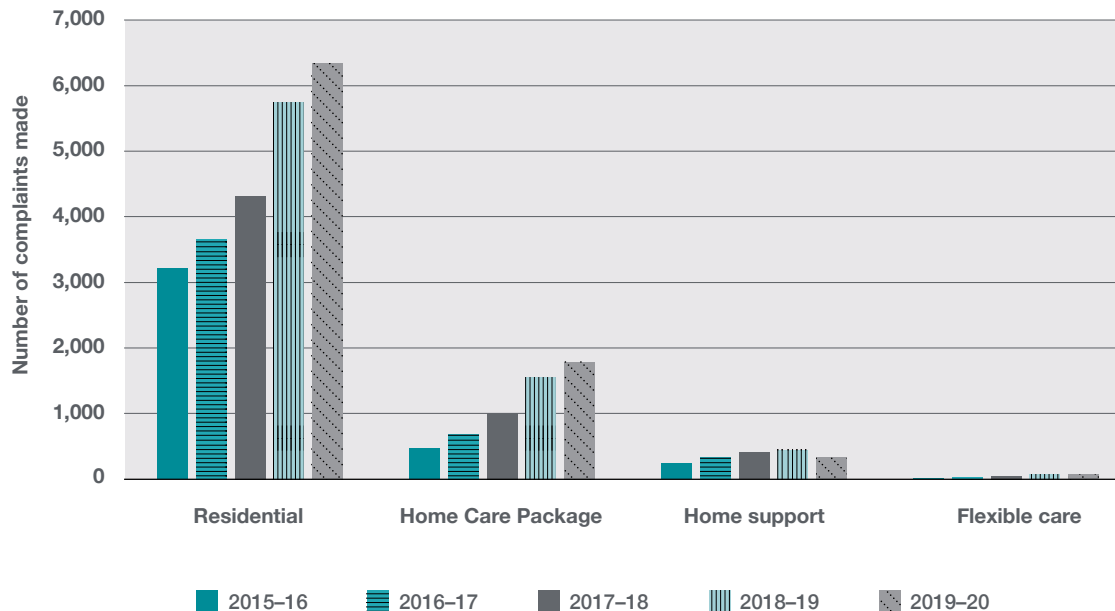
The survey results across the six domains of care are indicative of significant levels of substandard care across all four respondent groups. The data on concerns adds more detail and context to build my understanding, with at least three-fifths of respondents across all care types having at least one main concern. I acknowledge that not every type of concern raised was indicative of substandard care—for example, value for money concerns or concerns about transparency of fees and charges may not be a reflection on the quality of care. However, the vast majority of concerns raised were either directly indicative of substandard care—such as medication management, falls and fall prevention, and all other concerns about medical and personal care, a lack of choice, being treated like a child, concerns about food, loneliness or boredom, and access to medical services—or were about concerns that often lead to substandard care such as understaffing, staff training, continuity of staff, unanswered call bells, communication issues, lack of clarity about entitlements, and inability to make choices about care.

The representative sample of respondents reached by these surveys captures the experiences and impressions of people accessing the aged care system. Sadly, the survey results are consistent with the evidence of direct experience witnesses, and stories told to us in community forums and submissions. They indicate inexcusable levels of substandard care in Australia's aged care system.

Complaints

The dataset relating to formal complaints provides an opportunity to identify individual instances of substandard care. Residential aged care services are over-represented in complaints data compared with home care, home support (the Commonwealth Home Support Programme) and flexible care (see Figure 1). In 2019–20, 74% of all complaints were associated with residential care.⁴⁴⁷ In 2019–20, there were an average of 2.59 formal complaints made to the Aged Care Quality and Safety Commission per 100 people receiving permanent residential aged care.⁴⁴⁸ This equates to an average of 2.33 complaints raised per residential service.⁴⁴⁹

Figure 1: Complaints made to the Aged Care Quality and Safety Commission and its predecessor by aged care program, five years to 2019–20⁴⁵⁰



Source: Annual reports of the Aged Care Complaints Commissioner, Aged Care Quality and Safety Commission and the Productivity Commission, *Report on Government Services*.

Approximately two-thirds (66.6%) of residential aged care services had two or fewer complaints raised against them in 2019–20.⁴⁵¹ However, about 2% of residential aged care services had 10 or more complaints each.⁴⁵² The most frequent types of residential aged care complaints were about health care, particularly medication administration and management.⁴⁵³

The number of complaints made about residential aged care and home care increased significantly between 2014–15 and 2019–20, with smaller increases observed in the complaints about flexible care and home support services.⁴⁵⁴ The Aged Care Quality and Safety Commission has attributed this growth to increased public awareness of its role.⁴⁵⁵ It could also be because people have increased concerns about the quality of their care.

The rates of formal complaints are unlikely to be representative of the quality of care provided. Almost 60% of Home Care Package respondents to the National Ageing Research Institute survey reported at least one ‘main concern’ but less than 1% of respondents reported their concerns to the Aged Care Quality and Safety Commission or other organisations such as My Aged Care or the National Aged Care Advocacy Program.⁴⁵⁶ Respondents who received residential aged care, Commonwealth Home Support Programme respite and residential respite did not report any concerns to these bodies.⁴⁵⁷

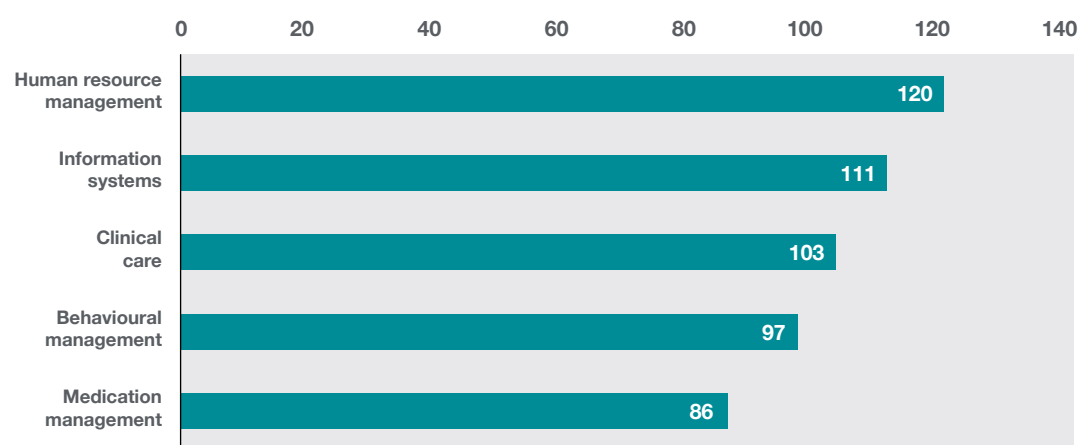
Complaints are an important feedback mechanism and provide some insight into concerns held by people receiving care and their families. However, I do not believe that the complaints data accurately represents the extent of substandard care in aged care. There are several reasons for this, one of which is fear of reprisal.

Accreditation data

Accreditation data is another source of data that informs our understanding of the extent of substandard care across the system. This data provides a high-level point-in-time view of the potential extent of substandard care across the aged care sector. I consider it likely that where a service provider fails to meet accreditation requirements, they are providing or have at times provided substandard care. The converse is not the case. A provider that has met all accreditation requirements may still be providing substandard care that has not been identified by the regulator. Accreditation outcomes are shaped by the approach of the regulator—the more inquisitive and thorough a regulator is, the more likely they are to find non-compliance where it exists.

Approximately one in five audits in 2018–19 concluded that the residential aged care service failed to meet at least one expected outcome under the former aged care Accreditation Standards.⁴⁵⁸ During audits, the most common issues that had not previously been identified by the regulator ('new' issues) were for the outcomes 'human resource management', 'information systems' and 'clinical care'. These are outlined in Figure 2, below.

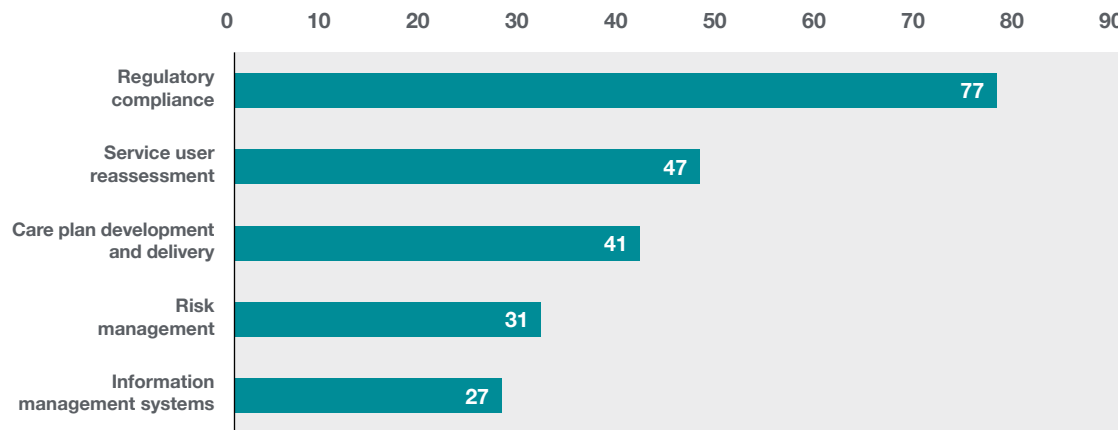
Figure 2: Top five new expected outcomes not met during site and review audits of residential aged care services in 2018–19 (total audits: 1248)



Source: Based on aggregated 2018–19 sector performance data published by the Aged Care Quality and Safety Commission.⁴⁵⁹

About one in five quality reviews of home care providers in 2018–19 concluded that the provider failed to meet at least one home care outcome.⁴⁶⁰ The most common outcomes that were identified as new issues during quality reviews were regulatory compliance, reassessment of service users and care plan development (see Figure 3).

Figure 3: Top five new expected outcomes not met during quality reviews of home care services in 2018–19 (Total audits: 602)⁴⁶¹



Source: Based on aggregated 2018–19 sector performance data published by the Aged Care Quality and Safety Commission.

We also reviewed accreditation data for the 2019–20 financial year to identify changes that occurred following the introduction of the new Aged Care Quality Standards on 1 July 2019. In 2019–20, there was a significant increase in the proportion of residential site audits that concluded that providers did not meet accreditation requirements.⁴⁶² During this time, two in five residential audits identified that at least one requirement was not met. Similarly, over two in five quality reviews or quality audits of home care services identified that at least one requirement was not met. However, I note that there were significantly fewer audits carried out during 2019–20 than previous years due to a pause in face-to-face audits in response to COVID-19.⁴⁶³

Ms Anderson, the Aged Care Quality and Safety Commissioner, explained one of the limitations of using accreditation data to determine the extent of substandard care:

Identified failures in meeting expected outcomes could result in a number of regulatory outcomes, including serious risk decisions, timetables for improvement and, in respect of residential services, decisions regarding the service's accreditation status and period of accreditation. Importantly, these statistics do not necessarily indicate that instances of substandard care have in fact occurred in respect of an individual care recipient. This is because many of the current standards go to organisational and governance processes which seek to prevent instances of substandard care from occurring in the first place.⁴⁶⁴

While I accept that not all instances of regulatory action indicate that instances of substandard care have occurred, historically the most common areas in which residential aged care services did not meet accreditation outcomes were human resource management, information systems, clinical care, behavioural management and medication management. I consider that failures to meet these outcomes have direct effects on the care that people received.

Far from overstating the extent of substandard care, accreditation data is likely to understate the extent of substandard care being provided. In the IRT William Beach Gardens Case Study, Commissioner Tracey and I found that IRT William Beach Gardens failed to provide appropriate care to Ms Shirley Fowler in relation to the detection of her contractures, had failings in record keeping and documentation in relation to wound charts and allergies, and had unacceptably provided her with food containing lactose.⁴⁶⁵ The provider was, during the relevant time, assessed by the regulator as meeting all of their expected outcomes and was deemed to have met 44 out of 44 expected outcomes.⁴⁶⁶ This was not an isolated occurrence. Mr Clarence Hausler was subject to a series of degrading assaults at Japara Mitcham in 2015.⁴⁶⁷ Japara Mitcham was audited in 2015 and 2016 and on both occasions was assessed as meeting 44 out of 44 expected outcomes.⁴⁶⁸

While a finding of non-compliance is necessarily limited to the date(s) of the audit, the evidence before us shows that, at least on some occasions, a non-compliance finding on a particular date may reveal a longer period of non-compliance and substandard care for a period of time leading up to the date of the audit. On 18 October 2018, the regulator determined that the Bupa South Hobart residential service did not meet 32 of the 44 expected outcomes.⁴⁶⁹ Evidence before us showed that Bupa had conducted its own internal 'mock audit' between 22 and 24 February 2016 which examined Bupa South Hobart's compliance with the same expected outcomes.⁴⁷⁰ In the mock audit, Bupa South Hobart had failed to meet a number of the same outcomes that the later official audit assessed it as failing. Therefore, the period of non-compliance may have extended back at least as far as the mock audit in February 2016.

Accreditation data shows significant non-compliance by aged care providers with expected standards, which is likely to be indicative of substandard care. However, this data is not a comprehensive measure of substandard care.

Service provider survey

The service provider survey showed that the amount of substandard care reported by residential aged care providers was higher than that identified by accreditation and complaints data. The survey confirmed that there is not a shared understanding of substandard care. My analysis focused on residential care, where 81% of providers responded, because of low response rates in other areas of care.⁴⁷¹

In responses to the service provider survey, residential aged care providers reported a total of 272,546 incidents of substandard care for the five-year period to June 2018. For the 2017–18 financial year, residential aged care providers reported an average of 260 occasions of substandard care per 1000 people receiving permanent residential care. The service provider survey leads to the conclusion that residential aged care providers in Australia have widely varying understandings of what 'substandard care' means.⁴⁷² For example, one provider reported that a resident's friend being unhappy with the way he was informed of the resident's passing was an incident of substandard care. Other providers applied a more restrictive definition, capturing far fewer incidents of self-identified substandard care.⁴⁷³

At one end of the spectrum, a residential care provider reported over 15 occasions of substandard care per resident over a five-year period from 1 July 2013 to 30 June 2018 while at the other end a different residential care provider reported 0.01 occasions of substandard care per resident over the same period.

My review of the material provided suggests that neither of these figures is likely to be a true representation of substandard care. The residential care provider that reported the higher figure appears to have taken a broad view of substandard care. This is a good thing, as it means that they are proactively identifying and addressing issues, but is unfair to them in making direct comparisons. In contrast, the provider identifying 0.01 incidents per person receiving care is likely to be using a very high bar for 'substandard care', which may indicate a defensive approach that does not seek opportunities for improvement.

Public submissions

Of the 9282 public submissions within our Terms of Reference (excluding submissions made in response to Counsel Assisting's final submissions), 74% (6831) related to residential aged care and 23% (2153) addressed care in the home or community, including 12% (1124) that addressed both home and residential care. The remainder of the submissions related to other aspects of aged care.

A total of 77% of the submissions within our Terms of Reference highlighted concerns, complaints and problems, and a further 11% included a mix of positive and negative experiences. Submissions that were neither positive nor negative accounted for 11% of the total, while less than 2% were about the positive experiences people had with the aged care system.⁴⁷⁴ Of the 77% of submissions that raised only concerns and complaints, many areas of care were raised including workforce issues, provider governance, communication difficulties and social and clinical direct care. Direct social and clinical care concerns included:

- neglect (28%)
- clinical care (28%)
- dignity (27%)
- medication (26%)
- control (25%)
- nutrition (24%)
- dementia care (24%).⁴⁷⁵

Over two in five (42%) of the online public submissions within our Terms of Reference were marked by their submitter as relating to substandard or unsafe care. This likely understates the proportion, as we know that the term 'substandard care' is not well understood in either the aged care sector or the wider community. For example, 32% of the online public submissions that referred to abuse or neglect were not marked by their submitters as substandard care. This was also the case for some submissions that described other issues we would generally consider to be substandard care, such as use of restraint (39%).

The purpose of our public submissions was not to provide conclusive data about the extent of substandard care. However, the remarkable response to our call for submissions demonstrates extensive community experience of, and concern about, substandard care in Australia.

3.5.5 Low expectations of care

I am concerned that substandard care might sometimes be accepted as normal and that some people have low expectations of care. This is apparent from the National Ageing Research Institute's findings in relation to concerns and complaints. Very few respondents who had concerns about their care used the formal complaints handling processes. This is also evident in the administrative complaints dataset discussed above, which shows a relatively low rate of external complaints in home care, home support (the Commonwealth Home Support Programme) and flexible care compared with residential care.

Even though two-thirds of people in residential care had at least one main concern, just under half of those main concerns were not shared with anyone.⁴⁷⁶ The main reasons people in residential care did not share concerns were because they believed they were 'too minor' to report or they felt that 'nothing would change' if they were reported.⁴⁷⁷ However, these included things we consider to be substandard care, such as being hurt, shouted at by staff members, or treated roughly. It also suggests that older people may be prepared to accept quite low standards of care.

Just over 30% of the main concerns raised by home care respondents were not shared with anyone.⁴⁷⁸ People receiving Home Care Packages said that the main reasons that they did not report concerns were: they 'did not think anything would change' (17%); the concern was 'too minor' (14%); or they 'didn't want to be a nuisance or make a fuss' (14%).⁴⁷⁹ However, these unreported concerns included key indicators of substandard care, including continuity of staff and staff training, and matters suggestive of a lack of choice and control, including value for money and lack of clarity about entitlements.

With respect to the two respite care programs, 40–42% of main concerns were not shared with anyone.⁴⁸⁰ The most common reasons for not reporting concerns among Commonwealth Home Support Programme respite and residential respite clients were: the client was 'only there for a short time, not worth complaining' (70%–72%); the client had 'no capacity to complain' (19%–25%); or the client 'didn't want to be a nuisance or make a fuss' (9%–22%).⁴⁸¹ These unreported concerns included key indicators of substandard care including complaints about staff training, understaffing, loneliness and boredom.⁴⁸²

All of this data suggests that some people receiving aged care services have low expectations of aged care, and may therefore put up with substandard care because they do not expect any better. It is important that people receiving aged care understand that they are entitled to high quality care and that they are encouraged to speak up when care is not up to scratch.

3.6 Extent of substandard care in particular areas of care

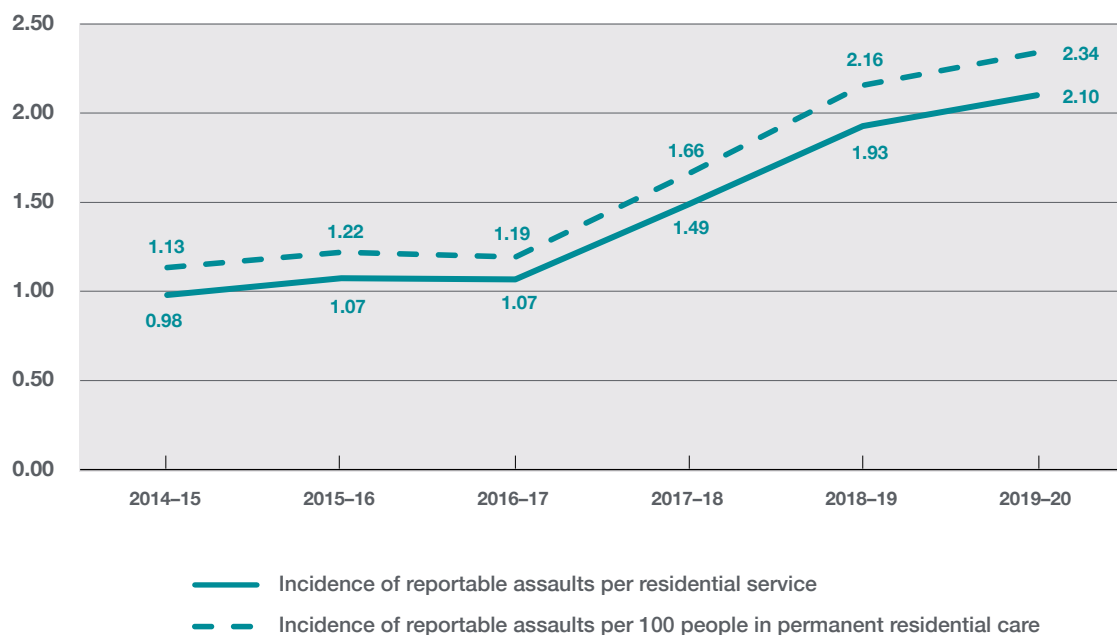
We both agree that in some areas of care, clearer data about the extent of substandard care in residential aged care is available. This is the case for assaults, restrictive practices, medication management, hospitalisation and falls.

3.6.1 Assault—mandatory reporting data

Since 1 July 2007, the Australian Government has required approved residential aged care providers to report allegations or suspicions of physical and sexual assault that occur in their facilities.⁴⁸³

In 2019–20, residential aged care facilities reported 5718 allegations of assault.⁴⁸⁴ During this time, 244,363 people received permanent residential care. This means that the incidence of reports of suspected or alleged assaults was 2.3%.⁴⁸⁵ The average number of service providers that reported allegations of assault increased over the past six years, as has the number of reports per provider. In 2014–15, 45% of residential aged care services reported an allegation of assault, increasing to 64% in 2019–20.⁴⁸⁶ Over the same period, the number of reports per service increased from 0.98 to 2.10. This is illustrated in Figure 4, below.

Figure 4: Incidence of reportable assaults per 100 people in permanent residential care and incidence of reportable assaults per residential service, 2014–15 to 2019–20



Source: *Report on the Operation of the Aged Care Act 1997 for financial years 2014–15 to 2019–20*.⁴⁸⁷

The number of allegations of sexual assault have increased over the past six years in line with overall assaults. There were 426 allegations of sexual assault in 2014–15, which increased to 851 reports in 2019–20.⁴⁸⁸ This is deeply concerning.

This increase in the reporting of allegations of assault, including sexual assault, was far greater than could be accounted for by the increase in permanent residents over the same time period. Many of these reports alleged serious instances of substandard care, with the accused abusers consisting of staff members, family members and strangers.

The number of reportable assaults may be underestimated due to some poor reporting practices. A representative for Japara Mitcham explained that an incident had not been reported because she considered it to be ‘rough handling’ rather than assault, despite evidence from the Chief Executive Officer of Japara that ‘there are no separate criteria applied in distinguishing rough handling from reportable assaults’.⁴⁸⁹

The actual rate of assaults is likely to be much higher than is captured in this data because not all assaults are required to be reported. Allegations of assault where the victim is a staff member, family member or other non-resident are not included within the data. Most significantly, the reporting requirement does not apply if the alleged perpetrator is a fellow resident with a diagnosed cognitive or mental impairment and the provider puts in place arrangements to manage the alleged perpetrator’s behaviour.⁴⁹⁰ Yet, we know that over half of all permanent residents had a diagnosis of dementia in 2019 (53%).⁴⁹¹ Instances of this type of assault could be indicative of poor care for people with complex behaviours.

As an example, the residential care service with the highest number of reports in 2018–19 (42 reports during the year) reported allegations of abuse that involved residents with a diagnosed cognitive impairment.⁴⁹² The residential service explained that it had an internal policy to report all assaults affecting residents, even if these assaults were exempt from reporting. In contrast to this conscientious reporting, many other providers only report those assaults they are required to report. For example, between 10 July 2015 and 6 February 2019, Oberon Village recorded 82 assaults in its reportable assault register.⁴⁹³ Only 10 of these were reported to the Australian Department of Health. The remaining 72 assaults involved residents with a diagnosed cognitive impairment, making them exempt from reporting requirements.

In 2019, the Australian Department of Health engaged consultancy firm KPMG to complete an analysis of assault data submitted by 178 residential aged care services. Its analysis found that resident-on-resident assaults were significantly more prevalent than suggested by publicly available figures.⁴⁹⁴ KPMG estimated that 26,960 to 38,898 physical and/or sexual assaults per year were occurring that were exempt from reporting across Australia.⁴⁹⁵ When these estimates are added to the existing assault allegations for the 2018–19 financial year, the incidence of assaults increases from 2.16 to 13–18 per 100 residents.⁴⁹⁶ This is much higher than the incidence of 2.4% for allegations of assault reported by people over 15 years of age who live in the wider community.⁴⁹⁷ Alarming, the KPMG report indicated that as many as 1730 additional reports of sexual assault may result if a broader definition of reportable assault was applied.⁴⁹⁸

We heard that in some cases family members encourage their loved ones to move into residential care because they felt that it would be safer for them or because safety was a concern.⁴⁹⁹ But on the contrary, people living in residential aged care likely face a much higher risk of assault than people living in the community.

3.6.2 Quality indicator data

The National Aged Care Mandatory Quality Indicator Program data provides some insight into the extent of substandard care in some areas—restraints, pressure injuries and unplanned weight loss—in residential aged care. This program became mandatory for all residential aged care providers from 1 July 2019. In Victoria, government-run residential aged care facilities have been required to report on quality indicators since 2006.⁵⁰⁰

National quality indicators are reported publicly as an incidence per 1000 days in care.⁵⁰¹ In reality, not all residents are assessed, but their days in care are still counted, potentially resulting in underestimates. Using number of days in care also implies residents in a facility are assessed every day, however those that are assessed are only checked one day a month for restraints and once per quarter for pressure injuries.⁵⁰² Where possible, to assist with clarity, we have calculated and expressed national quality indicator data as an average per 100 people receiving residential care or as a proportion of people receiving residential care.⁵⁰³ We have used the denominator of ‘1000 days in care claimed from the Australian Government’ in reporting on restraint because reporting on number of actual residents assessed was not available.

Not all instances of physical restraint, pressure injury and unplanned weight loss represent instances of substandard care. Generating accurate quality indicator data relies on staff members having the ability and time to make the observations. As a result, quality indicators data may underestimate the total number of incidents. Professor Sussman and Ms Ryan of Wounds Australia said that some staff lack the knowledge and skill to recognise a deteriorating wound or wound of concern, leading to a lack of wound diagnosis.⁵⁰⁴

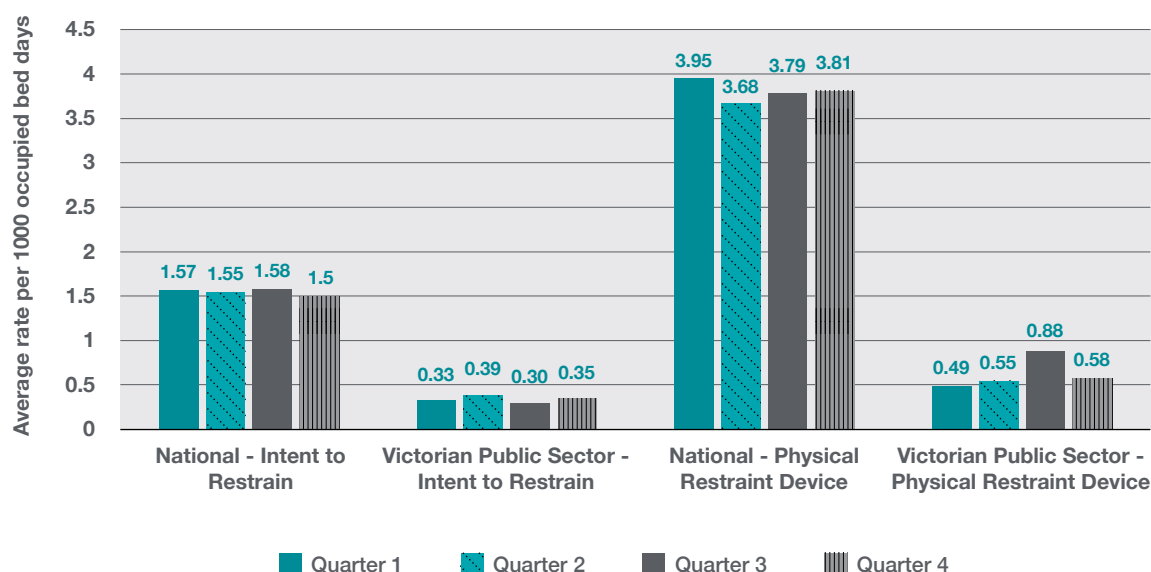
Physical restraint—quality indicator data

The mandatory national quality indicators include two measures for physical restraint. One is ‘intent to restrain’, which refers to whether a resident’s movement has been intentionally restricted by the use of a device, removal of mobility aid, use of physical force, or actions that limit the resident to a particular environment. The second measure is ‘physical restraint devices’. This refers to a device that can impede a person’s movement, which may include bedrails, chairs with locked tables, seatbelts other than those used in active transport, safety vests, shackles and manacles.⁵⁰⁵

The use of physical restraint is too high at a national level across the aged care sector. This is clear when comparing the national quality indicators data with the Victorian quality indicator data on restraints. As noted, Victorian public sector residential aged care services have been collecting quality indicator data, including on restraint, for over 10 years. This is collected in a similar fashion to the national data.

In the last quarter of 2019–20, residential aged care services across Australia made 24,681 reports of intent to restrain and 62,800 reports of physical restraint devices.⁵⁰⁶ When adjusted for the number of occupied bed days, the use of restraints was significantly higher at a national level than in Victorian public sector residential aged care services.⁵⁰⁷ This is outlined in Figure 5, below.

Figure 5: Use of restraint in residential aged care as reported through quality indicator data 2019–20



Source: Quality indicator data published by the Australian Institute of Health and Welfare and confidential response provided by the Victorian Department of Health and Human Services.

Victorian public sector residential aged care services have arrangements in place that may reduce the use of physical restraint, such as the existence of mandated nurse ratios. The level of oversight posed by the recording of quality indicators may also have contributed to the low levels of physical restraint in Victorian public sector residential services. When Victoria first began collecting quality indicator data, use of physical restraint was higher than current national figures, with intent to restrain reaching a high of four reports per 1000 occupied bed days in 2007–08.⁵⁰⁸ This represents a 91% reduction in the use of physical restraints over the past decade in Victorian public sector residential aged care services.⁵⁰⁹

The inappropriate use of physical restraint is widespread in residential aged care facilities in Australia. All unnecessary restraint is substandard care.

Pressure injuries—quality indicator data

A pressure injury is an injury to the skin that can involve the underlying tissue. Current guidelines grade pressure injuries into six different categories or ‘stages’.⁵¹⁰

In the last quarter of 2019–20, the national quality indicator data showed there was an average of 6.79 observations of pressure injuries per 100 residents assessed (or 11,988 observations out of 176,657 residents). Of these, 42% (5027) were recorded as stage 1 pressure injuries, 42% (5077) as stage 2 pressure injuries, 6% (718) as stage 3 pressure injuries, 2% (248) as stage 4 pressure injuries, 5% (596) as un-staged pressure injuries and 3% (322) as deep tissue injuries. The total number of pressure injuries reported did not change significantly over the 2019–20 financial year.⁵¹¹ We are concerned by the prevalence of pressure injuries in residential aged care throughout Australia. The persistent reports of stage 3, 4, and un-staged or deep tissue injuries are of particular concern.

Unplanned weight loss—quality indicator data

There are two measures for weight loss recorded through the National Aged Care Mandatory Quality Indicator Program: ‘significant unplanned weight loss’ and ‘consecutive unplanned weight loss’. Significant unplanned weight loss involves a resident losing three kilograms of weight or more over a three-month period. Consecutive unplanned weight loss involves a resident experiencing consecutive weight loss over three successive months. Exclusions apply for residents who are in hospital, receiving respite care or receiving end-of-life or palliative care.

In the last quarter of 2019–20, a total of 8% of people assessed experienced significant unplanned weight loss (13,239 out of 165,560 people). In the same period, 8% of those assessed experienced consecutive unplanned weight loss (12,820 out of 161,496 people).⁵¹² The proportion of residents that experienced significant unplanned weight loss and consecutive unplanned weight loss fluctuated throughout 2019–20. Significant unplanned weight loss is generally an indication of substandard care, and data about its prevalence builds on the evidence about problems with food and nutrition we explored earlier. This is an area requiring substantial improvement across the aged care sector.

3.6.3 Medication management

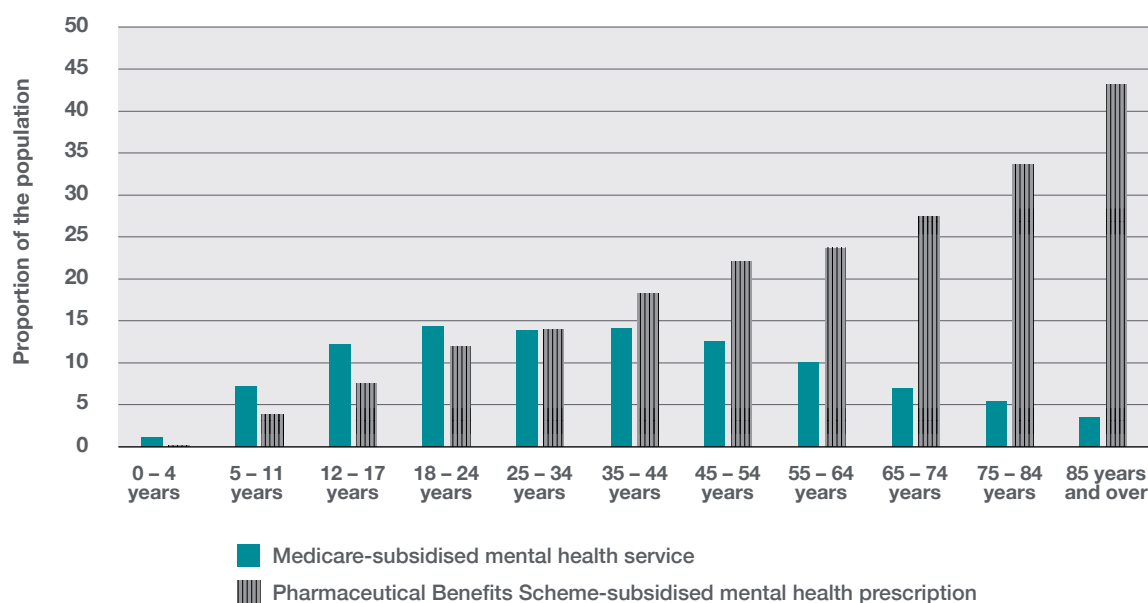
There is no current medication management quality indicator. The Australian Government has announced plans to introduce a medication management quality indicator for residential care with effect from 1 July 2021.⁵¹³

Analysis from the Australian Institute of Health and Welfare identified that medications such as antipsychotics that cause sedation were frequently used in residential care, especially when compared with use for people who were receiving aged care in their homes. It found that in 2016–17, over 1 in 4 people in residential care were dispensed an antipsychotic medicine.⁵¹⁴ Comparatively, fewer than 1 in 12 people who received home care services had an antipsychotic prescription dispensed, and only 1 in 25 people who received home support had an antipsychotic prescription dispensed.⁵¹⁵ Unless people have been prescribed these medications in accordance with clinical criteria and guidelines, we consider that this constitutes chemical restraint.⁵¹⁶

In 2019, the Australian Government's Aged Care Clinical Advisory Panel, comprised of experts from across the health and aged care sectors, estimated that only about one in 10 of the antipsychotic medications and benzodiazepines used in residential aged care was clearly justified in the treatment of mental illness and some rare, acute psychotic manifestations of dementia.⁵¹⁷ Dr Westbury (now Breen) gave evidence that rates of antipsychotic use in residential care have ranged from 13% to 42% of residents from 2001 to 2017 in published studies.⁵¹⁸ The significant use of antipsychotics and other medicines such as benzodiazepines in residential care strongly suggests that many of these medications are being used as chemical restraint. This is substandard care.

We are also concerned that older people are disproportionately likely to be prescribed medicines over other treatments for mental health conditions such as depression. Analysis of 2018–19 data by the Australian Institute of Health and Welfare identified that use of government-funded mental health services decreases with age, while use of mental health prescription medicines increases. Figure 6 suggests that there is a tendency towards medicating older people, rather than enabling them to access other health services.

Figure 6: Proportion of Australian population who accessed subsidised mental health-related services and medications by age group, 2018–19



Source: Data tables released by the Australian Institute of Health and Welfare, Mental health services in Australia, 2020.⁵¹⁹

3.6.4 Hospitalisation data

There is a large number of people aged 65 years or over in residential care who are being hospitalised, some for reasons that are potentially preventable. By matching records from State and Territory hospital and emergency data and Australian Government aged care records, we have identified that 37% of residents presented to an emergency department

at least once in 2018–19, and 31% of residents were admitted to a public hospital at least once.⁵²⁰ The dataset shows some people are being hospitalised for reasons that are potentially preventable. For example, in 2018–19:

- 10.5% of residents had one or more hospitalisations for a fall
- 5.4% of residents had one or more hospitalisations for a fracture
- 1.9% of residents had one or more hospitalisations with weight loss/malnutrition
- of the residents with a dementia diagnosis, 4.1% had a hospitalisation with dementia or delirium
- 0.5% of residents had a hospitalisation for an adverse medication event
- of the residents entering or re-entering an aged care facility from hospital, 22.2% had an emergency department re-presentation within 30 days
- 3.4% of residents had one or more hospitalisations with a pressure injury.⁵²¹

This dataset is the first time residential aged care data has been linked to hospital data for all States and Territories. We are unable to draw specific conclusions about the extent of substandard care from this data alone, but over time it has the potential to be a useful quality indicator. There is significant variability in hospitalisation rates between residential aged care facilities, even after accounting for differences in resident age, gender and health conditions. This suggests the data could be used to identify facilities at risk of delivering poor quality care, as well as enabling facilities to compare their performance.⁵²² It will also assist in establishing benchmarks for acceptable rates of transfers to hospital for particular conditions.

3.6.5 Staffing data

Accreditation data for residential aged care services shows that the most common outcome that was not met in 2018–19 related to ‘human resource management’. Many of the other outcomes that were frequently not met, including clinical care, behavioural management and medication management, can also be linked to staffing levels and skills. Incidents of substandard care are often associated with understaffing or poorly trained staff.

While issues with staffing were not as clearly reflected in accreditation data for home care services, data from the National Ageing Research Institute’s home and respite care survey indicated that one-third of respondents (33.4%) had concerns about staff, including continuity of staff (18.0%) and staff not being adequately trained (15.0%).⁵²³ In their residential care survey, about 46.7% of residents had concerns about staff, including understaffing, unanswered call bells, high rates of staff turnover, and agency staff not knowing the residents and their needs.⁵²⁴ A total of 41% had experienced times when they were not satisfied with the amount of time that staff spent with them.⁵²⁵ Inflexibility in staff care routines was noted by 44% of residents.⁵²⁶

In 2019, Commissioners Tracey and Briggs commissioned research on residential aged care staffing levels by the University of Wollongong. This research found that when Australian staffing levels were compared to benchmarks set by comparable countries such as the United States, more than half of Australian aged care residents (57.6%) were living in residential aged care facilities with what the authors considered to be unacceptable levels of staffing.⁵²⁷

3.6.6 Extent of substandard care in particular provider types | Commissioner Briggs

The extent of substandard care varies across different provider types, including the organisation type—for-profit, not-for-profit, government—as well as the size of the provider and type of service provided. Differences between service types are discussed elsewhere in this chapter. Here, I focus on differences between residential aged care providers by organisation type and size, noting that there are some differences in resident demographics within different organisation types. It is not possible to draw a strong link between care quality in home care settings and the type of aged care provider. This is unsurprising given the lack of quality data in the home care setting. There is also insufficient data to draw conclusions about the extent of substandard care in flexible care settings.

Organisation type

In residential aged care, government-run service providers perform better on average than both for-profit and not-for-profit aged care providers. The University of Queensland study on the costs of delivering care concluded that government-owned facilities were more likely to be higher quality facilities (Q1), with for-profit providers overrepresented in the lower quality (Q3) group, followed by not-for-profit providers.⁵²⁸ This is outlined in Table 2.

Table 2: Number and proportion of residential services across different quality levels by service provider type⁵²⁹

Service provider type, n (%)	Quality levels			
	Q1	Q2	Q3	Total
Not-for-profit	207 (13%)	1,273 (78%)	162 (10%)	1,642 (100%)
For-profit	35 (4%)	793 (82%)	132 (14%)	960 (100%)
Government	60 (24%)	166 (68%)	19 (8%)	245 (100%)
Total	302 (11%)	2,232 (78%)	313 (11%)	2,847 (100%)

Q1: quality level 1; Q2: quality level 2; Q3: quality level 3

Source: University of Queensland, *The cost of residential aged care*, 2020.

These findings were broadly consistent with the National Ageing Research Institute surveys. The Residential Care Survey highlighted that for-profit aged care services had poorer performance in terms of residents' satisfaction with their lives and the care that they received. Residents with the greatest number of concerns were living in for-profit residential care services. Strikingly, life satisfaction was highest in government-run services (with an average of 8.5 out of 10), followed by not-for-profit (7.9) and then for-profit (7.0).⁵³⁰

A review of accreditation data also supports the suggestion that government-run providers generally do better than other services in residential aged care. In 2018–19, a higher proportion of for-profit residential aged care services (18%) did not comply with the applicable accreditation standards during unannounced site visits when compared with government-run (13%) and not-for-profit services (16%).⁵³¹

Government residential care services were also less likely to have a finding of serious risk made against them. These findings are made when there is a potential failure in the standard of care that may place a person's safety, health or wellbeing at risk. In 2018–19, a higher proportion of unannounced site visits conducted at for-profit residential aged care services (7%) resulted in a serious risk decision compared with those in government-run (4%) and not-for-profit (5%) residential care services.⁵³²

Aged care compliance data also indicates that for-profit residential services were over-represented among those that received sanctions. In 2018–19, the Australian Department of Health issued 53 Notices of Decisions to Impose Sanctions to residential aged care approved providers.⁵³³ Twenty-eight of these notices were issued to for-profit residential care providers, 24 to not-for-profit providers, and one to a State Government-run provider.⁵³⁴ Though the majority of notices (53%) were issued in relation to services run by for-profit residential care providers, they represented only 33.9% of total residential care services in 2018–19.⁵³⁵

Government-operated residential aged care services were on average less likely to have residents affected by pressure injuries. In the first quarter of 2018–19, an average of 7.21 pressure injuries were observed per 100 residents assessed in government-operated residential care services. For-profit residential aged care services observed an average of 8.23 pressure injuries per 100 residents assessed, and not-for-profit residential aged care services observed an average of 8.44 pressure injuries per 100 residents assessed.

Similar findings applied to weight loss, with people living in government run residential aged care services on average less likely to experience significant unplanned weight loss. In the first quarter of 2018–19, an average of 1 in every 15.6 residents in government-operated residential aged care services experienced significant unplanned weight loss, compared with 1 in every 11.8 residents in not-for-profit residential aged care services and 1 in every 11.1 residents in for-profit residential aged care services.⁵³⁶

Service size

There is also a difference in the average performance of aged care providers based on their size. This analysis has largely focused on residential care services and the number of care places they have been allocated. The average size of residential care services has increased over the past decade. Only about 39% of residential services had over 60 places in 2008, compared with 60% in 2019.⁵³⁷

The University of Queensland research suggests that quality in residential aged care services is highly correlated with size.⁵³⁸ Small residential care services perform better than larger residential services in terms of quality. The research classified a high proportion of very small and small services, defined as those with fewer than 30 beds, as higher quality. This is outlined in Table 3.

Table 3: Quality of care provided in residential aged care services across Australia by service size⁵³⁹

Facility size	Quality levels			
	Q1	Q2	Q3	Total
1–15 places	33 (41%)	47 (59%)	0 (0%)	80 (100%)
16–30 places	66 (26%)	177 (68%)	15 (6%)	258 (100%)
31–60 places	129 (17%)	569 (75%)	57 (8%)	755 (100%)
61–120 places	63 (5%)	1018 (83%)	150 (12%)	1231 (100%)
121–200 places	11 (2%)	394 (81%)	84 (17%)	489 (100%)
Over 200 places	0 (0%)	27 (79%)	7 (21%)	34 (100%)
Total	302 (11%)	2232 (78%)	313 (11%)	2847 (100%)

Q1: quality level 1; Q2: quality level 2; Q3: quality level 3

Source: University of Queensland, *The cost of residential aged care*, 2020.

Similar conclusions can be drawn from the National Ageing Research Institute's residential care survey, where the rate of concerns for residents living in medium-sized services (61–100 places) and large services (100+) were 50% and 16% higher respectively than for residents living in smaller services (0–60). Further, the number of main concerns increased as the size of the service increased. The residents from smaller residential services had a statistically significantly lower number of main concerns (average of 1.31) compared with residents from medium-sized services (1.74) and large services (1.70). Residents in smaller facilities also rated their general life satisfaction (average of 8.1 out of 10) as statistically significantly higher than those living in medium-sized (7.4) and larger-sized (7.5) residential aged care facilities. Additionally, residents from smaller-sized facilities had greater self-reported quality of life (average of 37.8 out of 48) than residents from medium-sized (36.5) or large facilities (36.6).⁵⁴⁰

3.7 Conclusion

Our inquiry has shown unacceptable levels of substandard care in Australia's aged care system.

The breadth of the evidence and the consistency of people's experiences suggest that high quality aged care is not being delivered consistently in our aged care system, particularly in residential aged care. Looking at people's experience of substandard care and the available data about quality, people in aged care cannot be confident that they will receive the care that they need, whether it be in relation to their health, social, cultural or emotional needs, or that they will avoid experiencing restrictive practices or abuse.

The extent of substandard care in Australia's aged care system is inexcusable. On the best evidence available, Commissioner Briggs concludes that at least 1 in 3 people accessing residential aged care and home care services have experienced substandard care. Commissioner Pagone does not put a specific figure on the extent of substandard care. However, we agree that the extent of substandard care in the current aged care system is deeply concerning and unacceptable by any measure.

Discovering the extent of substandard care in any human service should be quite straightforward. In Australia's aged care system it is exceedingly difficult. Those who run the aged care system do not seem to know about the nature and extent of substandard care, and have made limited attempts to find out. There has been a reluctance to measure quality.

Australians have a right to know how their aged care system is performing; their government has a responsibility to design and operate a system that tells them; and aged care providers have a responsibility to monitor, improve and be transparent about the care they provide.

The extent of substandard care in Australia's aged care system reflects both poor quality on the part of some aged care providers and fundamental systemic flaws with the way the Australian aged care system is designed and governed. People receiving aged care deserve better. The Australian community is entitled to expect better. In the following chapter we explore the widespread problems in the aged care system that contribute to this substandard care.

Endnotes

- 1 Commonwealth of Australia, *Letters Patent*, 6 December 2018, paragraph (a).
- 2 Exhibit 1-23, Adelaide Hearing 1, Statement of Glenys Beauchamp, WIT.0022.0001.0001 at 0027 [116]; 0037 [163].
- 3 Exhibit 1-23, Adelaide Hearing 1, Statement of Glenys Beauchamp, WIT.0022.0001.0001 at 0036 [158]; Exhibit 1-38, Adelaide Hearing 1, Statement of Janet Anderson, WIT.0023.0001.0001 at 0037 [145].
- 4 Exhibit 1-23, Adelaide Hearing 1, Statement of Glenys Beauchamp, WIT.0022.0001.0001 at 0036 [159].
- 5 Exhibit 1-38, Adelaide Hearing 1, Statement of Janet Anderson, WIT.0023.0001.0001 at 0037 [145].
- 6 Commonwealth of Australia, *Letters Patent*, 6 December 2018 as amended on 13 September 2019 and 25 June 2020.
- 7 Royal Commission into Aged Care Quality and Safety, *FAQ on Aged Care Approved Provider Information Request*, 2019, <https://agedcare.royalcommission.gov.au/submissions/service-provider-survey>, viewed 7 January 2021.
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- 9 Flinders University, *Australia's aged care system: assessing the views and preferences of the general public for quality of care and future funding*, A research study for the Royal Commission into Aged Care Quality and Safety, Research Paper 6, 2020, p 2.
- 10 S Biggs, Submission 235—Submission to Elder Abuse Discussion Paper, cited in Australian Law Reform Commission, *Elder Abuse—A National Legal Response*, 2017, p 103.
- 11 Transcript, Cairns Hearing, Sandra Iuliano, 16 July 2019 at T3656.1–4.
- 12 Transcript, Cairns Hearing, Sharon Lawrence, 16 July 2019 at T3656.44–3657.17
- 13 Transcript, Darwin Hearing, Joan Ostaszewicz, 11 July 2019 at T3282.2–7.
- 14 Australian Law Reform Commission, *Elder Abuse—A National Legal Response*, 2017, pp 112–113, 144–147.
- 15 Australian Department of Health, *2019–20 Report on the Operation of the Aged Care Act 1997*, 2020, p 90.
- 16 KPMG, *Prevalence study for a Serious Incident Response Scheme (SIRS)*, 2019, p 37.
- 17 Transcript, Perth Hearing, Kay Patterson, 26 June 2019 at T2550.16–22.
- 18 See, for example, Name withheld, Public submission, AWF.001.00172.01 at 0002; Name withheld, Public submission, AWF.001.01744 at 0001; Name withheld, Public submission, AWF.001.01756 at 0001.
- 19 Exhibit 8-24, Brisbane Hearing, Statement of Gwenda Darling, WIT.0329.0001.0001 at 0002 [13]–0003 [14].
- 20 Exhibit 5-9, Perth Hearing, Statement of Noleen Hausler, WIT.1124.0001.0001 at 0010 [80]–[81].
- 21 Exhibit 5-8, Perth Hearing, Mitcham tender bundle, tab 39, JAH.0001.0003.2494 at 2494.
- 22 Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, 2019, Vol 2, p 207.
- 23 Exhibit 6-20, Darwin Hearing, Statement of Lisa Backhouse, WIT.0221.0001.0001 at 0005 [27]–[28].
- 24 Name withheld, Public submission, AWF.001.00398 at 0001–0002.
- 25 Name withheld, Public submission, AWF.001.02225 at 0001.
- 26 Name withheld, Public submission, AWF.001.00331 at 0001.
- 27 Exhibit 3-32, Sydney Hearing 1, Statement of DF, WIT.0102.0001.0001 at 0002 [10]–0003 [19]; Exhibit 3-33, Sydney Hearing 1, Statement of Marian Anderson, WIT.0135.0001.0001 at 0006 [39].
- 28 Exhibit 3-29, Sydney Hearing 1, Oberon Village tender bundle, tab 49, CAC.0001.0010.0044 at 0046; tab 62, CAC.0001.0002.0088.
- 29 Exhibit 3-28, Sydney Hearing 1, Statement of Kathryn Nobes, WIT.0143.0001.0001 at 0001 [8]; 0006 [34]–[36].
- 30 Name withheld, Public submission, AWF.001.00699.02 at 0005.
- 31 Name withheld, Public submission, AWF.001.00464 at 0001.
- 32 Transcript, Melbourne Hearing 1, Lisa Corcoran, 9 September 2019 at T4824.29–32.
- 33 Transcript, Sydney Hearing 1, 'Elizabeth', 15 May 2019 at T1687.33–39.
- 34 Transcript, Sydney Hearing 1, Susan Walton, 15 May 2019 at T1706.39–40.
- 35 Name withheld, Public submission, AWF.001.00184 at 0001.
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- 37 Name withheld, Public submission, AWF.001.01170.01 at 0001.
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- 40 See, for example, Exhibit 3-2, Sydney Hearing 1, general tender bundle, tab 2, CTH.0001.4000.4879 at 4883.
- 41 See, for example, E Bellenger et al., 'The Nature and Extent of Physical Restraint-related Deaths in Nursing Homes: A Systematic Review', *Journal of Aging and Health*, 2018, Vol 30, 7, p 1043 (Exhibit 3-2, Sydney Hearing 1, general tender bundle, tab 29, RCD.9999.0032.0093); Exhibit 3-70, Sydney Hearing 1, Statement of Joseph Ibrahim, WIT.0115.0001.0001 at 0037 [188], 0038 [193]–[194]; Transcript, Sydney Hearing 1, 'Elizabeth', 15 May 2019 at T1710.35–42; Exhibit 3-2, Sydney Hearing 1, general tender bundle, tab 27, RCD.0010.0001.0022 at 0040 [47].
- 42 Australian Commission on Safety and Quality in Health Care and Australian Institute of Health and Welfare, *The Third Australian Atlas of Healthcare Variation*, 2018, p 23.
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- 44 Exhibit 8-1, Brisbane Hearing, Earle Haven tender bundle, tab 95, CTH.4010.2000.0708 at 0712.
- 45 Exhibit 3-68, Sydney Hearing 1, Statement of Stephen Macfarlane, WIT.0125.0001.0001 at 0025 [128].
- 46 Exhibit 3-55, Sydney Hearing 1, Statement of Brendan Murphy, WIT.0129.0001.0001 at 0009 [25].

- 47 Transcript, Adelaide Hearing 1, Barbara Spriggs, 11 February 2019 at T41.15–17.
- 48 Transcript, Mildura Hearing, Rosemary Cameron, 29 July 2019 at T3886.7–13.
- 49 See, for example, Name withheld, Public submission, AWF.001.00870 at 0001; Name withheld, Public submission, AWF.001.01147 at 0001.
- 50 Maggie Simmons, Public submission, AWF.001.01161.00 at 0003.
- 51 Name withheld, Public submission, AWF.001.01659.00 at 0001–0002.
- 52 Name withheld, Public submission, AWF.001.00271 at 0001–0002; Name withheld, Public submission, AWF.001.00870 at 0001; Name withheld, Public submission, AWF.001.00159 at 0001–0002; Public submission, AWF.001.02011.00_0004_E at 0009.
- 53 Name withheld, Public submission, AWF.001.00271 at 0002.
- 54 Name withheld, Public submission, AWF.001.02011.00_0004_E at 0009.
- 55 Transcript, Sydney Hearing 1, Michelle McCulla, 7 May 2019 at T1237.29–30.
- 56 See, for example, Name withheld, Public submission, AWF.600.00214.0001 at 0006; Name withheld, Public submission, AWF.600.00127.0002 at 0007; Tricia Dearborn, Public submission, AWF.001.00041 at 0001.
- 57 Name withheld, Public submission, AWF.600.00214.0001 at 0006.
- 58 Tricia Dearborn, Public submission, AWF.001.00041 at 0001.
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- 60 Transcript, Sydney Hearing 1, Stephen Macfarlane, 15 May 2019 at T1764.20–23.
- 61 Transcript, Sydney Hearing 1, Michelle McCulla, 7 May 2019 at T1236.13–33.
- 62 See, for example, Elisa Toome, Public submission, AWF.001.00255 at 0001.
- 63 Delecia Hall, Public submission, AWF.001.00978 at 0002.
- 64 Exhibit 3-28, Sydney Hearing 1, Statement of Kathryn Nobes, WIT.0143.0001.0001 at 0005 [28].
- 65 Exhibit 6-15, Darwin and Cairns Hearing, Statement of Anamaria Ng, WIT.0169.0001.0001 at 0003 [18].
- 66 Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, 2019, Vol 2, p 289.
- 67 Transcript, Sydney Hearing 1, Tamar Krebs, 14 May 2019 at T1596.35–1597.4.
- 68 Exhibit 3-84, Sydney Hearing 1, Statement of Kate Swaffer, WIT.0127.0001.0001 at 0004 [29].
- 69 Exhibit 3-68, Sydney Hearing 1, Statement of Stephen Macfarlane, WIT.0125.0001.0001 at 0016 [71].
- 70 Exhibit 1-14, Adelaide Hearing 1, Statement of Edward Strivens, WIT.0021.0001.0001 at 0007 [63].
- 71 Exhibit 1-44, Adelaide Hearing 1, Statement of Maree McCabe, WIT.0005.0001.0001 at 0007 [28.11].
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- 73 See, for example, University of Sydney Cognitive Decline Partnership Centre, *Clinical Practice Guidelines and Principles of Care for People with Dementia*, 2016, p 4 (Exhibit 3-2, Sydney Hearing 1, general tender bundle, tab 14, RCD.9999.0031.0002).
- 74 Transcript, Adelaide Hearing 1, Edward Strivens, 13 February 2019 at T207.17–21.
- 75 Exhibit 17-8, Melbourne Hearing 4, Statement of Harry Lovelock, RCD.9999.0309.0001 at 0006–0007 [28].
- 76 Exhibit 1-50, Adelaide Hearing 1, Statement of Nicolas Mersiades, WIT.0011.0001.0001 at 0003 [20.1]; Exhibit 17-8, Melbourne Hearing 4, Statement of Harry Lovelock, RCD.9999.0309.0001 at 0004 [17]–0005 [19]; Exhibit 17-7, Melbourne Hearing 4, Statement of Mark Silver, RCD.9999.0307.0001 at 0002 [3].
- 77 Exhibit 17-8, Melbourne Hearing 4, Statement of Harry Lovelock, RCD.9999.0309.0001 at 0005 [22].
- 78 Exhibit 17-6, Melbourne Hearing 4, Statement of Sunil Bhar, RCD.9999.0308.0001 at 0003 [4].
- 79 Exhibit 17-8, Melbourne Hearing 4, Statement of Harry Lovelock, RCD.9999.0309.0001 at 0006 [24].
- 80 Transcript, Melbourne Hearing 4, Alison Argo, 15 July 2020 at T8113.45–8114.6.
- 81 Exhibit 17-2, Melbourne Hearing 4, Statement of UX, WIT.0747.0001.0001 at 0005 [40].
- 82 Exhibit 17-2, Melbourne Hearing 4, Statement of UX, WIT.0747.0001.0001 at 0006 [49].
- 83 Exhibit 17-2, Melbourne Hearing 4, Statement of UX, WIT.0747.0001.0001 at 0006 [49]–0007 [50]; 0010 [71].
- 84 Geoffrey Byron, Public submission, AWF.001.00294 at 0001–0002; Name withheld, Public submission, AWF.001.01166 at 0001–0002; Name withheld, Public submission, AWF.001.00293 at 0001.
- 85 Name withheld, Public submission, AWF.001.00293 at 0001.
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- 88 Exhibit 7-4, Mildura Hearing, Statement of Rosemary Cameron, WIT.0309.0001.0001.
- 89 Transcript, Melbourne Hearing 4, Stephen Macfarlane, 15 July 2020 at T8135.10–16.
- 90 Transcript, Melbourne Hearing 4, Stephen Macfarlane, 15 July 2020 at T8136.8–18.
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- 92 Andrea Wilson, Public submission, AWF.001.00113 at 0003.
- 93 Name withheld, Public submission, AWF.001.00892 at 0001.
- 94 Exhibit 10-13, Melbourne Hearing 2, Statement of Elizabeth Cosson, WIT.0219.0001.0001 at 0006 [38].
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- 96 Transcript, Melbourne Hearing 2, Duncan McKellar, 8 October 2019 at T5478.2–17.
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- 98 Exhibit 10-8, Melbourne Hearing 2, Statement of Brian Lynch, WIT.0513.0001.0001 at 0005 [33]–[35].
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- 103 Exhibit 5-38, Perth Hearing, Statement of Jane Fischer, WIT.0159.0001.0001 at 0004 [27]–[28]; Exhibit 5-37, Perth Hearing, Statement of Jennifer Tieman, WIT.0173.0001.0001 at 0003 [15].
- 104 Exhibit 5-33, Perth Hearing, Statement of Joshua Cohen, WIT.0179.0001.0001 at 0011 [61].
- 105 Exhibit 5-38, Perth Hearing, Statement of Jane Fischer, WIT.0159.0001.0001 at 0006 [35].
- 106 See, for example: Transcript, Perth Hearing, Dale Fisher, 27 June 2019 at T2767.45–46.
- 107 Exhibit 5-33, Perth Hearing, Statement of Joshua Cohen, WIT.0179.0001.0001 at 0008 [45].
- 108 Transcript, Perth Hearing, Jane Fischer, 27 June 2019, T2763.38–43.
- 109 Exhibit 5-32, Perth Hearing, Statement of Shannon Ruddock, WIT.1132.0001.0001 at 0013 [121]–0014 [129].
- 110 Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, 2019, Vol 2, p 215.
- 111 See, for example, Sharon Hammad, Public submission, AWF.001.00791 at 0002.
- 112 Transcript, Sydney Hearing 1, DJ, 13 May 2019 at T1488.33–35.
- 113 Exhibit 13-3, Hobart Hearing, Statement of Helen Valier, WIT.0599.0001.0001 at 0015 [127]–[129].
- 114 Transcript, Hobart Hearing, Helen Valier, 11 November 2019 at T6618.39–47.
- 115 See, for example, Name withheld, Public submission, AWF.001.00958.01_0001_E at 0002.
- 116 Name withheld, Public submission, AWF.001.00156 at 0001.
- 117 See, for example, Name withheld, Public submission, AWF.001.01955 at 0002.
- 118 Transcript, Melbourne Hearing 3, Sandra Nisi, 15 October 2019 at T5891.4–20.
- 119 Sharon Rodgers, Public submission, AWF.001.00048 at 0003.
- 120 Exhibit 5-39, Perth Hearing, Statement of Elizabeth Reymond, WIT.0187.0001.0001 at 0019 [78a], emphasis in original.
- 121 Exhibit 14-23, Canberra Hearing, Statement of Peter Jenkin, WIT.1314.0001.0001 at 0036 [213].
- 122 Exhibit 14-23, Canberra Hearing, Statement of Peter Jenkin, WIT.1314.0001.0001 at 0036 [214], citing Palliative Care Australia, Public submission, AWF.001.04620.01 at 0011.
- 123 Heather Sing, Public submission, AWF.001.00961.01 at 0002.
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- 125 Exhibit 23-6, final tender bundle, Uniting NSW.ACT, *Response to Approved Provider Survey*, 2019, SUB.0001.0014.0002 at 0042 [5.8.1].
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- 130 Transcript, Darwin Hearing, Hayley Ryan, 11 July 2019 at T3336.40–43.
- 131 See, for example, Exhibit 14-4, Canberra Hearing, Statement of Kristine Stevens, WIT.1308.0001.0001 at 0005 [42]; Exhibit 6-15, Darwin and Cairns Hearing, Statement of Anamaria Ng, WIT.0169.0001.0001 at 0014–0015 [85].
- 132 Exhibit 6-30, Darwin and Cairns Hearing, Statement of Geoffrey Sussman and Hayley Ryan, WIT.0257.0001.0001 at 0004 [16].
- 133 Transcript, Darwin Hearing, Catherine Sharp, 11 July 2019 at T3301.1–47; Transcript, Darwin Hearing, Hayley Ryan, 11 July 2019 at T3330.9–15; Transcript, Darwin Hearing, Geoffrey Sussman, 11 July 2019 at T3330.17–37.
- 134 Transcript, Darwin Hearing, Geoffrey Sussman, 11 July 2019 at T3331.10–11.
- 135 Transcript, Cairns Hearing, Sandra Iuliano, 16 July 2019 at T3656.23–35.
- 136 Exhibit 6-30, Darwin and Cairns Hearing, Statement of Geoffrey Sussman and Hayley Ryan, WIT.0257.0001.0001 at 0006 [24].
- 137 Exhibit 6-13, Darwin and Cairns Hearing, Assisi tender bundle, tab 207, ACL.501.0004.0003 at 0006; Submissions of Assisi, Darwin and Cairns Hearing, Assisi Case Study, 31 July 2019, RCD.0012.0017.0002 at 0017 [104]–0018 [106].
- 138 Exhibit 6-15, Darwin and Cairns Hearing, Statement of Anamaria Ng, WIT.0169.0001.0001 at 0014–0015 [85]; Exhibit 6-17, Darwin Hearing, Statement of Paul Cohen, WIT.0258.0001.0001 at 0044 [208].
- 139 Transcript, Darwin Hearing, Eric Tay, 10 July 2019 at T3122.3–40.
- 140 See, for example, Susan Smith, Public submission, AWF.001.00675 at 0001–0002; Name withheld, Public submission, AWF.001.02711 at 0001–0002; Marie Toulmin, Public submission, AWF.001.00236 at 0001.
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- 142 Transcript, Cairns Hearing, Robert van Duuren, 15 July 2019 at T3516.9–23.
- 143 Transcript, Cairns Hearing, Robert van Duuren, 15 July 2019 at T3517.40–3518.15; Exhibit 6-35, Darwin and Cairns Hearing, Avondrust tender bundle, tab 98, MIC.0001.0001.0149 at 0150.
- 144 Exhibit 14-4, Canberra Hearing, Statement of Kristine Stevens, WIT.1308.0001.0001 at 0004 [31].
- 145 Exhibit 14-4, Canberra Hearing, Statement of Kristine Stevens, WIT.1308.0001.0001 at 0004 [30]–0006 [42].
- 146 See, for example, Name withheld, Public submission, AWF.001.01730.0007 at 0004; Marie Toulmin, Public submission, AWF.001.00236 at 0001; Susan Smith, Public submission, AWF.001.00675 at 0001; Name withheld, Public submission, AWF.500.00066.0001 at 0008.

- 147 Christine Kingsley, Public submission, AWF.001.01623.00 at 0002.
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- 151 Transcript, Sydney Hearing 1, Constance Pond, 14 May 2019 at T1631.4–8; Transcript, Sydney Hearing 1, 'Elizabeth', 15 May 2019 at T1710.40–46.
- 152 Exhibit 6-50, Darwin and Cairns Hearing, Statement of Frances Batchelor, WIT.0267.0001.0001 at 0003 [9].
- 153 Transcript, Cairns Hearing, Sandra Iuliano and Sharon Lawrence, 16 July 2019 at T3655.42–3656.36.
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- 157 Exhibit 13-21, Hobart Hearing, Statement of Diane Daniels, WIT.0583.0001.0001 at 0004 [25].
- 158 Transcript, Hobart Hearing, Judith King, 12 November 2019 at T6719.2–3; T6719.20–26.
- 159 Exhibit 6-9, Darwin and Cairns Hearing, Statement of Lyndall Fowler, WIT.0103.0001.0001 at 0007 [57].
- 160 Jennifer Cocks, Public submission, AWF.001.04343.02 at 0001.
- 161 Erl Winter, Public submission, AWF.001.05225 at 0002.
- 162 Exhibit 5-32, Perth Hearing, Statement of Shannon Ruddock, WIT.1132.0001.0001 at 0011 [101].
- 163 Exhibit 3-6, Sydney Hearing 1, Statement of Eresha Dassanayake, WIT.0109.0001.0001 at 0006 [30].
- 164 Exhibit 6-54, Darwin and Cairns Hearing, Statement of FA, WIT.0208.0001.0001 at 0003 [23]–0005 [37].
- 165 See, for example, Exhibit 6-9, Darwin and Cairns Hearing, Statement of Lyndall Fowler as amended, WIT.0103.0001.0001 at 0010 [91]–[92]; Exhibit 6-15, Darwin and Cairns Hearing, Statement of Anamaria Ng, WIT.0169.0001.0001 at 0007 [37]; Exhibit 8-28, Brisbane Hearing, Statement of Sarah Holland-Batt, WIT.0330.0001.0001 at 0005 [30].
- 166 Transcript, Canberra Hearing, Kristine Stevens, 9 December 2019 at T7223.23–29.
- 167 See, for example, Janice Falzon, Public submission, AWF.001.00028 at 0001; Name withheld, Public submission, AWF.001.00227 at 0001; Name Withheld, Public submission, AWF.001.00235 at 0001; Marie Toulmin, Public submission, AWF.001.00236 at 0001.
- 168 Karyn Steer, Public submission, AWF.001.00256.01 at 0001.
- 169 See, for example, Name withheld, Public submission, AWF.001.00648 at 0002; Name withheld, Public submission, AWF.001.00793 at 0001–0002; Name withheld, Public submission, AWF.001.02556 at 0001.
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- 171 Exhibit 6-15, Darwin and Cairns Hearing, Statement of Anamaria Ng, WIT.0169.0001.0001 at 0008–0009 [49].
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- 177 See, for example, Exhibit 6-46, Darwin and Cairns Hearing, Statement of Maggie Beer, WIT.0202.0001.0001 at 0011 [50]; Exhibit 6-47, Darwin and Cairns Hearing, Sandra Iuliano, WIT.0204.0001.0001 at 0005 [21].
- 178 Transcript, Cairns Hearing, Sandra Iuliano and Sharon Lawrence, 16 July 2019 at T3655.40–3656.36.
- 179 Transcript, Cairns Hearing, Sharon Hammad, 16 July 2019 at T3656.44–3657.29.
- 180 Exhibit 6-48, Darwin and Cairns Hearing, Statement of Robert Hunt and Sharon Lawrence on behalf of the Dieticians Association of Australia, WIT.0205.0001.0001 at 0010–0011 [53]; Exhibit 6-1, Darwin and Cairns Hearing, General Tender Bundle, tab 82, DAA.0001.0001.0079 at 0080–0082.
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- 182 See, for example, Name withheld, Public submission, AWF.001.00323 at 0001; Name withheld, Public submission, AWF.001.00576 at 0001; Gary John Chinnock, Public submission, AWF.001.00005 at 0001 Anne Robinson, Public submission, AWF.001.00071 at 0001–0002.
- 183 Anne Robinson, Public submission, AWF.001.00071 at 0001.
- 184 See, for example, Vicki-Anne Knight, Public submission, AWF.001.03994 at 0003; Kathleen Knight, Public submission, AWF.100.00013_0004_E at 0009.
- 185 See, for example, Sharon Hammad, Public submission, AWF.001.00791 at 0001; Jane Seaholme, Public submission, AWF.001.01939.01 at 0003.
- 186 Exhibit 5-25, Perth Hearing, Statement of Patti Houston, WIT.1130.0001.0001 at 0004 [15]–[16].
- 187 Exhibit 5-22, Perth Hearing, Statement of Gaye Whitford, WIT.1129.0001.0001 at 0004 [30].
- 188 Transcript, Cairns Hearing, Nicholas Hall, 16 July 2019 at T3622.17–35; Transcript, Cairns Hearing, Timothy Deverell, 16 July 2019 at T3622.39–43.
- 189 Transcript, Cairns Hearing, Timothy Deverell, 16 July 2019 at T3622.39–43.

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- 191 Exhibit 3-52, Sydney Hearing 1, Statement of Lynette Goldberg, WIT.0120.0001.0001 at 0006 [24] and [26].
- 192 Exhibit 3-52, Sydney Hearing 1, Statement of Lynette Goldberg, WIT.0120.0001.0001 at 0007 [26].
- 193 Exhibit 6-46, Darwin and Cairns Hearing, Statement of Maggie Beer, WIT.0202.0001.0001 at 0002 [7]; 0010 [48].
- 194 Exhibit 6-46, Darwin and Cairns Hearing, Statement of Maggie Beer, WIT.0202.0001.0001 at 0010 [49].
- 195 Exhibit 6-48, Darwin and Cairns Hearing, Statement of Robert Hunt and Sharon Lawrence, WIT.0205.0001.0001 at 0017 [86a]; 0018 [89].
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- 197 Transcript, Cairns Hearing, Sandra Iuliano, 16 July 2019 at T3673.10–45; Exhibit 6-46, Darwin and Cairns Hearing, Statement of Maggie Beer, WIT.0202.0001.0001 at 0008 [40]; C Hugo et al., 'What does it cost to feed aged care residents in Australia?', *Nutrition & Dietetics*, 2018, Vol 75, pp 6–10.
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- 203 Transcript, Cairns Hearing, Johanna Aalberts-Henderson, 15 July 2019 at T3470.34–3471.22; T3472.4–10.
- 204 Transcript, Darwin Hearing, Jo-Ann Lovegrove, 12 July 2019 at T3357.4–7.
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- 206 Gary Chinnock, Public submission, AWF.001.00005 at 0001; Janenne Wells, Public submission, AWF.001.01258 at 0001; Name withheld, Public submission, AWF.600.00326 at 0003.
- 207 Name withheld, Public submission, AWF.001.01015 at 0002; Janenne Wells, Public submission, AWF.001.01258 at 0001; Name withheld, Public submission, AWF.600.00326 at 0003; Name withheld, Public submission, AWF.001.01492 at 0001.
- 208 See, for example, Jane Seaholme, Public submission, AWF.001.01939.01 at 0003; Name withheld, Public submission, AWF.001.03947.01 at 0001; Vicki-Anne Knight, Public submission, AWF.001.03994 at 0003.
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- 211 Transcript, Adelaide Hearing 1, Edward Strivens, 13 February 2019 at T200.7–9.
- 212 Transcript, Darwin Hearing, Catherine Maloney, 12 July 2019 at T3397.35–37.
- 213 Transcript, Cairns Hearing, Adrienne Lewis, 16 July 2019 at T3681.26–30; T3682.10–3683.4; Exhibit 6-49, Darwin and Cairns Hearing, Adrienne Lewis, WIT.0246.0001.0001 at 0003 [15].
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- 216 Exhibit 17-10, Melbourne Hearing 4, Statement of Nicole Stormon, RCD.9999.0299.0001 at 0005 [19.2].
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- 220 Transcript, Canberra Hearing, Kristine Stevens, 9 December 2019 at T7232.9–14.
- 221 See, for example, Name withheld, Public submission, AWF.001.00026 at 0001; Name withheld, Public submission, AWF.001.00199.00 at 0009; Name withheld, Public submission, AWF.001.00469 at 0001; Name withheld, Public submission, AWF.001.01390 at 0001.
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- 228 Domenic Pezzano, Public submission, AWF.001.00653.00 at 0009; Name withheld, Public submission, AWF.001.00278.01 at 0003.
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- 235 Exhibit 6-32, Darwin and Cairns Hearing, Statement of Janet Sluggett, WIT.0251.0001.0001 at 0003 [9]; Transcript, Sydney Hearing 1, Constance Pond, 14 May 2019 at T1617.18–28.
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- 237 See, for example, Exhibit 1-9, Adelaide Hearing 1, Statement of Paul Versteeg, WIT.0009.0001.0001 at 0010 [53]; Exhibit 6-48, Darwin and Cairns Hearing, Statement of Constance Pond, WIT.0118.0001.0001 at 0007 [22] and [24].
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- 241 Transcript, Sydney Hearing 1, Brendan Murphy, 14 May 2019 at T1648.44–1649.29.
- 242 Exhibit 17-1, Melbourne Hearing 4, general tender bundle, tab 29, CTH.1000.0004.0739 at 0795 [200]–0796 [203].
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- 246 Marietta Zentai, Public submission, AWF.001.00122 at 0001; Name withheld, Public submission, AWF.001.00515 at 0002.
- 247 Name withheld, Public submission, AWF.001.00063 at 0002.
- 248 Exhibit 8-28, Brisbane Hearing, Statement of Sarah Holland-Batt, WIT.0330.0001.0001 at 0004 [23].
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- 250 See, for example, Marietta Zentai, Public submission, AWF.001.00122 at 0001–0002; Name withheld, Public submission, AWF.001.00231 at 0001; Name withheld, Public submission, AWF.001.00316 at 0001; Louise Plater, Public submission, AWF.001.00441 at 0001.
- 251 Name withheld, Public submission, AWF.001.00375 at 0001.
- 252 See, for example, Transcript, Melbourne Hearing 2, Janette McGuire, 8 October 2019 at T5461.5–9; Exhibit 10-14, Melbourne Hearing 2, Statement of Janette McGuire, WIT.0527.0001.0001 at 0005 [40].
- 253 Exhibit 3-3, Sydney Hearing 1, Statement of Darryl Melchhart, WIT.0113.0001.0001 at 0002 [7c]; Transcript, Sydney Hearing 1, Darryl Melchhart, 6 May 2019 at T1138.46–1139.16.
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4. Systemic Problems in the Aged Care System

4.1 Introduction

Our Terms of Reference require us to inquire into ‘the causes of any systemic failures’ in the quality and safety of aged care services.¹ In this chapter, we identify systemic problems in the aged care system. We do this to share what we have learned, and to inform an understanding of how a redesigned aged care system might do better in the future.

In the previous two chapters, we have examined the aged care system from the experiences of those seeking or receiving care. Here, we direct our attention to problems with the design and operation of the aged care system. The systemic problems identified in this chapter are serious and recurrent issues that stem from problems inherent in the system. They may be faults embedded in its structural design or by the lack of any discernible design. They may be funding, policy, cultural or operational issues. The common characteristic of the problems we identify is that, in our view, they are problems that significantly and repeatedly contribute to the system not providing consistently high quality care to the people who need it. These systemic problems are interconnected. None of them exist in isolation and they often have a compounding effect on the quality and accessibility of aged care.

Systemic problems in aged care exist for many reasons. They often result from unintended consequences or arise over time as a result of inattention or inaction. But in some cases the systemic problems we identify are deliberate choices in the design of the system.

The challenge for systemic redesign of the aged care system is to understand the interests, measures and complexity involved. To seek reform by focusing upon perceived failures would be like having the tiger by its tail. What is needed is a deep understanding of and, at times, empathy with each of the parts of the system and how those parts have worked and how they may be made to work better. In this chapter, we dwell upon what have been presented as failures, challenges and systemic problems, but we do so to gain an understanding of what may be done better.

Commissioner Pagone considers that Senior Counsel Assisting in submissions correctly observed that the aged care system that we now have is operating as it was designed to operate.² A feature of that system is that it is primarily designed to limit government expenditure and is based on the premise that the role of government is limited to funding and quality regulation. An understandable need to marshal government expenditure has led to rationing of benefits and limiting the needs that have been met. The funding of providers has not encouraged or permitted expenditure on such things as leadership and governance or, critically, workforce development. The fear of opening the Pandora’s Box of reform has atrophied innovation and ritualised regulation. The system adopted by the

Government has relied too heavily upon an assumption that the aged care system can be left to the operation of an ordinary market—the assumption being that a market for supply of aged care services exists and will provide market-based solutions obviating the need for active governance.

The systemic problems addressed in this chapter include:

- an absence of leadership and governance at a system level
- insecure, insufficient funding
- financing arrangements that do not support a sustainable sector
- inequitable means testing
- inattention to market structure, evolution and local conditions
- piecemeal approach to reform
- variable provider governance, management and leadership
- an undervalued aged care workforce
- attitudes and assumptions about ageing and aged care
- a reactive model of care
- the lack of voices of older people and diverse communities
- ineffective regulation
- a lack of transparency in the system
- a lack of research translation and innovation
- poor cooperation across the health and aged care systems.

4.2 An absence of leadership and governance at the system level

The Minister responsible for the aged care portfolio, and, through the Minister, the Australian Government, is ultimately responsible for aged care in Australia. The Minister and the Government are supported in this by the Australian Department of Health.

Over the last several decades, successive Australian Governments have brought a level of ambivalence, timidity and detachment to their approach to aged care—even though the aged care system cares for more than 1.3 million older people and employs another 360,000 people.³ Access to high quality aged care is an essential part of living well into older age, and yet, aged care is often treated by the Australian Government as a lower order priority. It has rarely been seen to merit its own Minister at Cabinet level. There has been little vision and a tendency to avoid frank and difficult discussions about what high quality care looks like and what it costs.

Ms Claerwen Little, National Director of UnitingCare Australia, said:

We believe that the country is at a point where we need a Cabinet Minister...a Minister for Longevity...we need leadership from our politicians to help us as a country understand that we are ageing. We have a national anthem that says we are young and free, and we need to understand that we are young in age as in maturity possibly as a country but we are an ageing population and we have not come to terms with that.⁴

We are pleased that the Prime Minister announced the elevation of the aged care portfolio into Cabinet on 18 December 2020.⁵

The Australian Department of Health has a critical role in supporting and advising the Minister for Health and Aged Care and the Australian Government. The Department's approach has typically reflected a narrow view of its role, namely to assist Ministers and Government as required, to perform statutory functions and to perform some limited role as a market steward. This is clearly not enough in a policy area where the Government provides about three-quarters of the funding.⁶

The aged care system requires both a steering wheel and a driver.

The aged care system is complex and constantly evolving; it is not 'set and forget'. It requires clear goals, close monitoring and timely interventions, both nationally and locally, to ensure that high quality care is provided to those who need it. Responsibility for these critical governing functions has not been articulated adequately. Throughout our inquiry, it has been apparent to us that this work is simply not done. Instead, the system is governed in a reactive fashion, with action that is fragmented and generally overdue and/or limited.

The governance of the system is characterised by a lack of curiosity, particularly when it comes to data and information about the aged care system and the people who use it. The Australian Department of Health must have access to comprehensive data to assess the performance and impact of services provided to older people. It does not.

The lack of data collection, poor interoperability between databases and the absence of data analysis are systemic problems that have been raised repeatedly in our inquiry. Examples of key data gaps include data about:

- the provision of health services to people receiving aged care⁷
- how people with diverse needs access and experience aged care⁸
- the characteristics of younger people living in residential aged care⁹
- what services are purchased through Home Care Packages.¹⁰

Ms Mary Patetsos, Chairperson, Federation of Ethnic Communities' Councils of Australia, highlighted the critical nature of data in plain terms: 'without it we don't know what's going on'.¹¹ Even where data is collected, it is not brought together and translated into meaningful metrics that can be used to drive change in the aged care sector.¹²

This absence of leadership at a system level is at the heart of many of the problems that we outline below. For example:

- Despite longstanding problems with staffing levels, remuneration and skills, responsibility for responding to workforce challenges has primarily been left with the aged care sector, which is fragmented and uncoordinated.
- The Australian Government and the Australian Department of Health have tended to listen to the same limited group of stakeholders on aged care, and have not prioritised the voices of older people receiving care.
- Reform has been reactive. Responses to the numerous reviews that have recommended change have been slow and confined in scope, and have often avoided the most difficult issues.
- While individual needs in the aged care system have changed, and acuity in residential care has increased, controls over the supply of services and the standards of services have not properly reflected these changes.
- No attempt has been made to understand the actual cost of providing high quality aged care. Rather, the focus has been on constraining expenditure.
- There has been continued fragmentation and passing of responsibilities between the aged care and health care systems.

Any comprehensive response to the problems we have found in Australia's aged care system requires us to tackle this absence of leadership. The future aged care system requires a model for system governance that provides leadership, vision and ambition, and exemplifies curiosity and accountability.

4.3 Insecure, insufficient Government funding

Funding for aged care is insufficient, insecure and subject to the fiscal priorities and wide-ranging responsibilities of the Australian Government. This affects access to, and the quality and safety of, care.

The aged care system has been affected by piecemeal approaches and policy compromises that detract from quality care. For several decades, one of the priorities for governments dealing with the aged care system has been to restrain the growth in aged care expenditure. This priority has been pursued irrespective of the level of need, and without sufficient regard to whether the funding is adequate to deliver quality care. This has occurred through limiting expenditure without accounting for the actual cost of delivering services, rationing access to services, and neglecting reform of the funding model. Each of these topics is explored below.

These should not be thought of as inadvertent errors in the design of the aged care system in Australia. These are design features. For example, a Cabinet Memorandum dated 27 March 1997 and now available from the National Archives, identifies billions in savings

that had been achieved to that point by capping service provision.¹³ It goes on to describe the other mechanisms that the Australian Government has at its disposal to control costs:

Government has total control over all of its parameters—the number of care classifications, the number of residents in each of them and the amount of funding that attaches to each classification—and so total control of its theoretical cost.¹⁴

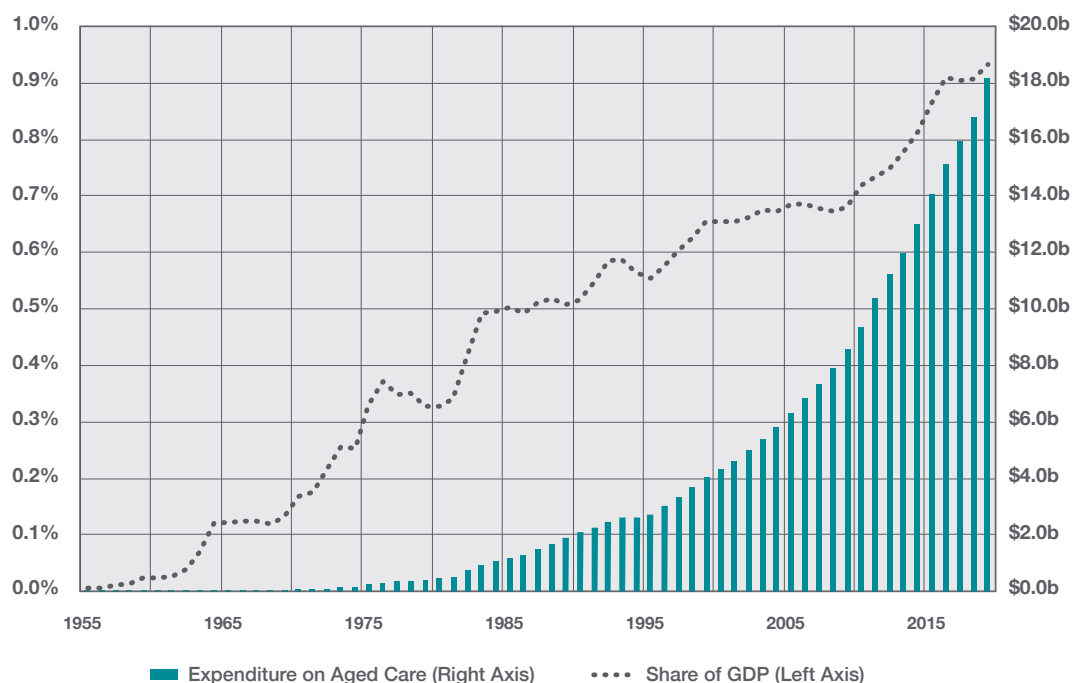
The funding arrangements for aged care have been deliberately designed to constrain costs, and access to care and the quality of care have been compromised as a result.

4.3.1 Limiting expenditure and rationing access

Since at least 1984–85, the Australian Government’s level of expenditure on aged care has not kept pace with demand. Insufficient funding affects almost every aspect of care, from the numbers and skill mix of the workforce, to infrastructure and physical environments, to access to technology and effective linkages between systems. These, in turn, impact on the quality and safety of care.

The amount the Australian Government expends on aged care has continued to increase, but the rate of that increase has slowed since around 1984–85. Figure 1 shows the growth in expenditure on aged care, including as a proportion of gross domestic product (GDP) since 1954–55. After a period of rapid initial growth in expenditure, growth since 1984–85 has averaged 8.4% per year.¹⁵ In 2018–19, the Australian Government spent \$19.9 billion (or 1.02% of gross domestic product) on aged care services. There has also been an ageing population—in 1927, people aged 65 years and over made up 5% of Australia’s population. By 1977, that figure was 9%; in 2017, it was 15%.¹⁶

Figure 1: Australian Government expenditure in aged care 1954–55 to 2018–19¹⁷

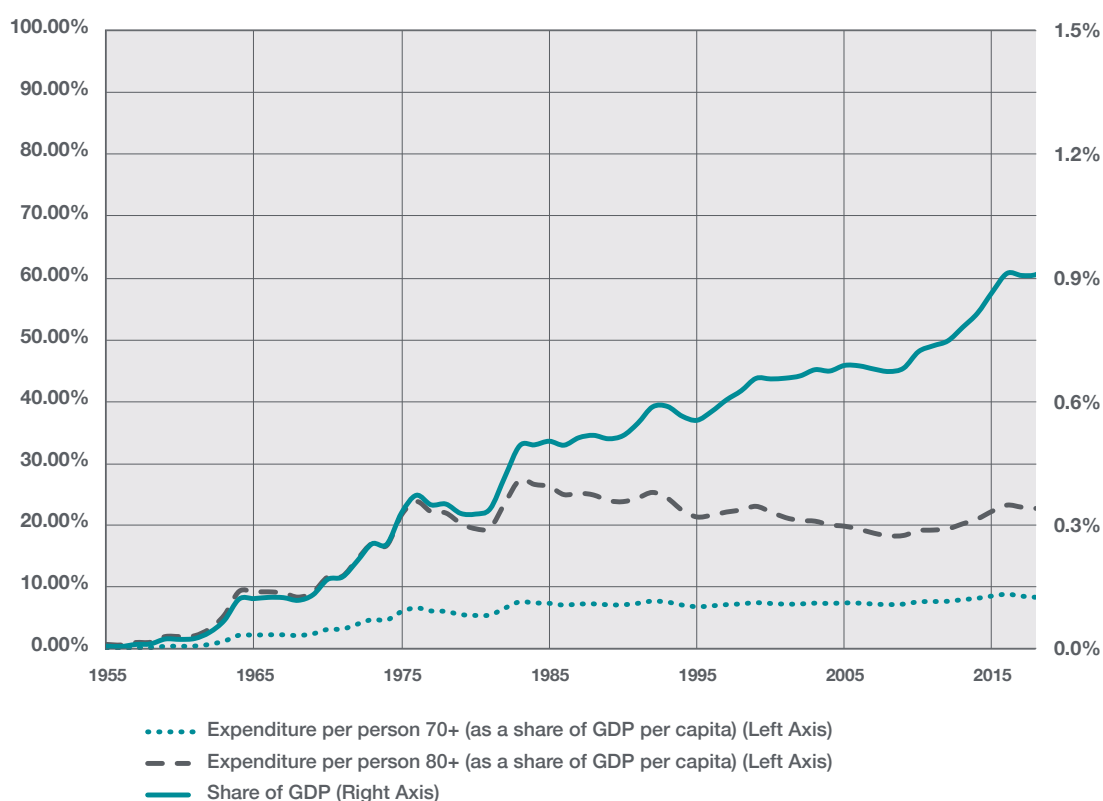


Source: Office of the Royal Commission, Expenditure, Constraints and Major Budget Measures, 2020.

Figure 2 sets out the history of Australian Government spending on the three major aged care programs—residential aged care, Home Care Packages and the Commonwealth Home Support Programme and predecessors—against three metrics:

- expenditure as a share of gross domestic product
- expenditure per person aged over 70 years expressed as a share of gross domestic product per capita
- expenditure per person aged over 80 years expressed as a share of gross domestic product per capita.¹⁸

Figure 2: Australian Government expenditure in aged care 1954–55 to 2018–19¹⁹



Source: Office of the Royal Commission, Expenditure, Constraints and Major Budget Measures, 2020.

Between 1963–64 and 2018–19, Australian Government expenditure on aged care grew from 0.12% of gross domestic product to 1.02% of gross domestic product.²⁰ However, a change in the share of gross domestic product spent on an activity is not necessarily associated with a commensurate change in the quality or coverage of the services that is supported by the expenditure. This is especially true if the population who requires or are likely to require those services—referred to as the ‘demand population’—grows at a different rate to the population as a whole.

Commissioner Pagone notes the following additional matters evident from Figure 2. Gross domestic product per capita shows a country’s gross domestic product divided by its total population. All other things being equal, an increase in gross domestic product per

capita is correlated to a real increase in standards of living. On average, total expenditure in respect to an individual cannot, across the entire economy, be greater than 100% of gross domestic product per capita. Quantifying expenditure on an individual for a particular purpose—for example, aged care—in terms of the share of gross domestic product per capita represented by the expenditure therefore allows for an analysis of the extent to which the quality of the services supported by that expenditure, in terms of quality or quantity / coverage, has moved in line with general living standards. Moreover, normalising the expenditure by the size of demand population for the services controls for increases in expenditure driven by increases in the demand population. As a result, identifying a variable such as ‘Government expenditure per person in the demand population (for example, people aged 80+ years), expressed as a share of gross domestic product per capita’ allows an analysis of the extent to which expenditure has increased in line with demand from a quantitative perspective and in line with community standards from a qualitative perspective.

Australian Government expenditure on aged care per person in the 70+ years population (measured as share of gross domestic product per capita) grew between 1963–64 and 2018–19, from 2.21% of gross domestic product per capita to 8.35% of gross domestic product per capita. However, as Figure 2 shows, expenditure per person in the 70+ years population (as a share of gross domestic product) was relatively constant between 1981–82 and 2009–10, fluctuating between 6.5% and 7.5% of gross domestic product per capita. Over the last four years, since 2015–16, expenditure per person in the 70+ years population (as a share of gross domestic product per capita) has been declining.

The decline in Australian Government expenditure per person in the 80+ years population (as a share of gross domestic product per capita) since the mid-1980s is even more apparent.

There are three primary reasons that expenditure has not kept up with costs and demand:

- the rationing of access, including through the Aged Care Target Provision Ratio, which is poorly targeted to capture growth in demand
- indexation of funding is not well matched with provider input costs
- various measures explicitly intended to achieve savings to the budget bottom line.

Access to aged care is controlled by the Australian Government. With respect to the Commonwealth Home Support Programme, the Australian Government provides grants to service providers, effectively limiting services to within that grant funding. With respect to home care, residential care and restorative care, the Australian Department of Health rations access according to the Aged Care Target Provision Ratio. The ratio was introduced in 1984–85, with a commitment to 100 residential aged care places for every 1000 people aged 70 years or older within a region.²¹ In the early 1990s, Home Care Packages were introduced to the Target Provision Ratio and have progressively increased as a proportion of the overall target.²² The current ratio is 125 places per 1000 people aged 70 years and over, split into 78 residential care places, 45 Home Care Package places and two restorative care places.²³

Planning ratios can be an effective method to estimate the demand for aged care. However, the Target Provision Ratio has been set on an inappropriate basis and, as a result, serves to limit access to care. Commissioner Briggs notes that the effect has been to shift the burden of ageing onto older people and their families, with terrible consequences for many older people and their loved ones.

While aged care should be available for all older people, we do not accept that the age of 70 years is still the correct age group from which to determine the aged care needs of the population, and it has not been for some time.

The majority of people receiving residential and home care are aged over 80 years.²⁴ This group is expected to continue to increase significantly in raw numbers and as a proportion of the population.²⁵ As Figure 2 above shows, the expenditure on aged care per person aged over 80 years has declined significantly and fairly consistently since the mid-1980s. Between 1984–85 and 2018–19, the population aged over 80 years increased by 240%, compared with 162% for the population aged over 70 years.²⁶ If the aged care supply in 1984–85 had been expressed as an Aged Care Target Provision Ratio for the over-80 age group and used to determine subsequent supply, an additional \$4.7 billion would have been available for aged care in 2018–19.²⁷ Continuing to link the Target Provision Ratio to people aged over 70 years obscures the care needs of the majority of people receiving residential aged care and home care.

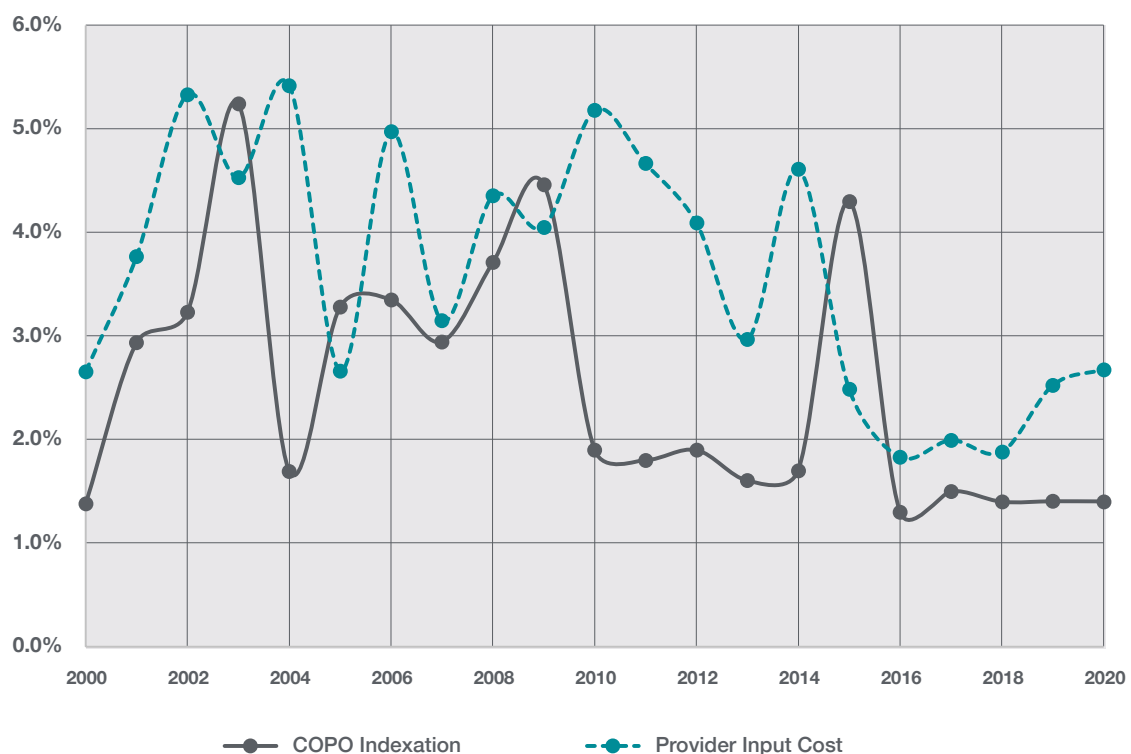
One consequence of this is that there are not enough Home Care Packages for the number of people assessed as needing them. This is both because the proportion of home care places to residential care places is not reflective of relative demand for the programs and because the Target Provision Ratio does not reflect need. Since February 2017, Home Care Packages have been assigned through a National Prioritisation System that equates to a national waiting list. Until the implementation of the National Prioritisation System, unmet demand for home care was not quantified or visible.²⁸ In late 2018, when this Royal Commission was established, there were only 90,646 people with a Home Care Package and the number of people on the waiting list was greater than the number of people actually receiving a Home Care Package at their approved level.²⁹

The waiting list has been reducing in size and the numbers of packages allocated has gone up, but assessed demand still exceeds supply. By 30 June 2020, there were 142,436 people with a package, including 27,005 interim packages at a lower level than the person was assessed as eligible for. A total of 102,081 people had not yet been offered a package at their assessed level.³⁰

The gap between the number of packages and the number of people waiting remains enormous. While they wait, older people are at risk of a deterioration in their health and wellbeing. The longer that people wait on the list, the greater the risk of mortality.³¹ The rationing of Home Care Packages is, at least in part, a consequence of a Target Provision Ratio that has not been properly adjusted to match demand or meet need.

Similar to the Aged Care Target Provision Ratio, the Australian Government's approach to indexation of funding levels for all aged care services has not kept up with real cost increases over many years.³² Subsidy levels have been consistently indexed each year at a lower rate than provider input costs. Figure 3 shows how this disparity has restricted the indexing of the aged care subsidy paid to providers to a rate that is lower than providers' input costs, such as wages and goods. Between 1999–2000 and 2018–19, subsidy levels increased by 70.3%, in nominal terms, but the providers' input costs increased by 116.3%.³³

Figure 3: Comparison of the rates of growth of subsidy levels and provider input costs³⁴



Source: Office of the Royal Commission, Expenditure, Constraints and Major Budget Measures, 2020.

The estimated combined effects of inadequate indexation of Australian Government subsidies since 1999–2000 and the rationing of access to aged care since 1984–85 are summarised in Table 1. It shows that 2018–19 expenditure on aged care would have been \$9.791 billion (53.9%) higher if planning arrangements had been targeted to the population that generates residential aged care demand, and if subsidies had been appropriately indexed.

Table 1: Impact of constraints on aged care expenditure³⁵

	Expenditure	% of GDP	Increase
2018–19 expenditure	\$18.180 b	0.93%	
Adjust for 80+ years population growth	\$22.851 b	1.17%	25.7%
Adjust for 80+ years population growth and indexation disparity	\$27.971 b	1.44%	53.9 %

Source: Office of the Royal Commission, Expenditure, Constraints and Major Budget Measures, 2020.

These long-term constraints on aged care expenditure have left the aged care sector with substantially less funding than an analysis of increased costs or increased needs would have indicated. This effect has been compounded by changes to the funding available under different sections, or domains, of the Aged Care Funding Instrument. Professor Mike Woods, Professor of Health Economics at the University of Technology Sydney, described these actions as ‘directly related to the very parlous state of many providers in being able to provide adequate levels of staffing and care’.³⁶

In 2012–13, the Australian Government made matters worse by changing the indexation of funding levels and the Aged Care Funding Instrument scoring criteria to reduce growth in aged care expenditure to approximately the amounts that had been forecast in budget estimates.³⁷ Similarly, after aged care expenditure exceeded the budget forecasts in 2014–15 and 2015–16, in 2016 the Australian Government again altered a domain of the Aged Care Funding Instrument, and suspended indexation increases to the amounts paid under the Aged Care Funding Instrument for 2017–18.³⁸ The Minister’s media release at the time said:

The current aged care funding model will also be improved by redesigning certain aspects of the **Aged Care Funding Instrument (ACFI)** to stabilise higher than expected growth. Expenditure on the ACFI is expected to blow out by \$3.8 billion over the next four years without action. This reform aims to maintain sustainable funding growth for the residential aged care sector and will save taxpayers \$1.2 billion over four years.³⁹

These measures were intended to slow the increase in the amount of funding that providers were claiming under the Aged Care Funding Instrument. The measures achieved the objective, but caused significant financial difficulty for many residential aged care providers, with 2017–18 marking a significant deterioration in the financial performance of aged care providers.⁴⁰ For people receiving care, these measures also impacted on the amount of funding available for care, without reference to the actual cost of care.

The consequence of these funding arrangements for older people is that they may not be able to access care when they need it, due to rationing of services, and when they do access care, funding may not be sufficient to meet the cost of providing the high quality care they need. The current state of Australia’s aged care system is a predictable outcome of these measures to limit expenditure.

Commissioner Briggs observes that for the last 30 or so years, Governments have lost sight of the value of provision of high quality and safe aged care and have neglected it in favour of fiscal objectives. This must be turned around. It does not match the attitudes of the general public to the funding of aged care. Research conducted for us by the Caring Futures Institute shows the general public ‘believe significantly more government funding should be allocated to achieve higher quality aged care’ and ‘a majority of current income taxpayers would be willing to pay more income tax to ensure a high-quality aged care system is achieved’.⁴¹

4.3.2 Funding models and funding levels

There is no mechanism for the independent review of the costs of providing high quality aged care. In its 2011 report, the Productivity Commission recommended the introduction of an independent authority to bring transparency to price setting.⁴² The Australian Government did not accept that recommendation because the ‘benefits of an independent regulatory agency are unlikely to outweigh the substantial start-up costs of establishing such an agency and its ongoing operation’.⁴³

At no point has the level of funding for aged care in Australia been determined by the actual cost of delivering aged care services to a specified quality standard. The amount spent on aged care services in Australia reflects the available funding envelope rather than the cost of delivering high quality care. This has had serious consequences for older people and the aged care sector.

According to the Australian Department of Health, the Aged Care Funding Instrument is intended to reflect the costs of care in a residential environment.⁴⁴ However, the instrument lacks a mechanism to link residents’ care needs to the cost of providing that care.⁴⁵

We heard evidence that a better understanding of the true costs of aged care is required.⁴⁶ Mr David Hallinan, Acting Deputy Secretary of Aged Care Group, Australian Department of Health, agreed that ‘there is a case for annual cost studies or cost studies on a regular basis that would inform the basis under which the services are funded’.⁴⁷

It follows that changes to aged care funding models in recent years have largely been reactive and intended to limit expenditure in response to increased costs. They were not made in response to structural issues within the sector and did not address the reasons behind increasing costs.

One of these structural issues is the changing demographics of the people who access aged care. The evidence provided to us by multiple witnesses, ranging from service providers, academics and health care professionals, suggests that there has been an increase in the acuity of people receiving care over time.⁴⁸ Recent research by the Registry of Senior Australians also indicates that people receiving aged care are increasingly frail and have high rates of comorbidities.⁴⁹

We can see this increase in frailty reflected in claims for care subsidies through the Aged Care Funding Instrument, although the Australian Government has suggested this is driven by ‘higher than appropriate claiming’ rather than reflecting an actual increase in frailty.⁵⁰

Some combination of these factors is possible. When the Aged Care Funding Instrument was introduced in 2008, the average care subsidy for a permanent resident was 55.6% of the maximum possible care subsidy. In 2018, the average care subsidy was 80.8% of the maximum. With the current distribution across the 64 Aged Care Funding Instrument casemix groups—that is, cohorts of people with similar care needs—the majority of people are assigned to a small number of more expensive categories, and 24 out of 64 categories have almost no claims. As a result, the Aged Care Funding Instrument is not an effective casemix model for the current cohort of people in residential aged care.⁵¹

In the home care sector, block funding for the Commonwealth Home Support Programme limits service provision to the ‘specified number of outputs per type of service for which funding is received’.⁵² Funding does not correspond to individualised need. Home Care Packages are available at four different levels, which are attached to different levels of funding. These funding levels have not changed significantly since they were introduced. In addition, indexation increases have remained low. Paul Sadler, Chief Executive Officer of Presbyterian Aged Care, described the effect that this has had on care delivery:

The result has been a gradual but inexorable erosion in the relative purchasing power of both HCP individual budgets and CHSP grants...In the case of HCPs, an Extended Aged Care at Home package some 15 to 20 years ago would provide around 20 hours of direct care per week. Today, a Level 4 HCP will provide around 10–12 hours of direct care per week.⁵³

A further example is funding for residential respite care, which continues to be paid in accordance with high and low classifications.⁵⁴ This funding scheme is based on the Resident Classification Scale which was used prior to the adoption of the Aged Care Funding Instrument and has not been used for any new permanent residents for over a decade.⁵⁵ Before the introduction of the Aged Care Funding Instrument in 2008, the maximum subsidies for respite care were higher than the average payments that providers received for people living in permanent care.⁵⁶ Over time, the subsidy rates for residential respite care have increased at a slower rate, which has acted as a disincentive to deliver respite care.⁵⁷

In the absence of an understanding of the actual costs of delivering care, funding for aged care over the years has been poorly directed and has led to unintended consequences. Funding for delivering care should cover the costs of care delivery, and funding for accommodation should cover the costs of delivering accommodation. However, it is unclear if this is actually the case because of the lack of transparency in the financial reporting arrangements. The Aged Care Financing Authority’s latest report suggests that in 2018–19, residential care providers had profits of around \$2.8 billion on care and living (dropping to \$544 million when administration expenses are included) and \$337 million on accommodation.⁵⁸ In contrast, the StewartBrown June 2020 *Aged Care Financial Performance Survey Sector Report* suggests that on average, during the first wave of COVID-19, aged care providers made \$15.33 per bed day on care and living, which became a loss of \$21.56 when administration costs of \$36.88 were deducted. There was an average profit of \$11.71 per bed day on accommodation.⁵⁹

One reason for the different profit and loss results for care and for accommodation is that care expenses have risen at a faster rate than accommodation expenses. The Aged Care Financing Authority reported that between 2017–18 and 2018–19, residential care expenses rose by 8%, while accommodation expenses rose by 6.4% and administrative expenses rose by 0.7%.⁶⁰

When providers are forced to cross-subsidise the costs of delivering care by using funding allocated to accommodation, the ability to fund future refurbishments of facilities may be affected.⁶¹ Funding shortfalls that require organisations to cross-subsidise under-funded services from more profitable services make it less likely that purpose-built facilities and innovative services will be developed.⁶² They also mean that residential aged care providers may focus on aspects of the business that generate a profit, at the expense of those that do not.

In the absence of an informed assessment of the cost of delivering high quality care, there can be no confidence that funding for aged care will meet actual care needs, or that it will be well targeted.

4.4 Financing arrangements that do not support sustainability

Commissioner Pagone considers that the financing of aged care is not well set up to support a sustainable system into the future. Financing of the aged care sector is characterised by a fairly rudimentary approach to financing operational costs, through general revenue. We both consider that the complex capital financing arrangements for residential aged care accommodation can distort incentives for older people and providers.

Historically, general taxation has proven to be resilient in financing the growth in aged care expenditures. However, aged care expenditure is projected to grow at a significantly faster rate than overall Australian Government expenditure.⁶³ This growth is a result of projected demographic changes and subsequent increasing demand for aged care services. Even as aged care expenditure is expected to grow, the number of working Australians for every Australian aged over 65 years is expected to decline from 4.2 in 2019 to 3.1 by 2058.⁶⁴ These competing trends create a sustainability challenge for aged care funding.

Commissioner Pagone considers that ongoing financing of the aged care system through general revenue exposes the sector to the annual budget cycle and fiscal priorities of the Government of the day. The existing financing arrangements place aged care in a vulnerable position to future cost control measures. This approach is inadequate and puts the sustainability, quality, and safety of the aged care sector at risk.

In terms of capital financing for residential aged care, providers access capital from two main sources:

- equity capital invested in residential aged care providers (\$13.5 billion or 25.7% of total provider assets in 2018–19)
- debt capital as follows:
 - interest-free loans from residents receiving care in the form of Refundable Accommodation Deposits (\$30.2 billion, which represents liabilities corresponding to 57.4% of the value of total provider assets in 2018–19)
 - loans from banks (\$2.1 billion, corresponding to 4.1% of total provider assets in 2018–19)
 - loans from related parties (\$2.3 billion, corresponding to 4.4% of total provider assets in 2018–19).⁶⁵

Providers also receive some limited capital funding from grants and philanthropic donations.

Refundable Accommodation Deposits are by far the largest source of capital. They have played a central role in funding residential aged care accommodation, and have facilitated significant investment in the sector. However, as explored below, we both consider that the sector has become too reliant on them.

As an alternative to Residential Accommodation Deposits, people receiving residential aged care services can pay a Daily Accommodation Payment, or a combination of the two. Refundable Accommodation Deposit values are converted to Daily Accommodation Payments using the Maximum Permissible Interest Rate, which is currently set at 4.02%.⁶⁶ Over time, an increasing proportion of residents have chosen to pay Daily Accommodation Payments rather than Refundable Accommodation Deposits. Between 2014–15 and 2018–19, the proportion of people choosing to pay Daily Accommodation Payments (or Daily Accommodation Contributions when only a part Refundable Accommodation Deposit is paid) increased from 33% to 41%.⁶⁷ This is making it harder for providers to attract replacement funds when they are required to repay a Refundable Accommodation Deposit when a resident dies or leaves care.

The move away from Refundable Accommodation Deposits also makes it difficult for providers to secure loans from financial institutions. Both the banks and approved providers gave evidence about the role of Refundable Accommodation Deposits in supporting the development of new residential aged care homes. The Australian and New Zealand Banking Group told us that Refundable Accommodation Deposits are ‘fundamental’ to aged care development lending.⁶⁸ A provider’s ability to attract Refundable Accommodation Deposits is currently a key lending criterion applied by the banks.⁶⁹

A further issue is that there is a greater preference for Daily Accommodation Payments (or Daily Accommodation Contributions) in regional and remote areas compared with metropolitan areas.⁷⁰ The National Australia Bank said that this impacted lending decisions, stating that:

In general terms NAB considers providers operating in metropolitan areas to be lower risk than providers operating in regional, rural or remote areas, given metropolitan operators can generally attract higher RAD / DAP paying residents (in line with higher median house prices of metropolitan areas), have access to a larger resident catchment area, and can more readily attract and retain staff. Regional providers also have potentially diminishing future demand.⁷¹

A number of submissions raised concerns about the impact of Refundable Accommodation Deposits on people receiving care. The Grattan Institute said that ‘there is a power imbalance during payment negotiations between providers and incoming residents’.⁷² COTA Australia told us that providers use this power imbalance to pressure older people and their families into paying a Refundable Accommodation Deposit:

Despite the fact that legally residents are required; to have free choice as to whether they pay by RAD or DAP or a combination, there are many providers that require a RAD or they will not accept the new resident. They may be informed that they have a choice but then then it will be made clear that a place in this facility is only possible if they pay a RAD. This pressure is inevitable when providers are over-dependent on RADs.⁷³

In addition, there is some evidence that Refundable Accommodation Deposits are encouraging business models that are built around property rather than care. Ms Julie-Anne Mizzi, Partner and Global Co-Head of Social Care at AMP Capital and a Board Member of Opal Aged Care, told us that Refundable Accommodation Deposits have been so successful in attracting capital that:

accommodation is currently the only component on which aged care providers are able to earn a return, the aged care sector has effectively become a property industry rather than a care industry.⁷⁴

The Grattan Institute submitted to us that Refundable Accommodation Deposits encourage undesirable investment, in light of the preference of older people to remain in their own home:

The vast majority of older Australians want to receive care at home, rather than in a residential care facility. Yet the current financing model encourages a growing residential aged care sector. The interest-free financing for residential care providers encourages reinvestment of these funds into yet more residential care infrastructure.⁷⁵

Capital financing arrangements should not disadvantage people in regional and remote areas, nor should they provide incentives for residential aged care providers to focus on the provision of accommodation at the expense of the provision of care that will meet older people’s needs now and into the future.

4.5 Inequitable means testing

While means testing should ensure that services and payments are directed towards those that need them the most, the current aged care means testing arrangements are insufficiently progressive. They are not well set up to achieve equitable access to care. The arrangements include separate income and asset tests, and the amount of Australian Government subsidy payable by an individual is reduced by the sum of the results of the two tests. There are also daily, yearly and lifetime limits on the amounts of means tested contributions people can be required to pay.

The current arrangements are inequitable in three ways. First, the assets test in particular is insufficiently progressive. Individuals with assets just above the threshold of \$50,500 are required to pay 17.5 cents in aged care contributions for every dollar in assets. By contrast, under the pension assets test, pensions are reduced by 7.8 cents for every dollar in assets in excess of about \$268,000 for a single non-home owner, or \$482,500 for a home owner.⁷⁶

Second, the current settings have a disproportionate impact on people with assets in the range from \$171,535 to about \$500,000 compared with wealthier individuals. For example, a single pensioner who owns a house valued at more than \$171,535 and has no other assets will be required to pay the Basic Daily Fee of \$19,019 per annum, and will almost certainly be asked by their provider to pay a daily accommodation payment at least as high as the full accommodation supplement payable by the Government for some residents of \$21,181 per annum. This will leave them paying \$15,648 more per annum than their pension of \$24,552 per annum. If the pensioner has any additional assets, they will face uncapped accommodation charges and their financial position will be even worse.⁷⁷

Third, the means test can result in very high effective marginal tax rates for some people. For example, a person with no assets and a private income of \$20,000 will pay \$90.80 in increased taxes and aged care contributions if their income increases by \$100 (an effective marginal tax rate of 90.8%). Pensioners with a private income of between \$23,000 and \$45,000 face an effective marginal tax rate of 99.5%.⁷⁸

A self-funded retiree with a taxable income of \$55,000 and no assets is not entitled to a pension. If their taxable income increases by \$100 then their income tax and aged care contributions will increase by \$86.00. Self-funded retirees with taxable incomes between \$96,000 and \$126,000 face an effective marginal tax rate of 92.0%. However, the effect of the annual cap on means tested fees means that the effective marginal tax rate of self-funded retirees with taxable incomes between \$126,500 and \$180,000 is only 39%.⁷⁹

Insufficiently progressive means testing impacts on equitable access to quality aged care.

4.6 Inattention to market structure, evolution and local conditions

The Australian Government has done little active management or shaping of the market for aged care services. With the exception of regulating the quality of services, the Australian Government's approach has generally been that the market will take care of itself without the need for the Government's monitoring and management.

It is not correct to assume that the aged care system is a functioning market in all places for aged care services. Rather, the current aged care system is better seen as a quasi-market. A quasi-market can be defined as a 'set of market-based policies in social policy which are often underwritten by public money that introduces market based competition into contracting and/or individual budget arrangements'.⁸⁰

Quasi-markets require active monitoring and management to guard against the risks posed by market gaps and failures. Associate Professor Gemma Carey, Research Director at the Centre for Social Impact, told us that 'there has long been acknowledgement that quasi-markets will require more attentive regulation from government than regular private markets...The role of central government in stewarding quasi-markets cannot be understated'.⁸¹ Mr Mike Callahan AM PSM, former Chair of the Aged Care Financing Authority, said:

My interpretation of 'market management' in the aged care sector involves implementing the necessary steps to help encourage a stable, efficient and competitive market for all aspects of aged care services. This stems from the view that appropriately regulated market forces are an important aspect of ensuring that the aged care sector can efficiently meet the needs of the Australian community.⁸²

In a true functioning market, quality is usually assumed to be protected through consumer choice, with consumers choosing not to use poor services. In aged care, consumer choice can be limited because some care services are rationed and in short supply and older people often access aged care in unplanned stressful circumstances, where decisions need to be made quickly. It is also not easy for many people to change services. As a result, in quasi-markets, effective quality regulation and monitoring becomes central to maintaining quality services.⁸³

There is a clear absence of market management by the Australian Government. Some market governance functions are not included in current Government activities or are vastly underdone. Price regulation and costing studies, planning and demand modelling, research and data collection, standard setting, quality monitoring and complaints management are not at the level required for a properly functioning system. There is only a rudimentary and general financial reporting system and monitoring of the financial management of providers.

The Australian Government's tendency has been to respond to individual instances of market failures one by one. This approach has not been successful. The reliance on market forces to put downwards pressure on prices or upwards pressure on quality has been misplaced. Professor Kathy Eagar, Director of the Australian Health Services Research

Institute at the University of Wollongong, said that ‘After more than two decades, the private market model has not resulted in the improvements that were expected—more competition, more choice, improved efficiency, improved access and so on’.⁸⁴

Effective leadership of systems, such as the aged care system, is no simple matter. Approved providers have responsibilities for ensuring the quality of their services, and the autonomy providers have presents special challenges for the way this leadership should be exercised. However, aged care services are defined, regulated and about three-quarters funded by the Australian Government, providing a number of levers to shape the market. The Australian Government has control over decisions relating to entering and exiting the market, the response to changes in demand, and broader changes in market conditions.⁸⁵ But these strategies are not being used effectively. For example, we outline below key areas of risk for changes in market structure and composition, and particular local market issues that have not been effectively managed.

4.6.1 Changes in market structure and composition

The Australian Government has not adequately responded to the changing composition and risk profile of aged care providers. It has allowed the network of providers to become more concentrated over the last decade, with a significant expansion in very large providers.⁸⁶ This creates regulatory risk as providers become ‘too big to fail’.

In traditional markets, it is expected that poorer performing providers will fail and exit the market. Managing out poor providers and encouraging better providers to enter the market is a normal feature of market governance. But in a care context, unsuccessful providers are a risk to the reliable provision of care—and as the market becomes more concentrated, that risk may increase because failure of a single provider may affect thousands of vulnerable people receiving care across many locations.

Another area of risk arises from the rapid expansion in home care providers, with limited scrutiny applied to assess their suitability. Such a rapid expansion can be seen over recent years. The number of approved providers of home care increased by 42% between 30 June 2016 to 30 June 2017 and by another 24% by 30 June 2018 (with a nominal decrease in 2019–20).⁸⁷ An employee of the Australian Department of Health, who gave evidence under the pseudonym of BE, said that the number of applications for approval as a home care provider since 2017 had been relentless, the standard of applications for approval were not always good and consultants may have been selling ‘off-the-shelf’ applications.⁸⁸ Mr Graeme Barden, Assistant Secretary, Residential and Flexible Care Branch, Australian Department of Health, confirmed that the Department assessed applicants on the basis of a written application and supporting documents together with some limited research.⁸⁹

Another area where governance of the market has been ineffective is the use of the Aged Care Approvals Round process to ensure the needs of diverse groups are met. The Australian Government allocates particular places for people in what the *Aged Care Act 1997* (Cth) calls ‘special needs’ groups in the Aged Care Approval Rounds in an attempt to provide equity of access to services for those people.⁹⁰ But the Australian Department of Health does not follow up on whether the allocation of those places actually leads to

people in that group getting the places, and whether they are getting the specialist care they need. Mr Jaye Smith, First Assistant Secretary, Residential and Flexible Aged Care Division, confirmed the Department does not undertake monitoring to understand whether the allocation of places was improving access for those diverse groups, nor to ensure that approved providers were complying with the conditions imposed under the Aged Care Approvals Round allocations.⁹¹

4.6.2 Limited focus on local and regional context

There are wide variations in local conditions and resources that affect the delivery of aged care. Effective market governance requires local capacity and engagement with local networks. Instead, aged care remains highly centralised within the Australian Government and there is little presence at the regional and local level.⁹²

The centralised process for Commonwealth Home Support Programme grants, without sufficient knowledge of local conditions and links to local networks, has resulted in non-responsiveness and a disconnect from what is happening on the ground. Since assuming responsibility for all forms of home-based care from 2012, the Australian Government has failed to establish local systems to replace the roles previously played by States and Territories under the former Home and Community Care Program. This has led to gaps in planning, development and management of services.⁹³ These gaps create inconsistency in service distribution.

For example, South Australia has over double the number of people accessing assistive technology as each of the remaining States and Territories. South Australia has 7136 distinct clients accessing this service as opposed to only 386 in New South Wales. Victoria has over double the number of clients accessing allied health and personal care services as New South Wales does.⁹⁴ Despite New South Wales having the largest population, it does not always have the home support services to match. The Australian Government has not steered the market to ensure an even and comprehensive distribution of home support services.

Another example of the limited focus on local issues is the underserved markets in regional, rural and remote areas. Services in certain places, or for certain groups of people, may lack viable market forces to ensure good services are available.⁹⁵ In regional, rural and remote areas, and even in more populated regions where there are fewer or no trusted organisations, there can be little to no market within which to make a choice about services. This is sometimes referred to as a ‘thin market’. In outer regional or remote locations, providers may operate on a smaller scale, which is associated with higher relative operating costs, an inability to achieve efficiencies through economies of scale and increased vulnerability to unpredictable income streams.⁹⁶ The Older Persons Advocacy Network said:

the aged care system is big-city focused. It is not responsive, nor does it recognise the nuances of smaller communities in regional, rural and remote areas. If we leave planning for services delivery and making decisions around the service delivery model to the market the “market” will go to where they can make the money.⁹⁷

Service availability in rural and remote areas is an example of a potential mismatch between incentives for providers and the objectives of the Australian Government. And yet, the Australian Government has not actively monitored these vulnerable markets—as Professor Hjalmar Swerissen from the Grattan Institute said:

regional system governance is needed for market management to identify and rectify market failures...Where there is insufficient demand for services (e.g. geographically dispersed populations), service intervention is necessary to encourage the development of viable services.⁹⁸

There are a number of clear examples of markets that are not workably competitive, whether in particular locations or for particular groups.⁹⁹ However, data about unmet demand is limited. Without reliable data, risks will inevitably be missed or mismanaged. The data that does exist suggests that specific planning or incentives to meet the needs of people in regional, rural and remote locations is not happening to the extent necessary.¹⁰⁰

In the case of home care, Mr Barden acknowledged that the 2017 introduction of the National Prioritisation System has resulted in a reduction in Home Care Packages for people in remote and very remote areas.¹⁰¹ The potential risks of this policy change for access in outer regional and remote locations were foreseeable and capable of mitigation, but would have required local intelligence, monitoring of developments and swift action to address emerging risks. This did not occur. Commissioner Briggs observes that it was a mystery to many people who appeared before us as to how the National Prioritisation System works—and why it fails to deliver equal access to aged care services.¹⁰²

The Australian Government has not taken responsibility for shaping the market for aged care. A stronger system management approach is required to ensure that older people can get the services they need, wherever they live and whatever their needs may be.

4.7 Piecemeal approach to reform

Aged care reforms have been reactive, responding to financial, demographic or other concerns of the time. This has triggered repeated reviews, which have tended to be confined to particular areas of focus.¹⁰³ Many of these previous reviews have examined the same issues that have arisen in our inquiry, including:

- the difficulty people have in understanding and navigating the aged care system¹⁰⁴
- poor access to care, especially for people with chronic conditions or complex needs, and long waiting times for access to services for many people, especially those who seek care at home¹⁰⁵
- the excessive and inappropriate use of chemical and physical restraints on people who live in residential aged care¹⁰⁶
- serious current and projected shortages of appropriately skilled and qualified nurses and personal care workers¹⁰⁷
- ineffective regulatory oversight of aged care providers, and a lack of focus on the quality of care.¹⁰⁸

Throughout these many reviews, a consistent underlying concern has been that the system has not delivered the care and outcomes that it should. The Australian Government has responded with ad hoc changes to elements of the system, adopting limited aspects of the recommendations made.¹⁰⁹ However, governments have not successfully resolved the underlying problems with a system that has not provided the Australian community with the high quality and safety in aged care that Australians want. It is clear to us that piecemeal adjustments and improvements have not achieved, and will not achieve, the change that is required to ensure high quality care in the future.

While we acknowledge that the Australian Government is not obliged to adopt all of the recommendations in any review, there have been some instances of significant delay in addressing or implementing important and urgent recommendations. A conspicuous example is the Australian Government's delay in implementing the ten recommendations of the Carnell-Paterson review, *Review of the National Aged Care Quality Regulatory Processes*, which concluded in October 2017.¹¹⁰

The Carnell-Paterson review, carried out by Ms Kate Carnell AO and Professor Ron Paterson ONZM, was a focus of the Brisbane Hearing in August 2019. At the time, the recommendations from the Carnell-Paterson review had been with the Australian Government for almost two years. A number of witnesses described progress of the implementation of these ten recommendations, including Professor Paterson. He described the degree of progress as 'disappointing'.¹¹¹ Ms Amy Laffan, then Assistant Secretary of the Aged Care Quality Regulatory Design and Implementation Branch, Australian Department of Health, said that 'all ten recommendations of the Carnell-Paterson review have been adopted in whole or in part by the government'.¹¹² But she agreed that, at the time of the hearing, there were still pending decisions as to whether and, if so, how the Australian Government might implement some of the recommended actions.¹¹³ There should be no delay in implementing recommendations that will improve the aged care system.

The Carnell-Paterson review is an example of the concerns we hold about a piecemeal approach to review and reform. We do not propose to repeat the analysis in Chapter 2 of Volume 1 of the Interim Report or the Royal Commission's background paper about a history of aged care reviews.¹¹⁴ There are many examples of significant policy reviews that have met with a limited response from governments, prioritising implementation of the easiest recommendations without tackling the longer-term systemic problems. The sheer volume of problems with the aged care system we outline in this chapter warrants a systematic response and fundamental reform.

4.8 Variable provider governance, management and leadership | Commissioner Pagone

Provider management and governance has a direct relationship with all aspects of care. When the people in charge of an aged care service do not have the appropriate skills, do not prioritise high quality care and are not accountable for their actions, the quality of care may be compromised. Direct care staff need their leaders to empower them to take the time to put the person at the centre of care.

Deficiencies in the governance and leadership of some approved providers have resulted in shortfalls in the quality and safety of care.¹¹⁵ Some boards and governing bodies lack professional knowledge about the delivery of aged care including clinical expertise.¹¹⁶ There is a risk that governing bodies may focus on financial risks and performance, without a commensurate focus on the quality and safety of care.¹¹⁷ In the Bupa South Hobart Case Study, Bupa accepted in its submissions that its strategies in the past to reduce staffing levels, together with cultural and governance deficiencies, contributed to instances of substandard care.¹¹⁸

Poor workplace culture has also contributed to poor care. Dr Duncan McKellar, Head of the Unit for Older Persons' Mental Health Services in the Northern Adelaide Local Health Network, speaking of the failures of care at Oakden Older Persons Mental Health Service, emphasised that it was 'critical to understand' that it was a 'cultural failing' of the 'organisation and...the people that worked within it' and that this was 'at the core of what went wrong'.¹¹⁹

There are not always structures in place to ensure that governing bodies are properly informed of care deficiencies and risks, and can take appropriate and timely action to address them. Some providers did not encourage complaints and a culture of learning from these.¹²⁰ The former Chief Executive Officer of Southern Cross Care (Tas), Mr Richard Sadek, acknowledged that no complaint was ever referred to him and accepted that the complaints process at the Southern Cross Care (Tas) Yaraandoo facility was 'virtually non-existent'.¹²¹ People receiving care, families and staff members sometimes did not make complaints to providers because they believed providers failed to respect and value their opinion, and were sometimes fearful of negative repercussions from making a complaint.¹²²

From the research we commissioned, it appears that deficiencies in complaints management processes are not limited to a small number of providers. The National Ageing Research Institute found, through the surveys it conducted, that a large number of people accessing aged care had concerns about complaint management. Between 18% and 23% of respondents in residential care 'were satisfied only sometimes (or less often) that they knew how to lodge a complaint, were comfortable lodging a complaint, and were confident that appropriate action' would be taken in response to a complaint.¹²³ Between 23% and 39% of respondents accessing home care identified similar experiences.¹²⁴ People in respite care had even less positive experiences of complaints processes.¹²⁵

When people receiving home care or respite services did make a formal complaint, mostly to their care provider, less than half were resolved to the person's satisfaction. The National Ageing Research Institute found that only 48% of Home Care Package recipients who raised complaints felt that these had been resolved, with even lower responses for other types of aged care. Around one-third of people who received respite care through the Commonwealth Home Support Programme (35%) and residential respite (37%) felt that their complaints were resolved to their satisfaction. Barely over one-quarter (27%) of people living in permanent residential care felt that their complaints were adequately resolved. These figures suggest that aged care providers across all service types are not using complaints to identify and address issues with the care and services they provide.¹²⁶

There is sometimes a lack of accountability, particularly when things go wrong.¹²⁷ In the Japara Mitcham Case Study, Commissioners Tracey and Briggs described Japara Mitcham as an organisation that was 'determined to avoid accountability for its actions', including the 'degrading assaults' that Mr Clarence Hausler experienced while in its care.¹²⁸

It is clear that provider management and governance needs to be addressed. Dr Penny Webster of Wilson and Webster Consultancy Services made the following observation about Bupa South Hobart:

I kept seeing the same problems over and over again, and a lot of the problems...arose out of the same kinds of issues, which was a lack of accountability, lack of people management skills, lack of placing the resident as central to the decision-making...and that focus on finances. To me that indicated that there was a systemic problem that was sitting underneath some of the smaller things that we saw.¹²⁹

Accountability begins and ends with the leaders of an organisation, the board and senior management.¹³⁰ If boards and governing bodies do not have the knowledge or skills to understand the care that is being delivered, they are unable to ensure that this care is high quality and safe. The values and behaviour of people in these senior positions have a significant impact on workplace culture and the quality of care that is delivered. When these values and behaviours are poor, so may be the care that people receive. Boards and governing bodies have the responsibility to listen and respond appropriately to complaints about their services.

I agree with Commissioner Briggs that more could be done to improve leadership and culture, but consider that there has been much done within the confines of the system as it has existed and the funds available. More particularly, in my view, many providers have been exemplary in prioritising quality care despite restricted financial resources.

I do not otherwise share the criticism by Commissioner Briggs of the providers in the terms below. The evidence available to us, in my view, does not support the breadth of those conclusions.

4.9 Provider behaviour | Commissioner Briggs

When someone receives care at home or in residential care, they and their families expect to receive high quality care. Older people and their loved ones hold approved providers in a position of trust, and they rely on providers to look after and care for them. Many have been let down.

In 2019 hearings and community forums, Commissioner Tracey and I heard many cases of alleged inappropriate and substandard care that resulted from the action or inaction of providers.¹³¹ Our hearings featured some disturbing examples of the poor practice by approved providers, including: poor responses to abuse; widespread use of physical restraints; overprescribing of sedative drugs to keep people quiet and compliant; poor continence management; failure to keep people clean; poor quality food; poor wound care; depression; oral and mental health not being attended to; discrimination; poor communication; patchy palliative care; and so on. The examples in chapters 2 and 3 of this volume, and those published in Commissioner Tracey and my Interim Report, highlight the consequences for older people.¹³²

When leaders of approved providers turn a blind eye to substandard care, they provide the enabling environment for it to flourish. Collectively and individually, approved providers must take responsibility for what has happened on their watch. Their actions have contributed to many of the systemic problems in the delivery of aged care that we see today.

Provider management and governance has a direct relationship with all aspects of care. The extent of substandard care that Commissioner Tracey and I observed could not have taken place in a sector with robust provider governance arrangements focused on delivering safe and high quality care.

It emerged in evidence that some governing bodies are too often unaware or unresponsive to emerging and significant risks to the safety and wellbeing of older people receiving care from the provider.¹³³ They are disengaged from care governance, relying on the executive and management to ensure care quality.¹³⁴ Deficiencies in governance and leadership of some providers, across all types and sizes, have caused serious shortfalls in the safety and quality of aged care.¹³⁵

Some boards and governing bodies lack professional knowledge about the delivery of aged care including clinical expertise.¹³⁶ When the people in charge of an aged care service do not have the appropriate skills, do not prioritise high quality care and are not accountable for their actions, the quality of care may be compromised.

There is a culture in some aged care services of a lack of accountability and an apparent indifference to the concerns of older people receiving care, their representatives, and staff.¹³⁷ Over the course of our inquiry, the level of frustration and bewilderment older people and their families have at the lack of accountability within aged care for the standard of care provided was obvious.

I regret to say that some approved providers' leadership and culture appears not to be aligned with their mission and certainly not with the purpose of the aged care system. Boards and governing bodies are responsible for setting the values, mission and strategy of their aged care services. They should set out what is permissible and what is not acceptable, and they should be held to account for those decisions. For some providers, the members of their governing bodies have not demonstrated the integrity, skills and independence to enable them to act, first and foremost, in the best interests of the people receiving that care.¹³⁸

Direct care staff must be empowered by their leadership team to put older people at the centre of care arrangements. There is insufficient evidence across the aged care system that approved providers are seeking to develop and maintain an adequate and well qualified workforce. We have heard that ongoing training and continuing professional development is not readily available.¹³⁹ Approved providers have not invested in training or leadership to the extent needed to enable their services to function at the level necessary to provide high quality care. With some notable exceptions, providers have demonstrated little curiosity or ambition for care improvement, and have not prioritised enablement and allied health care. As a group, providers have not sufficiently valued nor invested in the aged care workforce.

It is evident that some governing bodies have focused on financial risks and performance, without a commensurate focus on the quality and safety of care.¹⁴⁰ As a result, care has become a series of transactions rather than a process of personal interaction, engagement, and compassionate and safe care.¹⁴¹ In the Bupa South Hobart Case Study, Bupa accepted in its submissions that its strategies in the past to reduce staffing levels together with cultural and governance deficiencies contributed to instances of substandard care.¹⁴²

Poor workplace culture has contributed to poor care. Dr Duncan McKellar, Head of Unit, Older Persons' Mental Health Service in the Northern Adelaide Local Health Network, speaking of the failures of care at Oakden Older Persons Mental Health Service, emphasised that it was 'critical to understand' that it was a 'cultural failing' of the 'organisation and...the people that worked within it' and that this was 'at the core of what went wrong'.¹⁴³

There are not always structures in place to ensure that governing bodies are properly informed of care deficiencies and risks, and can take appropriate and timely action to address them. Some providers did not encourage complaints and a culture of learning from these.¹⁴⁴ The former Chief Executive Officer of Southern Cross Care (Tas), Mr Richard Sadek, acknowledged that no complaint was ever referred to him and accepted that the complaints process at the Southern Cross Care (Tas) Yaraandoo facility was 'virtually non-existent'.¹⁴⁵ People receiving care, families and staff sometimes did not make complaints to providers because they believed providers failed to respect and value their opinion, and were sometimes fearful of negative repercussions from making a complaint.¹⁴⁶

Deficiencies in complaints management processes are not limited to a small number of providers. The National Ageing Research Institute found, through the surveys it conducted for us, that a large number of people accessing aged care had concerns about complaint management. Between 18% and 23% of respondents in residential care 'were satisfied only sometimes (or less often) that they knew how to lodge a complaint, were comfortable

lodging a complaint, and were confident that appropriate action' would be taken in response to a complaint.¹⁴⁷ Between 23% and 39% of respondents accessing home care identified similar experiences.¹⁴⁸ People in respite care had even less positive experiences of complaints processes.¹⁴⁹

When people receiving home care or respite services did make a formal complaint, mostly to their care provider, less than half were resolved to the person's satisfaction. The National Ageing Research Institute found that only 48% of Home Care Package recipients who raised complaints felt that these had been resolved, with even lower responses for other types of aged care. Around one-third of people who received respite care through the Commonwealth Home Support Programme (35%) and residential respite (37%) felt that their complaints were resolved to their satisfaction. Barely over one-quarter (27%) of people receiving permanent residential care felt that their complaints were adequately resolved. These figures suggest that aged care providers across all service types are not using complaints to identify and address issues with the care and services they provide.¹⁵⁰

There is sometimes a lack of accountability, particularly when things go wrong.¹⁵¹ In the Japara Mitcham Case Study, Commissioner Tracey and I described Japara Mitcham as an organisation that was 'determined to avoid accountability for its actions', including the 'degrading assaults' that Mr Clarence Hausler experienced while in its care.¹⁵²

It is clear to me that provider management and governance needs to be addressed. Dr Penny Webster, of Wilson and Webster Consultancy Services, made the following observation about Bupa South Hobart:

I kept seeing the same problems over and over again, and a lot of the problems...arose out of the same kinds of issues, which was a lack of accountability, lack of people management skills, lack of placing the resident as central to the decision-making...and that focus on finances. To me that indicated that there was a systemic problem that was sitting underneath some of the smaller things that we that we saw.¹⁵³

Accountability begins and ends with the leaders of an organisation, the board and senior management.¹⁵⁴ If boards and governing bodies do not have the knowledge or skills to understand the care that is being delivered, they are unable to ensure that this care is high quality and safe. The values and behaviour of people in these senior positions have a significant impact on workplace culture and the quality of care that is delivered. When these values and behaviours are poor, so may be the care that people receive. Boards and governing bodies have the responsibility to listen and respond appropriately to complaints about their services.

I consider that providers have been critical contributors to the systemic problems of the aged care system. When substandard care is at inexcusably high levels, this must reflect on the providers who deliver that care. It is clear that no amount of additional funding and improved regulation will be sufficient to achieve high quality care if providers do not do their part too, to ensure that the aged care system works appropriately on the ground and actually delivers on the promise of this report of high quality and safe aged care. Individually and as a group, providers must embrace their responsibility to lead, must be ambitious and innovative, and must make delivering high quality care their central objective. If they choose not to do so, they should lose their approved provider status.

4.10 An undervalued aged care workforce

We both consider that Australia's aged care is understaffed and the workforce underpaid and undertrained. Too often there is not enough staff, particularly nurses, in home and residential aged care. In addition, the mix of staff who provide aged care is not matched to need. Inadequate staffing levels, skill mix and training are principal causes of substandard care in the current system.¹⁵⁵

These are not new issues. Funding changes that occurred with the introduction of the Aged Care Act removed the obligation on approved aged care providers to spend a dedicated portion of their Australian Government funding on direct care staffing. The Aged Care Act requires providers only to 'maintain an adequate number of appropriately skilled staff to ensure that the needs of care recipients are met'.¹⁵⁶ Providers are to decide what an 'adequate number' is and what constitutes 'appropriately skilled' staff.

As a consequence, many aged care providers contain their labour costs by reducing their overall direct care staffing or replacing more expensive nurses with lower paid personal care workers.¹⁵⁷ For some years there has been a relative decline in the proportion of nurses in the residential aged care workforce and a corresponding increase of personal care workers. The proportion of registered nurses in the workforce dropped from 21% in 2003 to 14.6% in 2016, and enrolled nurses dropped from 13.1% to 10.2%. In the same period, personal care worker representation has increased from 58.5% to 70.3% of the workforce.¹⁵⁸ The 1997 changes resulted in providers replacing nursing staff with personal care workers to reduce costs. There has also been a decline in the proportion of the workforce who are allied health professionals or assistants, from 7.4% in 2003 to 4.6% in 2016.¹⁵⁹

Aged care is part of the health care and social assistance sector, which has been the fastest-growing industry every year in Australia since 2015. Research from the Australian Government projects that there will be 129,100 new jobs for community and personal service workers in the five years to May 2023, an increase of 23.6%. In the same period, the overall projected growth for all occupations is 7.1%.¹⁶⁰

Several witnesses in the Southern Cross Care (Tas) and Bupa South Hobart case studies shared their perception that a reduction of staffing levels had a detrimental impact on the quality of care and quality of life of the residents.¹⁶¹ Mr Brian Harvey, who was a resident at the Southern Cross Care facility, Yaraandoo, in Tasmania, described the impact that short staffing had on his quality of life:

When neglected like that, I feel I have been dehumanised: left as a carcase in an aged care abattoir; ready to be processed like a slab of meat in a sausage processing factory at some future time.¹⁶²

In 2019, the Centre for Health Service Development of the Australian Health Services Research Institute at the University of Wollongong, headed by Professor Eagar, produced a report for us entitled *How Australian residential aged care staffing levels compare with international and national benchmarks* ('the University of Wollongong Report').¹⁶³ The report's findings present a sobering picture of the state of staffing in Australia's residential aged care facilities.

The researchers compared staffing levels—direct care hours overall and direct care hours delivered by registered nurses—in Australian residential aged care facilities with the staffing levels applied under the CMS Nursing Home Compare rating system used in the United States. This rating system gives facilities a rating from 1 to 5 stars. The researchers found that:

- More than half (57.6%) of Australian residents receive care in aged care homes that have unacceptable levels of staffing (1 and 2 stars).¹⁶⁴
- To bring staffing levels up to an acceptable level would require an increase of 37.3% of staff hours in those facilities that had unacceptable staffing levels.¹⁶⁵
- Only 1.4% of older people in residential aged care are in facilities rated 5 star (best practice care) for registered nurse staffing.¹⁶⁶

The University of Wollongong's research shows that by 2019, staffing levels within large parts of Australian residential aged care had fallen well short of what the researchers described as 'acceptable' practice standards, let alone high quality.¹⁶⁷

The 1997 changes were made in the context of a philosophical repositioning of residential aged care as a person's home. In relation to this, Professor Eagar said:

If I go back 20 years homes were criticised because they were institutional, and this was a whole policy shift to say let's move away from an institutional model and feel and make them more homely. But I don't think anyone ever intended that you would move away from a clinically competent model towards more of an unskilled model, but that is actually what's happened.¹⁶⁸

As Professor Eagar said, people working in residential aged care today need 'more clinical skills, not less'.¹⁶⁹ Professor Charlene Harrington, Professor Emeritus of Sociology and Nursing at the University of California, San Francisco, and an elected fellow in the American Academy of Nursing and the National Academies of Medicine, told us that 'Nurse staffing levels are the most important factor that determines the quality of care provided by nursing homes'.¹⁷⁰

A lack of nurses featured in many of our case studies.¹⁷¹ For example, in the Bupa South Hobart case study, Ms Carolyn Cooper, Managing Director of Bupa Villages and Aged Care New Zealand, acknowledged that Bupa's policy of reducing nurse numbers had impacted on the quality of care and quality of life of residents.¹⁷² A lack of appropriately qualified staff means that clinical care tasks are left to personal care workers, sometimes without supervision.¹⁷³ In the MiCare Case Study, personal care workers undertook wound care for Mrs Bertha Aalberts's serious leg wound, even though it required high-level clinical care from nursing staff.¹⁷⁴

At times, people have had to wait too long for staff members to assist them, or have gone without care because no qualified staff were available.¹⁷⁵ In the Alkira Gardens Case Study, Commissioners Tracey and Briggs found that there were not enough suitably qualified staff to provide an adequate standard of care for Mr Vincent Paranthoienne.¹⁷⁶ Ms Shannon Ruddock, Mr Paranthoienne's daughter, said she was concerned there were not enough staff who were 'trained to provide appropriate palliative care, including how to administer' medications as necessary.¹⁷⁷

Some aged care providers said that they have difficulty attracting sufficient numbers of people with the right skills to work in aged care.¹⁷⁸ This is consistent with the findings of the 2016 Workforce Census and Survey, which indicated that skill shortages and difficulties filling positions are common, particularly in regional, rural and remote areas.¹⁷⁹

Not surprisingly, inadequate staffing is one of the issues that needs to be addressed to make the sector more attractive. High workloads and time pressures have been identified as key factors behind job dissatisfaction and intentions to leave the aged care sector. A University of Adelaide working paper, prepared for the Aged Care Workforce Strategy Taskforce, said that:

Inadequate numbers of staffing and the complex care needs of residents within residential settings, and travel time between appointments and a lack of adequate time allocated to tasks in community aged care contributed to workload pressures. High levels of, and inefficiencies in, administrative paperwork were also frequently reported across both settings. Consequently, workers frequently described a lack of time with clients, being unable to take breaks and undertaking considerable amounts of unpaid work.¹⁸⁰

A 2019 survey conducted by a research team from the University of New South Wales, Macquarie University and the Royal Melbourne Institute of Technology, and commissioned by United Voice, found that 74% of people who were working in home care reported that they had insufficient time ‘to listen and connect with older people’.¹⁸¹ The impact of time pressure on the capacity of personal care workers to provide high quality care may be compounded by challenges associated with unpaid travel time between clients, safety hazards in client’s homes, working in isolation with limited or no supervision and finding the time to undertake training and administrative tasks. We have heard that many home care workers are not adequately compensated for their travel time.¹⁸²

This reinforces the need for system-wide workforce changes to support high quality and safe care. The workforce will not stay in aged care if, day-to-day, the system in which they work is so inadequately funded or does not have the right funding incentives in place to promote and enable the workforce to be trained and educated, to provide safe and high quality care. As Professor Harrington said:

until nursing homes have adequate staffing levels, they are unlikely to be able to stabilize the workforce sufficiently to take advantage of better training and management programs.¹⁸³

There are other reasons why the sector as a whole has had difficulties attracting and retaining well-skilled people to work in aged care. These include low wages and poor employment conditions, lack of investment in staff and, in particular, staff training, limited opportunities to progress or be promoted, and no career pathways.

Many aged care workers would be paid more if they left aged care and went to work in other sectors, such as health or disability. The aged care sector does not offer competitive pay and employment conditions. Personal care workers and nurses in aged care are paid comparatively less than their counterparts in other health and social service sectors.¹⁸⁴

Underemployment is also a common problem. According to the 2016 National Aged Care Workforce Census and Survey, 30% of the residential direct care workforce and 40% of the home care workforce work fewer hours than they would like to.¹⁸⁵ The survey showed that a desire for better pay and preferred working hours are among the most common reasons that aged care workers leave their jobs.¹⁸⁶ Aged care is widely perceived to be a low status job which offers poor rates of pay.¹⁸⁷ We heard that in the context of the COVID-19 pandemic, the strategy employed by one provider to attract more staff to assist during the pandemic was to increase pay rates and align them with acute sector pay rates. We heard that this strategy worked.¹⁸⁸

Mr Charles Wann, First Assistant Secretary, Aged Care Reform and Compliance, Australian Department of Health, emphasised that ‘issues relating to remuneration and working conditions are matters for providers as employers’.¹⁸⁹ This is true, but the way the Australian Government funds the aged care sector directly impacts on how employers can negotiate pay and conditions. The Australian Government has, in the past, made some attempts to direct a portion of funding towards wages for aged care workers.¹⁹⁰ In announcing one initiative to increase wages, the former Minister for Mental Health and Ageing, the Hon Mark Butler MP, said:

Aged care workers don’t tend to work in the aged care sector for the money, they do it because they love the work. But that in itself has to stop being an excuse for paying such low wages for such important work.¹⁹¹

However, these initiatives did not translate into increased wages across the board.¹⁹²

Both the Australian Government and providers have a responsibility to lift the employment conditions and the status of aged care workers. We cannot rely on the commitment and goodwill of workers to build the aged care workforce. The sector needs to work harder to be attractive to a broad range of people. It needs to attract people with aptitude for aged care work and ensure that they have adequate training.

The bulk of the aged care workforce does not receive wages and enjoy terms and conditions of employment that adequately reflect the important caring role they play.

About three-quarters of the direct care workforce in aged care are employed on a permanent part-time basis. Casual and contract employment is also common.¹⁹³ In home care, in particular, workers have ‘fragmented working hours’, shorter shifts and hold multiple jobs.¹⁹⁴ Across the economy, participation in on-demand work—also referred to as platform or gig economy work—is growing.¹⁹⁵ A recent inquiry found that ‘Platform work is a statistically small but significant and growing part of the labour market’.¹⁹⁶ A shift toward this mode of engagement in aged care would mean fewer staff directly employed by providers, which has the potential to impact on the consistency and cohesion of care. There is limited investment by providers in the workforce to develop the skills of the aged care workforce, to nurture them, or to build a workplace culture or multi-disciplinary in-house care teams.

Aged care workers often lack sufficient skills and training to cater for the needs of older people receiving aged care services. Existing training and education systems for personal care workers and health professionals do not provide the specific knowledge and skills to meet to the needs of older people who require care. We have heard that personal care workers often lack skills and have little opportunity for effective training in dementia care, palliative care, trauma-informed care, nutrition, medication and falls management.¹⁹⁷ We have also heard that nurses working in aged care may lack sufficient skills and knowledge in relation to dementia and geriatrics.¹⁹⁸ We have heard calls for increased education and training for allied health professionals so that they are better equipped to support the physical, social and emotional wellbeing of older people.¹⁹⁹ Peak bodies for dentistry and oral health experts want dental practitioners to be better trained to cater to the needs of older people.²⁰⁰

There is no requirement for undergraduate nursing and medicine students to undertake placements in aged care during their training—and many do not.²⁰¹ Their preparedness can be greatly enhanced when they undertake good quality clinical placements in aged care.²⁰² This does not occur enough. As a result, health care is often delivered by professionals with little understanding of the particular needs of older people, which can affect the quality of care provided.

There is no minimum mandatory qualification for personal care workers. This means that some personal care workers have no formal training. It is certainly the case that not all personal care workers have the level of education and training required to provide safe and effective care services to older people. Mr Jason Burton from Alzheimer's WA summarised the implications of this for care quality and the ability of staff to provide care that focused on the person receiving care:

Staff training in aged care remains sporadic with no minimum training requirement and no national applied competency framework. Despite the complexity of providing high quality person centred care to a vulnerable older person, staff are often lacking in the knowledge and skills that are required to provide care outside of a task focused institutional paradigm.²⁰³

We heard about the implications of a lack of minimum qualification, or any ongoing training or refresher requirement, for personal care workers. For example, Ms Rosemary Dale, a personal care worker, expressed concern that a lack of adequately trained workers places additional pressure on those who are qualified.²⁰⁴ Ms Dale told us about her role training new workers through a buddy system. She said that new workers without Certificate III training are 'not aware of what they're coming for' and suggested that they need some sort of 'grounding' or training before they start.²⁰⁵

Even where personal care workers have undertaken training, witnesses told us that the quality and overall duration of vocational education and training courses for personal care workers are inconsistent and too often do not focus on the needs of the student and the aged care sector.²⁰⁶ For example, palliative care is not a core requirement within the current Certificate III aged care qualification.²⁰⁷ Personal care workers are often required to perform the task of nurses but lack the qualifications, training, skills, knowledge and experience to do that work appropriately.²⁰⁸ As Mr Robert Bonner, Director, Operations and Strategy at Australian Nursing and Midwifery Federation (SA Branch), said, 'we are preparing workers at a cert 3 level for roles that are requiring skills, knowledge and competence that are far beyond that'.²⁰⁹ This has a profound impact on care.

In addition to there being poor training, we heard that the aged care sector is one without clear career pathways. As Ms Sandra Hills OAM, Chief Executive Officer of Anglican Aged Care Services (Benetas), said:

The aged care sector needs to become a primary and attractive sector for talented individuals rather than secondary to the acute sector. This can partly be achieved through the deliberate creation of long and rewarding career paths.²¹⁰

A recent discussion paper prepared on behalf of the Aged Services Industry Reference Committee noted that: 'Currently it's challenging for those already within the industry to be able to use their existing experience or education to move beyond initial roles'.²¹¹ This needs to change.

Finally, a key factor relevant to retaining staff members is the level of worker engagement in the organisations for which they work. This was one of the findings of the Aged Care Workforce Strategy Taskforce, which noted that drawing on staff insights and perspectives on the organisation can promote job satisfaction and retention.²¹² Research in the early childhood education sector has found that listening to employees can aid in staff retention.²¹³ This is an area where providers can make immediate changes on the ground for their workforce. To do so will require strong leadership and management. Strong leadership from within providers is required to attract, engage, develop and retain the aged care workforce for the future.

The message we have heard is clear: aged care quality and safety is directly dependent on the number and quality of the people who provide it. It is clear to us that the quality of care that older people receive has been compromised because, all too often and despite best intentions, those people who work in aged care simply do not have the requisite time, knowledge, skill and support.

4.11 Attitudes and assumptions about ageing and aged care

Attitudes and assumptions about older people and aged care can affect the delivery of aged care. While there is no doubt that older people are valued, there is some evidence that, as a society, we underestimate and devalue older people's contributions to the community.²¹⁴ Commissioner Briggs considers that ageism is a systemic problem in the Australian community that must be addressed.

Dr Kate Barnett OAM, a social gerontologist, said:

ageism is just such a prevalent issue in our community and it, I believe, underlies a lot of the issues we have with aged care, the system and how it's designed and what might be the implicit meanings behind the way the funding goes...It's there under the surface the whole time. People usually don't come out and say it like I am now, but there you go.²¹⁵

Older people with a disability may receive fewer services through aged care than if they qualified for the National Disability Insurance Scheme. Similarly, older people are sometimes being refused access to health services, such as Medicare-subsidised mental health services or specialist palliative care services, simply because they are in aged care.²¹⁶ This is discriminatory. Unlike de-institutionalisation reforms in the disability system, institutionalisation and segregation of older people in the aged care system has persisted.²¹⁷

Assumptions in society and the aged care sector about the natural process of ageing may contribute to a lack of attention on prevention, reablement and maintenance. Some people working in the aged care sector may tend to accept that decline is inevitable, and that the most that people can wish for as they become more frail and dependent is to be kept safe and comfortable. There is a widespread view in the community that living in residential aged care will lead to an inevitable decline in control and quality of life as well as general unhappiness.²¹⁸

A counterpoint to this approach is the disability sector, which has a greater focus on not allowing a person's disability to be a barrier to fuller participation in life.²¹⁹ Ms Kate Swaffer, who gave evidence both as a person with direct experience in the aged care system and as the Chair and Chief Executive Officer at Dementia Alliance International, described her transition from aged care services to the National Disability Insurance Scheme:

Since transitioning to the National Disability Insurance Scheme (NDIS), which due to all the negative media, I was dreading, I can honestly say, for me, it has been an exceptionally positive experience...I have been supported to live positively, not only die from dementia. The focus of my first assessment was on my goals to live a good life, not just my activities of Daily Living; for example, not just a shower rail, or ramp, for when I would need it, which is what the aged care sector provided advice on.²²⁰

When it comes to improving health, some conditions, such as back pain or feelings of depression, may be put down to ‘old age’.²²¹ Dr Diane Corser, a clinical psychologist working in aged care, said of starting her role:

It was also challenging overcoming ageism where staff, family, and people residing in aged care centre thought mental illness (e.g. depression/anxiety) was a normal part of ageing.²²²

Associate Professor Michael Murray, Head of Geriatric Medicine at Austin Health, believed that ageism contributed to poor continence care in aged care because incontinence is sometimes considered a normal part of ageing.²²³ Dr Joan Ostaszkiewicz, registered nurse and Research Fellow at Deakin University in the Centre for Quality and Patient Safety Research, referred to research that suggested that incontinence products were being used in subacute care on older people who had not had episodes of incontinence:

So I suspect the same is happening in an aged care facility where we have ageist attitudes predominate, as they do in society more broadly, and we all know lots of examples of people admitted to hospital who are automatically put on a continence product with the assumption of just in case or, you know, they’re elderly.²²⁴

Commissioner Briggs notes that the provision of health care more generally may also be affected by health practitioner’s prioritising younger people. Mr Ian Yates AM, Chief Executive of COTA Australia, expressed ‘concern about discrimination’ in the health system. He said:

Older people are principal customers of that system, but there has been a slow process of recognising that they are equal citizens in that system.²²⁵

Mr Yates noted that health practitioners, such as general practitioners and specialists, sometimes do not give people in residential aged care the priority they should.²²⁶ Commissioner Briggs observes that during COVID-19, there were different approaches to whether people in residential aged care were transferred to hospital.²²⁷ In our special report on aged care and COVID-19, we noted that the ‘starting point’ in deciding whether a person with COVID-19 is transferred to hospital ‘must be to recognise that equal access to the hospital system is the fundamental right of all Australians young or old and regardless of where they live’.²²⁸

Associate Professor Lee-Fay Low, Faculty of Medicine and Health at the University of Sydney, noted the ‘assumption of narrative foreclosure’ that underlies residential aged care—this is the idea ‘that a resident has lived a good life and their life story is over—and they are to be maintained safely until death’.²²⁹ In contrast to this more common approach, Ms Josephine Boylan-Marsland and Dr Tim Henwood, both from the home and residential aged care provider Southern Cross Care (SA, NT and VIC), told us of their focus on maintaining and increasing function through their multidisciplinary allied health program.²³⁰ Ms Boylan-Marsland said she believes this approach offers people a ‘better quality of life right up until they die. So my goal is to keep people walking until they die’.²³¹

Witnesses called for a system that embraced ‘dignity of risk’—one that allows older people to make choices about their day-to-day activities, such as going for a walk even though they have an increased risk of falls, or eating a soft-boiled egg.²³² Associate Professor Stephen Macfarlane, Head of Clinical Services at the Dementia Centre, HammondCare, said that the current aged care system sometimes focuses on safety at the expense of a quality aged care experience that would allow people to take reasonably controlled risks to maximise their quality of life.²³³

Stereotypes about older people can lead to carers making assumptions about a person’s cognitive capacity. Ms UX told us that staff members assumed that her mother had dementia because she was frail and in her 80s.²³⁴ Ms Daryl Melchhart said:

Living in an aged care facility, I have a never ending battle to be seen as a fully competent adult. My thoughts and wishes are mostly disregarded by some of the staff and I am treated by some of the staff as if I am a child or have dementia.²³⁵

Assumptions about an older person’s cognitive capacity may lead to them being excluded from conversations, staff members talking about them as if they are not there, not respecting their privacy and speaking about their private medical information in front of others. Ms Janette McGuire, a Forgotten Australian, spoke about the lack of dignity, privacy and respect she experienced when she spent two weeks in a short-term residential aged care facility:

on several occasions, the social worker based at the facility came up to my bed and talked loudly about my personal business in front of other patients and their visitors. People could hear what the social worker was saying. I felt this was a breach of my privacy and my dignity.²³⁶

Ms Beryl Hawkins, who receives home care, said: ‘In my experience, people talk around me or to my carers as though I can’t understand them. It makes me feel alone’.²³⁷ Ms Beverley Johnson, a woman living in residential aged care, said: ‘Frequently, new staff do not introduce themselves and when asked their name, their reply can be, “You won’t remember it, dear”’.²³⁸

Some have seen attitudes and assumptions about older people in the language used in aged care. Examples of this include when people describe ‘toileting’ a person rather than helping them go to the toilet, or when a person going for a walk is ‘wandering’. This kind of language is seen by some to position the older person as an object or a ‘job’ that someone must complete. Dr Lisa Trigg, Assistant Director of Research, Data & Intelligence at Social Care Wales, said:

‘Abscond, wander, BPSD [behavioural and psychological symptoms of dementia],’ you know, these are people who are reacting to what’s going on around them. So those sorts of—that sort of language happens—matters. ‘The floor, feeding, toileting,’ you know. How would you feel if someone said they were going to toilet you, not help you go to the bathroom?...it’s essentially very ageist and very—yeah very inhumane.’²³⁹

The evidence we heard suggests that the approach of many Aboriginal and Torres Strait Islander communities to their Elders provides a valuable lesson for all of us. As was observed in the Interim Report, Aboriginal and Torres Strait Islander people see Elders as central to the future of culture, deserving of respect and entitled to be looked after with dignity.²⁴⁰ The wider Australian community can learn from this deep appreciation of older people. At the Broome Hearing, Ms Venessa Curnow, an Ait Keodal and Sumu woman and the Executive Director of Aboriginal and Torres Strait Islander Health at Torres and Cape Hospital and Health Service, said:

the old people are the ones that teach you how to go out on Country. They teach you all the songs, they teach you languages. So you have an innate respect for them and their place in community...we...wouldn't be here without the older people...looking after our older people is part of who we are...It's like our connection to their mother, and their mother before, and that's how we pass down our knowledge through the generations.²⁴¹

We would like to see an aged care system in which older people are consistently treated equally, with respect, dignity and independence.

4.12 A reactive model of care

Our inquiry has revealed that the prevailing model of care in the current aged care system is largely reactive. Aged care services are not generally geared towards people's enablement and do not maximise the maintenance and improvement of people's health.²⁴²

Dr Jennifer Hewitt, a Clinical Physiotherapist and Senior Lecturer and Clinical Educator at the University Centre for Rural Health, the University of Sydney, said that in aged care, maintenance is 'something to celebrate' and that maintaining older people's ability to function is an important goal.²⁴³ This approach should affect the care people receive. Unfortunately, intervention often only occurs when issues arise, and the focus of care is on symptoms, not causes.

There have been many examples of reactive care presented through the life of this Royal Commission. Physiotherapists were brought in to manage residents' pain rather than being actively involved in maintaining and restoring mobility.²⁴⁴ Nutritionists tend to be contacted when individual people have a special dietary requirement, or they have a 'red flag' or 'trigger' event, rather than to assist in the development of meal planning to meet the specific needs of older people.²⁴⁵ Pressure injuries were viewed as typical and to be expected in residential care, when they could have been prevented.²⁴⁶ Dr Ostaszkiewicz expressed concern that the manufacturers of continence products were filling a void in continence education, which resulted in promoting the use of incontinence products, such as pads, over preventative strategies.²⁴⁷

Some expert witnesses and providers said that the current funding structure provides incentives for reactive care rather than proactive care.²⁴⁸ That is, the current funding structure is based on episodic care which does not meet complex health care needs of many people in aged care. It is geared toward support that addresses deficits rather than building capability. Reactive episodic care is vital and necessary in any well-ordered health and care system, but attention needs also to be given to preventative care that could avoid the episode occurring in the first place. Ms Lucille O’Flaherty, Chief Executive Officer of Glenview Community Services, explained:

we are funded for the amount of medications we’re giving, how many times we shower someone, what meals we provide. We’re not funded for how happy a resident is and how we’ve reduced their sleep medication because they’re happier and sleeping better.²⁴⁹

A reactive approach can reduce access to health care services.²⁵⁰ For example, Ms Rhonda Payget said that staff members at her mother’s aged care service responded to the family’s queries, but lacked the capacity to provide high quality care and attention due to the number of residents they had to care for. As a result, a number of Ms Payget’s mother’s care needs were only met when family members raised them.²⁵¹ Ms Payget gave an example of a ‘reactive referral’ to a skin specialist only being made after the family raised its concern about a skin lesion.²⁵²

Poor and ineffective care planning, particularly in residential aged care, is another sign of a system that does not prioritise proactive and planned care. Aged care providers have obligations under aged care legislation and the Quality Standards to produce and maintain a care plan for people receiving care.²⁵³ That plan should be used to determine the health and wellbeing needs, goals and preferences of people and to outline how best to meet those needs.²⁵⁴

Yet care plans, at times, are either not made at all, not updated, have errors or gaps in information, are not used to inform the delivery of care, or are not well understood by the person receiving care and their loved ones. In the Bupa Willoughby Case Study, Ms DI explained that she did not realise that her mother had a palliative care plan until a staff member mentioned it at a meeting. She said that when she asked for a copy, the care plan ‘was just handwritten notes made by the palliative nurse in Mum’s progress notes’.²⁵⁵ Ms Helen Valier described her experience of a lack of clarity around care plans when her late husband was in residential aged care:

Then I started to become concerned about the lack of a care plan. We didn’t know what it involved. He did have a mobility plan. It was tacked to his bathroom door...When we did ask staff, they didn’t seem to know...the advice that we got variously was there were a number of plans, but nobody seemed to know what they covered.²⁵⁶

Some family members said they had not been involved in the development of care plans, despite having valuable knowledge about the needs of their family members in aged care.²⁵⁷ Even when care plans are documented, it does not necessarily equate to care provided—just because something is written down in a care plan, does not mean a resident actually receives that care.²⁵⁸

Too often, witnesses said that in residential aged care, the care plans were prepared primarily for the purpose of accessing funding under the Aged Care Funding Instrument.²⁵⁹ A number of physiotherapists told us of their frustration at not being able to provide the allied health care they knew their client needed because they were required to provide a limited range of non-evidence based pain management services that were covered under the Aged Care Funding Instrument.²⁶⁰

Deficits in care planning reduce the ability of care staff to deliver appropriate care.²⁶¹ For example, witnesses said that failing to plan for pain management, including appropriate medications, can cause people unnecessary pain and suffering.²⁶² Ineffective care planning is not good enough in a high quality aged care system. Dr Lisa Studdert, then Deputy Secretary, Ageing and Aged Care Group, Australian Department of Health, said that the absence of a care plan was a ‘great cause for concern because there is no documentation by which you could verify that a recipient—a client was getting appropriate care’.²⁶³ We agree. We are also concerned that care plans may prioritise funding considerations over care, are insufficiently detailed and rarely updated, and are not adhered to.

Older people need and deserve a proactive and preventative approach to their care. In the current system, the approach to care does not adequately prevent, support, identify and address the underlying causes of health concerns.

Commissioner Briggs observes that the reactive model of care also extends to an insufficient focus on the emotional and social needs of older people. We both agree that the dominant models of care delivery in aged care are task-based and focused on standardised processes.²⁶⁴ This approach to caring can leave people feeling depersonalised and like a passive object, rather than as a whole person with emotional and social needs. Ms Johnson, who lives in residential aged care, described occasions where staff members would enter her room as if she was not there, continuing their conversations with each other: ‘Often not a word is said to me. I feel as though I am just an object that has to be moved from A to B’.²⁶⁵

A person’s physical and medical care needs may be met, but they may still feel isolated, forgotten or bored.²⁶⁶ Mr Anthony O’Donnell, who lives in residential aged care, said:

The definition of care on both daytime shifts seems to be centred on making sure that there is something formally set down to do as a series of tasks. Actual care, as in the connecting with residents in order to see to their needs and to interact with them as people, left to the summoning of the Carer, or floating carers, by the resident pressing a button and once the resident’s immediate need is satisfied it’s off to the next most urgent task or call—leaving the parties neither satisfied nor fulfilled.

In one sense while immediate needs may well be met in this way, if considered objectively and without any intrusive thoughts about costs and the like, then such a definition of care is little more than is given to our sheep or cattle in the export business.²⁶⁷

The task-based approach to care reflects a misplaced belief that care is adequate so long as a person’s medical and physical needs are met.

This issue is exacerbated by demanding workloads for staff which limit opportunities for conversation and connection. Staff members can find it distressing that they are not able to spend time with the people to whom they provide care.²⁶⁸ Most aged care staff want to do the best for older people, but find themselves without enough time to provide adequate emotional and social support.²⁶⁹ Ms Emma-Kaitlin Murphy, a registered nurse, said:

I became a nurse because I want to care for people...We're doing documentation, we're doing medications, and while they're all equally important parts of a person's care, it's fundamental to be able to look after and nurture their emotional wellbeing.²⁷⁰

We conclude that the current system does not sufficiently recognise the importance of proactively supporting an older people's social and emotional wellbeing, instead taking a largely 'hands off' approach to this aspect of care.

4.13 The lack of voices of older people and diverse communities

When the design and delivery of a service or system does not take account of people's needs, preferences and circumstances, they can exclude and alienate the people they seek to assist. This can lead to a one-size-fits-all approach to program design and delivery. People receiving aged care and their local communities are not well represented in the aged care system. Professor John Pollaers OAM, former Chair of the Aged Care Workforce Strategy Taskforce, described aged care as a 'highly fragmented industry' with:

lots of different groups that...hadn't taken the time to listen to each other's opinions and points of view...and in many ways locked into a contest between government, industry and the unions, without really involving the community or the residents and the consumers themselves.²⁷¹

This was starkly illustrated by an aged care resident, Ms Johnson, who described the difficulties she had being heard and respected in the aged care facility where she lived. When asked about representation of residents in aged care facilities, she said:

Well, I would say, 'What representation?' There seems to be very little of it. And, like anyone in the community [residents] should have a right as to how you're treated. And residents, it would appear, once they pass through the front door of the facility, give up that right.²⁷²

Ms Noleen Hausler, speaking about her father's experiences in residential aged care, said:

The Royal Commission has given an unprecedented voice and opportunity to residents and families, and advocates in a safe, respectful environment to be heard and valued.²⁷³

Such a voice should not be unprecedented. It should be routine and used to ensure that the system is fulfilling the needs of the people it is designed to provide care for.

Other witnesses also commented on the lack of older people's influence in aged care policy development. Mr Glenn Rees, Chair of Alzheimer's Disease International, said that the voice of older people does not reach the Australian Department of Health and that some of the documents from national organisations do not always represent the values of people who receive aged care and their carers.²⁷⁴ According to Mr Rees, 'the government of the day has to look for mechanisms, however difficult, which bring the department and the political process face to face with people with dementia, with older people more generally'.²⁷⁵

Mr Geoffrey Rowe, Chief Executive Officer at Aged and Disability Advocacy Australia, said that the voice of older people is not represented compared with the interests of other parties, at both the service and system level.²⁷⁶ Mr Rowe said this was apparent in the development of the Aged Care Standards:

when I went to consultations and I looked at who was around the table, the minority group were the consumers. The majority group were the service providers and other interest groups. And, you know, putting it bluntly, I saw people who were wanting to use that instrument not as a tool for the aged care consumer, but as a tool that the service provider could use to hold the aged care consumer for paying their fees. And that was completely the wrong intent of the document. And I think that's indicative of some of the issues that we're seeing in the aged care system.²⁷⁷

Some advocacy groups for older people told us they are often not consulted. For example, Ms Swaffer claimed that Dementia Alliance International is 'almost never consulted by the government'.²⁷⁸ Ms Swaffer also said:

Dementia Alliance International is not influenced by anybody else's agenda. We're not influenced by what funding or getting funding because we don't have very much funding. We really are an authentic voice, and we're not out to make friends. We're out to try and change the world.²⁷⁹

It is particularly important that the policy developers and aged care providers listen to voices from, and community representatives for, groups that are already disadvantaged. Ms Samantha Edmonds, Chair of the Aged Care Diversity Sub-Group and Policy and Research Manager of the National LGBTI Health Alliance, acknowledged the Australian Department of Health's central role in supporting the work of the Sub-Group but said that she 'sometimes felt that the provider peaks' voices were given greater consideration than the voices of the consumers'.²⁸⁰ The Australian Department of Health acknowledges that there is disparity in the information it has about access to aged care available across different cohorts of people with diverse backgrounds and life experiences.²⁸¹ For example, there is limited data on veterans, people experiencing homelessness or at risk of homelessness, and people who are financially and socially disadvantaged. There is no data on care leavers, parents separated from their children by forced adoption or removal, or people from the LGBTI communities.²⁸² In the absence of data, it is even more important that policy developers work with local communities and representative groups.

There are many examples of the problems which can be caused by a one-size-fits-all approach. For example, much about the design and delivery of home care appears to be predicated on the assumption that people own their own home or have safe and secure housing.²⁸³ People working in the aged care sector may also assume an older person is able to rely upon the support of friends and family, when this is not always the case.²⁸⁴

Even when data about disadvantaged groups does exist, it is not sufficient for the system manager to rely on this alone. For example, we know that in 2018, the Australian Department of Veterans' Affairs estimated that there were 641,000 living Australian veterans.²⁸⁵ Of these, approximately 165,000 were Department clients and 55% of those were aged 70 years and over.²⁸⁶ Mr Nathan Klinge, Chief Executive Officer of RSL Care SA Inc., said that while many of the care needs of veterans in aged care align with those of the broader population, there are a number of specific differences and challenges to providing aged care for veterans.²⁸⁷ These factors, which can both predicate and be a barrier to entry into aged care, include entry to aged care at a younger age, substance abuse, family breakdown, post-traumatic stress disorder and social isolation.²⁸⁸

While the Veterans' Supplement in Residential Care is available to aged care providers to ensure a veteran's mental health does not act as a barrier to accessing care, a number of factors inhibit the effectiveness of this Supplement. The Supplement is only provided for veterans who have a diagnosed service-related mental health condition, yet both anecdotal and research evidence suggest that older veterans in particular are more likely to deny mental health and psychiatric symptoms.²⁸⁹ In any event, we received evidence that the \$7.08 per resident per day Supplement is not sufficient for an aged care provider with extensive knowledge and experience in veteran issues to care properly for this population—let alone enough for providers without this specialist capacity.²⁹⁰ Closer collaboration with veterans and their broader community would assist the Australian Government to develop a more proportionate response.

Professor Paterson said:

The absence of strong consumer voice in the aged care system is a notable feature of aged care in Australia. The voices of providers are prominent in the Australian system—and appear to be highly influential in policy debates, with Ministers, departments, agencies and officials—but the voices of consumers, families and consumer advocates are relatively weak.²⁹¹

We agree with that view. In overhauling the aged care system, the voices of people receiving care must be a priority to ensure that the system remains relevant and appropriate for the people it is intended to support.

An important part of ensuring that people receiving aged care have a strong voice in the aged care system, and that they are supported to complain and provide feedback, is robust and well-funded advocacy services. However, in Queensland, the aged care advocacy services were 'only supporting less than one per cent of aged care users', and that there was a wait list for advocacy services of up to six weeks.²⁹² Without adequate advocacy services to support feedback from people receiving care, substandard care may not be identified and opportunities to improve services may be missed, contributing to systemic failures in aged care.

4.14 Ineffective regulation

The Aged Care Quality and Safety Commission and its predecessors have not demonstrated strong and effective regulation. The regulatory framework is overly concerned with processes and is not focused enough on outcomes. The system is insufficiently responsive to the experiences of older people. The oversight of home care is underdeveloped. There is a poor track record—in both home care and residential care—on enforcement, and a reactive approach to monitoring and compliance. In the words of Professor Paterson:

the regulation of aged care in Australia has paid lip-service to the welfare of care recipients. The system fails to ensure the provision of safe, high quality care and pays insufficient attention to the quality of life of aged care users.²⁹³

The regulatory arrangements lack the transparency, accountability and responsiveness that would be expected of a contemporary regulatory regime.²⁹⁴ Overall, the system has not provided the assurance of high quality and safe care that older people and the community would reasonably expect.

The oversight of residential providers has relied far too heavily on a three-year cycle of accreditation audits against fixed standards.²⁹⁵ The three-year cycle of audits is inefficient and is not risk-based. It has not been effective in preventing, detecting or responding adequately to instances of poor quality care.²⁹⁶

The current approach to regulation takes insufficient account of other intelligence that might point to substandard care, such as the experience of people receiving care, complaints, reports of serious abuse or assaults, coronial reports and signs of provider financial distress.²⁹⁷ Where problems have been identified, the regulator has lacked curiosity about underlying patterns of performance and has been too ready to accept the assurances of providers in relation to their own performance.²⁹⁸

The assessments of residential aged care providers are based on a binary ‘met’ or ‘not met’ basis. Assessments of this kind do not permit a meaningful comparison of the performance of different services. This is particularly the case in circumstances where a high percentage of providers has historically been assessed as meeting all minimum standards and outcomes.²⁹⁹ As Professor Paterson observed, the binary assessment approach does not meet the ‘minimum standards’ of information.³⁰⁰ The assessments fail to provide enough information to encourage providers to pursue excellence or to provide older people with the information they need to judge the quality of care they might receive.³⁰¹

The quality and safety regulatory framework for home care is not strong, despite the risks of poor care or abuse being high. The New South Wales Ageing and Disability Commissioner, Robert Fitzgerald AM, told us that:

The highest risk for older people in the aged care system is within the home. I know all of the attention focuses in on the residential settings, and there are high risks in those...But the risks that occur at home are quite substantial because there is not the line of sight that you normally see in residential services.³⁰²

Ms Janet Anderson PSM, Aged Care Quality and Safety Commissioner, agreed that home care services have a risk to clients related to a lack of visibility of the service. She said: 'I'm not convinced that our regulatory gaze in home care is as strong as it needs to be'.³⁰³ This is despite the Aged Care Quality and Safety Commission and its predecessors having responsibility for home care regulation since 1 July 2014.³⁰⁴

Ms Gwenda Darling, a person receiving home care, gave evidence that 'the home care system is broken and it seems totally unregulated'.³⁰⁵ In August 2019, Ms Amy Laffan, then Assistant Secretary of the Aged Care Quality Regulatory Design and Implementation Branch, Australian Department of Health, outlined some gaps and weaknesses in the regulation of home care. These included:

- the absence of any requirement for accreditation against the standards before a provider commences providing services
- quality reviews happen at the providers' premises rather than in a place where the provider delivers care and services
- the results of quality reviews are not published, while accreditation results and re-accreditation audit reports in the residential care context are published
- an absence of information sharing with other social care systems, such as the National Disability Insurance Scheme.³⁰⁶

In addition, some key quality and safety regulatory tools that are used in residential care are either taking longer to be developed in home care or not developed at all. These include:

- quality indicators, which exist for residential care but not home care³⁰⁷
- differentiated performance ratings, which have been introduced in residential aged care, but not home care³⁰⁸
- a new serious incident response scheme, which is to be introduced in residential care in 2021, while work is still ongoing on options for extending the scheme to home care³⁰⁹
- risk profiling tools, where development has been prioritised for residential aged care (to commence by 1 July 2020) over home care (not due to commence until December 2022)³¹⁰
- no accreditation of home care services.

Ms Anderson also told us in September 2020 that 'regulatory activity, insofar as you would include quality reviews and assessment contacts, have declined' in relation to home care.³¹¹

It is important that the regulation of home care is effective, particularly given that older people want to remain in their homes for as long as possible. That care should be high quality and safe. Vulnerable older people living at home have a right to be safe and free from abuse. In 2018–19, the Aged Care Quality and Safety Commission conducted 602 quality reviews of home care services.³¹² In comparison, it conducted 1248 audits of residential aged care services during that time.³¹³ This is despite there being similar numbers of services / facilities operating during this period.³¹⁴

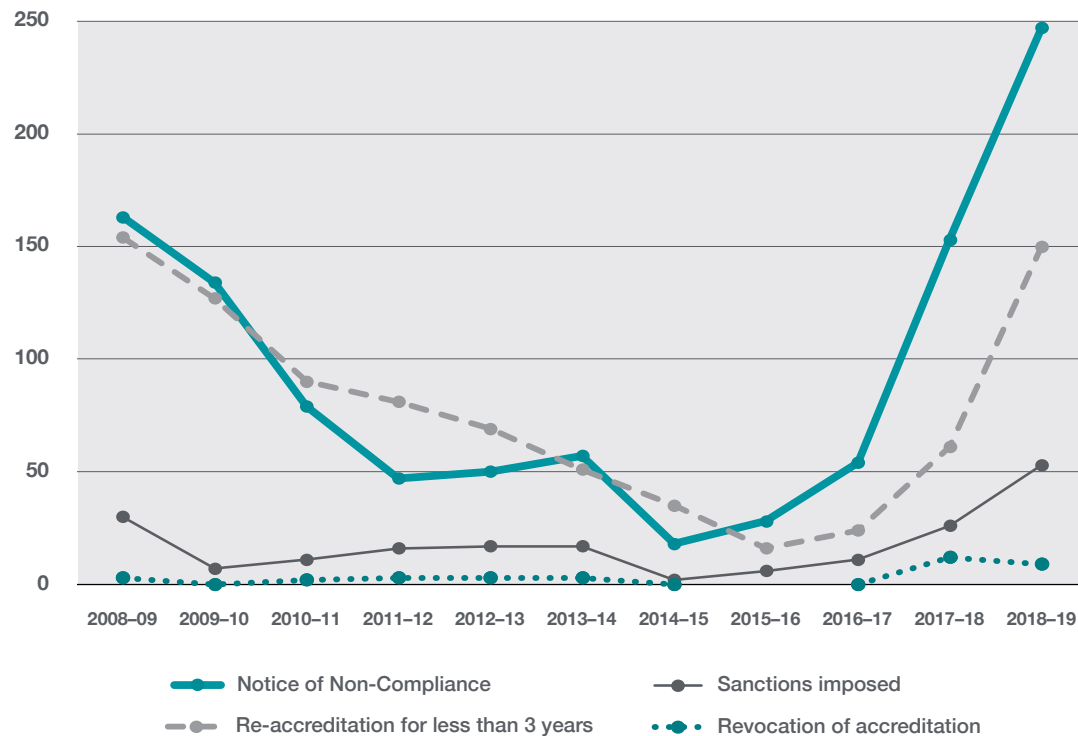
Another key problem is a weak approach to enforcing the responsibility of providers to provide high quality and safe care. The regulator is, amongst other things, an enforcement body. It has a responsibility to hold providers to account against the quality and safety standards that are set. Exercising enforcement power is an important part of ensuring that the regulatory system deters poor quality or unsafe care, and is credible and effective. Professor John Braithwaite, a leading expert in regulation, has described aged care enforcement in Australia as ‘enfeebled’.³¹⁵ Providing poor care has rarely had serious consequences for providers.³¹⁶ Governments typically play both a regulation and a funding role for aged care. These are different roles and need to be performed with functional separation so that concentration on funding does not diminish the regulatory role.

As discussed above, Ms Carnell and Professor Paterson undertook a review of aged care quality regulatory processes in 2017 (the Carnell-Paterson review). They observed that only a small number of aged care providers had faced revocation of approved provider status, and that ‘severe compliance action is very seldom used in the Australian aged care system’.³¹⁷

The regulator has rarely used its powers to sanction providers. When it has moved to sanction providers, the regulator has applied a remarkably uniform response to non-compliance that generally focuses on managing the provider back to compliance.³¹⁸ The one-size-fits-all approach to enforcement suggests a regulator that either lacks an appropriate range of enforcement tools or the necessary flexibility and imagination to deploy the right sanction to fit the individual case.

Figure 4 illustrates the use of key enforcement powers by the Aged Care Quality and Safety Commission and the Australian Department of Health between 2008–09 and 2018–19 across all types of aged care.³¹⁹

Figure 4: Enforcement options used by the Aged Care Quality and Safety Commission and the Australian Department of Health 2008–09 to 2018–19



Source: Analysis of Exhibit 8-27, Brisbane Hearing, general tender bundle, tab 146, CTH.0001.1000.8094.

Analysis of the enforcement activity by the quality and safety regulators over time suggests a highly varied approach to enforcement in aged care. There is a noticeable dip in enforcement activity from 2009–10 to 2015–16. Commissioner Pagone is more concerned with the increased activity appearing after 2016–17. The decline before then is consistent with the system working effectively such that enforcement had been less necessary. The more concerning feature, in Commissioner Pagone’s view, is the sharp increase in 2016, which seems to coincide with a freeze on indexation which necessarily resulted in less funding being available. That we cannot tell if the drop in enforcement was a good or bad sign is itself an indictment of the current arrangements.³²⁰

Commissioner Briggs understands from the evidence available to us that the dip in enforcement activity through to 2015–16 is not a sign of a system working effectively. It coincided with a significant across-the board reduction in key compliance and monitoring activities, specifically a significant drop in the number of review audits and assessment contacts, particularly unannounced audits. Over the same period, the number of reportable assaults and missing resident reports grew, and the number of complaints remained fairly steady.³²¹ With this context, the reduction of enforcement activity is suggestive of a regulator that has taken its hands off the wheel. It also coincided with the regulatory framework’s failure to detect significant failures of care at Oakden Older Persons Mental Health Service. The Carnell-Paterson review found that the regulatory system at the time was fragmented and inadequate.³²²

Since the 2017–18 financial year, there has been a significant increase in the use of the regulator’s power to revoke a provider’s accreditation. And, since the 2015–16 financial year, there has been an increase in the use of all enforcement powers. Nevertheless, it remains the case that the regulator’s approach to enforcement over recent years has been relatively weak when considered in light of the harm done to some older people as a consequence of poor quality care.

In addition, the regulator’s enforcement efforts to date have been hampered by the lack of flexible enforcement tools and powers. We have heard that the regulatory model would be strengthened by having access to a wider range of sanctions, including powers to hold directors to account.³²³ We make recommendations to address this in Volume 3.

We are concerned that the regulator has had a mindset of managing every provider back to compliance. Professor Paterson gave evidence that he thinks this mindset ‘holds grave dangers’. Reflecting on the Earle Haven Case Study, Professor Paterson said:

I think that’s something we were very much aware of in the context of Oakden in 2017, during the time of our review, and I have to say, having sat through the evidence on Monday, having looked at the transcript for yesterday and then having sat through the evidence this morning, it does feel as if there’s still this whole idea that we have a compliance model where we’re trying to manage providers back to compliance and we’re very reluctant to go to the apex of the triangle.³²⁴

The Earle Haven Case Study provided an example of where a stronger response by the regulator may have resulted in a different outcome. In that case, the approved provider, People Care, had a sustained history of far-reaching non-compliance. Mr Anthony Speed, the then Acting Assistant Secretary of the Australian Department of Health’s Aged Care Compliance Branch, accepted that some of the matters in this case should have led to further investigation and consideration of People Care’s suitability as an approved provider.³²⁵

We heard evidence that more timely regulatory interventions are required. Ms Bethia Wilson AM, Principal of Wilson and Webster Consultancy Services and former Health Services Commissioner, Victoria, had been engaged by Bupa to undertake a consumer engagement process with older people and their families at a number of Bupa services in Victoria and Tasmania. She observed that:

I think that the regulators...in the cases that we’ve seen were a bit slow to act. It wasn’t until the Royal Commission was announced that the sanctions began to be placed on the facilities that we visited, and that all happened very, very quickly once it started. So I guess I’m going back to that question of why weren’t they sanctioned earlier rather than why are we being sanctioned now...I think there needs to be much more scrutiny of the regulator who should be... the window to Commonwealth accountability.³²⁶

It is also important for the regulator to take strong enforcement action to send a clear message to the sector that substandard care is not acceptable. There should be a demonstrated willingness by the regulator to resort to the most serious enforcement measures, which in the aged care context are revoking accreditation or approval or otherwise taking poor performers out of the system. An underuse of these powers risks service providers viewing compliance as voluntary, and the regulator as lacking in credibility.³²⁷

As Dr Trigg said:

the new Aged Care Quality Standards will only result in better outcomes if other issues are addressed, for example, the legislative and enforcement powers of the Quality and Safety Commission and the appetite of the Australian government to close poor providers.³²⁸

Enforcement needs to be seen as the key function of the quality regulator. When appropriate, the quality regulator must be prepared to flex its 'regulatory muscle' and to impose sanctions for non-compliance.³²⁹

This underuse of enforcement powers provides an example of a lack of energy and drive from the regulator. Another example is in its approach to monitoring and compliance activities.

Professor John Braithwaite said the regulator needed to take an inquisitive or 'detective oriented' approach:

taking the initiative to seek out evidence from complainants, to seek out evidence from advocacy organisations, from community visitors, looking diagnostically at the quality indicators, coming to a view holistically about whether this is a high risk facility or not and having those conversations.³³⁰

Professor Paterson, reflecting on evidence received in the Earle Haven Case Study, said that:

I think there has been a total lack of curiosity. I think there has been a mechanistic approach to the role. It feels as if people have been going through the motions and not looking at what's right there in front of their noses.³³¹

The requirement to assess against the quality standards on a pass / fail or met / not met basis does not encourage, reward or showcase best practice. It does not differentiate between 'the people who have just passed and the people who are excellent'.³³²

Proactively seeking the views of older people receiving aged care services is an area where the regulator has been slow to implement change. The consumer experience interview and report process has the potential to be a powerful tool for the regulator to hear from older people about their experiences in aged care. Rather than wait for complaints to be made or issues to arise, the regulator can engage directly and proactively with people on the ground.³³³ However, the current consumer experience interview and report process provides quite limited opportunities for older people to provide input or feedback about their care. We have already outlined the problems in its ability to represent the views of people receiving residential aged care accurately. In residential care, there is a requirement to interview 10% of people during site audits and review audits.³³⁴ A recommendation by the Carnell-Paterson review that this should be increased to 20% has not been implemented. Ms Laffan said that the 20% requirement was too 'prescriptive'.³³⁵ The regulator should talk to more people, more often and in ways that elicit accurate information about the quality of their care. It should publish the outcomes.

In home care, there is no requirement to interview care recipients at all. During the Brisbane Hearing, a number of witnesses called for improvements to understanding older people's experience in home care. Ms Gwenda Darling, who accessed home care, said home care users should be surveyed for their views on the quality of service as part of the quality review process.³³⁶ Professors John and Valerie Braithwaite and Professor Toni Makkai encouraged the questioning of people receiving home care via phone calls to gauge the standard of service.³³⁷ We understand that, in the context of the COVID-19 pandemic, there have been over 5000 telephone calls made to people receiving home care services.³³⁸ This is a step in the right direction.

The regulator has recently implemented changes to the consumer experience interview process, and changes to the consumer experience report process are anticipated in 2021 that will enable the reports to be published.³³⁹ We hope that these changes will give greater voice to older people in aged care and, in particular, home care.

The compulsory reporting scheme for suspected or alleged assaults in residential aged care facilities is another example of a lack of proactive investigation in regulatory practices. The compulsory reporting scheme requires approved providers to report suspected or alleged assaults to the Aged Care Quality and Safety Commission within 24 hours of receiving the allegation.³⁴⁰ Before 1 January 2020, these compulsory reports were made to the Australian Department of Health. We heard that information provided to the Australian Department of Health was often accepted at face value, without investigation.³⁴¹ There was no requirement on a provider to name alleged offenders, so the Australian Department of Health was unable to identify alleged offenders of multiple allegations of assault. This approach left older people vulnerable to assault and unsafe practices. There have been some changes to the processes around compulsory reporting as part of the transfer of those functions to the Aged Care Quality and Safety Commission, but the inability to match alleged offender names in reports across the system persists.³⁴² The Australian Government recently introduced legislation to replace the existing compulsory reporting scheme with a new Serious Incident Response Scheme for residential care.³⁴³

While there have been some recent improvements in the regulatory framework for aged care, there are still problems. In particular, there is insufficient regulation of home care, there is a need for a consistently proactive and inquisitive approach by the regulator and more effort is required to obtain reliable information about older people's experiences of care.

4.15 An absence of transparency | Commissioner Briggs

A lack of transparency is a pervasive feature of the current aged care system. The consequences for the quality and safety of care have been profound.

Useful and relevant information on aged care services is difficult to come by. It remains difficult for people to make informed decisions about aged care services they are likely to receive. The importance of individual choice has been an enduring theme in aged care policy over the past decade or more. However, the exercise of choice requires information to inform a conscious selection between alternatives. The limited measures available offer few details about the performance of services and providers.

During the Brisbane Hearing, Professor Paterson criticised the amount of generally available information on the quality and safety of services and questioned the ‘secrecy’ of information regarding publicly funded providers ‘caring for the most vulnerable members of our community’.³⁴⁴ He said that drawing on restricted sources of information led to information asymmetry, especially when those sources were the approved providers, and where people needed good information they were otherwise ‘completely in the dark’.³⁴⁵

Without reliable information to support the comparative assessment of providers, older people are unable to exercise the choice that would drive improved performance over time. But the lack of transparency goes beyond the need to support older people to make choices about their care, important though that may be.

As Dr Ben Gauntlett, Disability Discrimination Commissioner, told us that transparency can allow a light to be shone on practices that may otherwise remain hidden.³⁴⁶ Public reporting can give a voice to people and provide a force for change. It is disturbing that the numbers of young people in residential aged care, the prevalence of the use of physical and chemical constraints, the frequency of assaults in aged care and other instances of abuse and substandard care have for so long been opaque.

Information on the outcomes achieved by the aged care system and the performance of individual service providers should also be of vital interest to the Australian Government and its agencies. Dr Ken Henry AC, a former Secretary of the Treasury, said:

the sector is not very transparent. I mean, as a client of the system, you wouldn’t know the relationship between what you’re paying for and how much it’s costing the provider, but then the Government probably doesn’t have much idea either. It does with respect to some things but not with respect to everything.³⁴⁷

The Australian Government needs access to comprehensive data to assess the performance and impact of services provided to older people, yet the information on which the Australian Government makes aged care decisions is often surprisingly limited.

For example, there has been a longstanding lack of detailed and reliable information on younger people in residential aged care.³⁴⁸ This information is essential to form a proper understanding of the reasons why younger people live in residential aged care, how they can be assisted to leave and the policy changes required to ensure that they are not forced to return to aged care.

Dr Bronwyn Morkham, National Director for Younger People in Nursing Homes National Alliance, explained:

The data that is collected is insufficient, it's not giving us the information we need to know. The Australian Institute of Health and Welfare has an aged care data clearing house now which takes information that nursing homes submit quarterly on the number of residents they have and it provides very imperfect information about these younger people. We don't know enough about them. We don't know enough about where they came from to go into nursing homes, we don't know what conditions they present with, acutely. We know something but not enough. We don't know if they would like to leave residential aged care, and if they do, where they would like to go.³⁴⁹

Without that understanding, it is more difficult to achieve long-lasting solutions to this important issue.

Despite the direction of billions of dollars of taxpayer and private funds into the aged care sector mandated by the Australian Government, there is limited public information on the governance and financial position of aged care providers. It is surprisingly difficult to find information about the skills and experience of the key personnel responsible for directing the delivery of care quality or about the internal governance arrangements and business models of aged care providers.

Financial information that providers are required to supply to the Australian Department of Health is not sufficient to enable timely and accurate assessments to be made of the financial health of the organisations to which the Australian community has entrusted billions of dollars and the care of some of our most vulnerable citizens.³⁵⁰ Much of this information remains inaccessible to the older people who have been required to invest their life savings in Refundable Accommodation Deposits held by providers.

Some of the difficulties in obtaining reliable information on the aged care sector are structural. The data is held in a range of systems and repositories controlled by a range of bodies from the Australian Government, State and Territory Governments and private organisations. The key Australian Government body responsible for integrating data about the aged care sector, the Australian Institute of Health and Welfare, acknowledges that current data is fragmented and incomplete.³⁵¹ Despite various integration projects across these data sources, no single, reliable source exists that is accessible to all who need to know about the quality and safety of aged care services in Australia.

The dissemination of information about the aged care sector has also been influenced by policy and design choices. Access to the information that does exist is too often restricted, or access is bound up in red tape, limiting the scope for external researchers and commentators to understand what is happening inside the aged care system and

to assess alternative policy and service delivery options. According to Ms Louise York, Head of Community Services Group, Australian Institute of Health and Welfare, a key issue is not around authority to collate data but authority to release it to an external party.³⁵²

In some cases, secrecy has been hardwired into the system. Under the current arrangements, secrecy provisions in aged care legislation restrict disclosure of ‘protected information’ about providers.³⁵³ One of the consequences is that when a complaint is made to the Aged Care Quality and Safety Commission about an approved provider, the provider’s response is not given to the complainant unless the provider consents.³⁵⁴ Ms Shona Reid from the Aged Care Quality and Safety Commission explained that providers are often reluctant to consent to release of the response:

it’s not an open and transparent complaints-management kind of best practice if you like, within services generally. They are a bit defensive and feel threatened by doing that sometimes, and that’s about open disclosure.³⁵⁵

In other cases, a preference against transparency appears to have been a policy choice by governments or their agencies. The need for the quality regulator to have clear performance measures and to be assessed against them has been a theme in external reports of the aged care sector for almost 20 years.³⁵⁶ Despite this, the quality regulator has, until recently, published very little useful information on its regulatory strategies or the outcomes it has achieved. The information that it currently provides falls well short of what I would regard as acceptable for a contemporary regulator. During the course of this Royal Commission, we have required the Australia Government to provide us with up-to-date information on compliance and enforcement outcomes and statistics that should already have been publicly available.

The lack of transparency in the aged care system is not a new phenomenon and I am not the first to comment on it. Previous reviews and inquiries into aged care have identified various information gaps and urged action by the Australian Government.³⁵⁷

For example, successive reviews and inquiries into the aged care system, since at least 2004, have proposed better access to provider performance information. These include the Hogan review in 2004, the Senate Community Affairs in 2005, the National Health and Hospitals Reform Commission in 2009, the Productivity Commission in 2011 and the Carnell-Paterson review in 2017.³⁵⁸ The Carnell-Paterson review recommended a star rating system that would incorporate information from accreditation audits and Consumer Experience Reports into an overall score for each facility.³⁵⁹

In April 2018, the Australian Government announced that it would increase transparency through a publicly available rating against the quality standards.³⁶⁰ The Service Compliance Ratings system subsequently introduced is far from enough. It does not provide any indication of performance against relevant clinical and quality indicators, information on staffing levels or information on the experience of older people, their families or advocates, as recommended by Carnell-Paterson.

It is difficult to understand why the Australian Government and the aged care sector have been reluctant to introduce measures that would increase transparency about aged care for older people. The Government and the aged care sector would also benefit from the performance insights that this additional transparency would provide. As Professor Paterson told us, the dissemination of performance information encourages better performing service providers and puts pressure on poorer-performing facilities to improve.³⁶¹

The absence of transparency is a significant problem in the aged care system. I consider that it has been an important contributing cause of a number of the quality problems that we have observed. It has adversely impacted on the choices available to people receiving aged care and their families, limited the scope for aged care providers to benchmark their performance against their peers, and prevented the community at large from holding governments and service providers to account for the quality of the care they deliver.

4.16 Missed opportunities for research and innovation

Research, evaluation, quality assurance and innovation help to build and maintain high quality care. When these activities are not given priority, the quality of care suffers. Aged care providers may make decisions about care without an appropriate evidence base. They may unwittingly use unproven or unsafe practices. They may miss opportunities to improve and excel. At a sector level, research, evaluation and quality assurance can help to identify and understand systemic problems and find solutions to them. The current aged care system has not adapted well to changing big-picture circumstances, such as in the age and health characteristics of those receiving care and the increasing prevalence of dementia.

There have been a number of missed opportunities in research and innovation in the aged care sector. First, compared with health research, the field of aged care research struggles to compete for research funding grants.³⁶² A very small proportion of grants from the major government research funds go to research projects that focus on aged care quality and safety.³⁶³ Often innovative models of aged care are not evaluated to assess their safety and effectiveness.³⁶⁴ Existing evaluations of technological interventions are generally of poor quality, limiting an understanding of the usefulness of the intervention for older people.³⁶⁵

Research on ageing and aged care is a national priority for the Medical Research Future Fund, but grant allocations from this fund favour medical and health research.³⁶⁶ Projects that explore the safety and quality of aged care often do not fit neatly within the medical and health research field. Research on aged care quality and safety may include consideration of medical, health, technological, organisational, environmental, cultural, ethical and social issues—or a combination of these. Objectives, questions and methods are often co-designed with older people and others who will benefit from the research. This makes it valuable because it is driven by the interests of older people and care providers to get the most meaningful outcomes for them.³⁶⁷ The limited funding available for this type of work undermines the volume, scale and impact of it.

Second, there is no strategy for the translation of research outputs into evidence-based best practice and continuous improvement that benefits the whole aged care sector.³⁶⁸ Despite the funding constraints, there are examples of valuable research on aged care quality and safety.³⁶⁹ But the aged care sector is slow to adapt in response to research, partly because it has not had a national, coordinated aged care research strategy and a body or network to facilitate research and its translation into everyday practice.

In October 2020, the Australian Government awarded a contract to Flinders University to establish the model for an Aged Care Centre for Growth and Translation Research.³⁷⁰ The centre has been designed to 'address long-standing barriers to the development, evaluation and uptake of aged care workforce research'.³⁷¹ While this centre has potential to boost research and development into how to improve aged care services, its focus on the aged care workforce is too narrow. We are concerned that its research activity will exclude other factors that contribute to aged care quality and safety. These include health, technological, organisational, environmental, cultural and socioeconomic factors.

A further missed opportunity in the translation of research into practice is that the current funding and service models do not support providers who wish to try new practices, products, technologies and models of care. We heard that providers are concerned about costs, and also see little incentive to accept the risks associated with innovation.³⁷² Those who do innovate have no incentive to share it with the sector.³⁷³

The adoption of technology in particular is impeded because the cost of initial investment can be significant. There are some government grants that providers can access to assist with small-scale and short-term innovation projects. However, the current aged care funding model does not adequately account for the costs of innovation.³⁷⁴ Costs may include the purchase of new technological devices and systems and the research, evaluation and quality assurance to assess their benefits, as well as training for staff. This means that the current funding model does not adequately recognise continuous improvement as a general operating cost. On top of these financial barriers, there is no particular regulatory incentive for approved providers to strive for more than compliance with the minimum care quality standards. There is no system-wide approach to fostering innovation that benefits all providers, regardless of their size and means.

Finally, the absence of quality data about older people and their experiences of aged care and other related services impedes the research, evaluation, and quality monitoring needed for the aged care sector to develop and safely adopt new and better care practices.³⁷⁵ In comparison with other sectors, such as health, the aged care sector has fallen behind in the basic measurement of quality of care and outcomes as well as access to data for research purposes. Until recently, the Australian Government has not captured robust data for the purpose of quality and safety monitoring and to inform continuous quality improvement of aged care services.³⁷⁶ Since 2019, approved providers of residential care have been required to provide information about three quality indicators to the Australian Department of Health in accordance with the National Aged Care Mandatory Quality Indicator Program.³⁷⁷ A further two indicators of quality will be added to the Program from July 2021.³⁷⁸ However, these provide inadequate insight into aged care quality and safety, and data on home care quality is still not collected for basic regulatory purposes.

As we discuss in Chapter 3 of this volume, the Consumer Experience Interviews need improvement and there could be better ways to measure quality of life. Data on other aspects of the aged care system, such as its workforce and financial performance is fragmented and incomplete.³⁷⁹

This mix of factors has resulted in an aged care sector that is behind the research, innovation and technological curves.

4.17 Poor cooperation across the health and aged care systems

One of the key causes of substandard care in aged care, particularly residential aged care, is that people are not consistently receiving the health care they need. As people age they are more likely to require the services of primary and allied health professionals. A lack of consistent access to appropriate preventative health care will result in avoidable health problems and reduce quality of life.

There are a number of causes for the systemic failures of access to health care, including:

- a lack of funding for proactive general health care services provided to people at their place of residence
- poor clarity about the respective roles and responsibilities of aged care providers and health care providers to deliver health care for people in aged care, particularly residential aged care
- an unwillingness by health care providers to provide their services at a person's place of residence, even though many people receiving aged care find it difficult to travel to services
- poor quality or incomplete clinical handover and communication between hospitals and aged care providers, which can result in clinical decisions based on misinformation.

These systemic issues are partially a result of dispersed responsibilities for health care and aged care between Australian and State and Territory Governments, within the Australian Government, and between health care providers and aged care providers. The Australian Government is responsible for the 'planning, funding, policy, management and delivery of the national aged care system'.³⁸⁰ Aged care is delivered by individual private providers and community organisations, as well as the States and Territories. The Australian Government is also responsible for the funding of large primary care programs, including the Medicare Benefits Schedule and the Pharmaceutical Benefits Scheme.³⁸¹ These schemes provide subsidised funding for, respectively, general practitioner consultations and medicines. The Australian Government also jointly funds public hospitals and dental services with the State and Territory Governments, although the State and Territory Governments are responsible for the system management of these.³⁸² The Australian and State and Territory Governments separately fund and deliver different aspects of mental health services.

This split of responsibilities is reflected in different streams of funding for different aspects of health care and aged care. These funding streams for particular types of care, such as general practice, aged care, mental health and public hospital care, can become siloed, particularly in resource-constrained environments. When this occurs, care provision becomes fragmented and service providers pass responsibility for care to other parts of the health and aged care system. For example, we heard evidence that State and Territory health services do not, at times, provide services to people in residential aged care because they see this as an Australian Government responsibility.³⁸³ Ms Nikki Johnston OAM, palliative care nurse practitioner at Clare Holland House, Calvary Public Hospital, said that:

Specialist palliative care in Australia is, generally, funded by the States. Commonwealth funds home-care packages and residential aged-care. So at the moment there's many State-run services that won't walk through the front door of a residential-aged-care facility. There's other services that won't as well—community nursing, wound care, lots of other people that just don't—so that reduces access.³⁸⁴

The fragmentation between the health care and aged care systems occurs even in areas where the Australian Government has sole responsibility. For example, some Medicare funded services, such as mental health treatment plans developed by general practitioners, are usually not available to people living in residential aged care. Professor Sunil Bhar, a psychologist at the Swinburne University of Technology, reflected on this situation:

The inequity and division between community-dwelling older adults and residential aged care residents in accessing Medicare benefits for psychological treatment must cease. The division has created confusion in the sector, and an unintended perception that aged care residents' needs for such treatment are less important compared to the needs of their community dwelling counterparts.³⁸⁵

The Australian Government has temporarily allowed access to these Medicare subsidies as part of its response to our special report about aged care and COVID-19.³⁸⁶

The lack of coordination between the health care and aged care systems reflects a focus on funding and resource allocation, at the expense of people and people's health care needs. Dr Ellen Burkett, a Fellow of the Australasian College of Emergency Medicine, told us that there is a lack of clarity about who was responsible for a resident's health care at any particular point. She said that:

across the care continuum, at any juncture in the resident's aged care facility or health care journey, it must be clear where the governance for that particular episode of care lies. And there must be good and clear handover of governance from one party of responsibility to the other, across the transitions of care. ...that's not happening optimally across the country.³⁸⁷

Dr Nigel Lyons, Deputy Secretary of New South Wales Ministry of Health, similarly outlined the importance of clarifying roles and responsibilities across the whole suite of health care and aged care services, noting that it is 'critical...to designing a system that can best support the care needs of the residents'.³⁸⁸ The focus of health care providers must be on the health care needs of people using aged care. In discussing aged care provided in residential care and in a home or community setting, Dr Hewitt said:

One factor missing from both settings is the integration of evidence- based management strategies that assess the person where they are, with all their health and psychosocial needs taken into consideration and developed with the person at the centre of the plan, rather than the funding mechanism.³⁸⁹

People in aged care deserve better than this. They deserve well-coordinated care across the aged care and health care systems on an ongoing basis. Ms Jennifer Walton, who believed that her mother, when in residential aged care, struggled to access appropriate care from general practitioners and to access specialist rehabilitation, told us:

continuity of care should be the standard, not the exception and it shouldn't be a fight to get consistent care across aged care and health settings. They should work together and provide wrap around support for people.³⁹⁰

It is clear to us that fragmentation and the passing of responsibilities between the aged care and health care systems must be dealt with initially at a national, interjurisdictional level.³⁹¹ As Professor Leon Flicker, Professor of Geriatric Medicine, University of Western Australia, said:

In general, one of the things I've noticed over the years that if you want something done you have to make it very clear at the national level—at the higher levels exactly who's responsible for what and where the money is coming from, otherwise people will retreat from the space.³⁹²

Dr John Wakefield PSM, Director-General of Queensland Health, said that in terms of accountability and responsibility for aged and health care, the system is currently designed to achieve the adverse outcomes that the Royal Commission has revealed, noting that funding drives behaviour.³⁹³ We agree.

As Professor Flicker said, in relation to acute and subacute care, 'without constant attention to this interface there will be a tendency for both Commonwealth and State Governments to withdraw' resources from older people in aged care.³⁹⁴ He considered that any assumptions that aged care providers would take charge of the provision of health care was 'highly dangerous' because they have neither the expertise nor the desire to do so.³⁹⁵ Professor Flicker concluded:

I have no doubt that without coordination of all levels of government that we will continue to see substandard and inappropriate care for the health issues for older people and this will be manifested by completely unacceptable sentinel events.³⁹⁶

We are encouraged that the Australian and State and Territory Governments, under the 2020–25 National Health Reform Agreement, have agreed to better coordination between the 'health, primary care, disability and aged care systems' to support 'positive outcomes for people through access to appropriate services, and reductions in avoidable hospital admissions, time spent in hospital and premature residential care admissions'.³⁹⁷ This is new language at a national level. But language change alone is not enough. We need to see this aspirational language implemented. We need to see better service provision. Governments, health professionals, health care providers and aged care providers must ensure improved access to health care for people in aged care.

4.18 Conclusion

Our examination of systemic problems in the Australian aged care system cannot help but paint a gloomy picture. The current state of the aged care system is a fairly predictable outcome of the various systemic problems we have identified. This is why significant change is required.

We have not set out the problems with the current system gratuitously. We see this volume as a necessary part of explaining how the future aged care system can and should be so much better. In examining the systemic failures and the substandard care that flows from them, we seek to honour older people and their carers and loved ones who told us about their experiences. We also offer our thanks to the many dedicated and compassionate people who work in aged care. The current system is failing those people too.

The delivery of aged care in Australia is not intended to be cruel or uncaring. Many of the people and institutions in the aged care sector want to deliver the best possible care to older people, but are overwhelmed, underfunded or out of their depth. Their good intentions and dedication are a key reason why we have such hope for the future.

We firmly believe in the potential for a future aged care system that Australia can be proud of. Through our recommendations set out in Volume 3, we reimagine and redesign the aged care system. Informed by our analysis of the past, the primary building blocks of this new aged care system are:

- an overarching vision for aged care that puts people first
- a System Governor providing leadership and oversight, and shaping the aged care system
- entitlement to care based on need through an aged care program that is responsive to individual circumstances and provides an intuitive care structure
- a clear understanding of what high quality aged care is, how to deliver it and how to measure it
- a valued, expert workforce of an adequate size
- access for older people to the primary and allied health care they need
- a focus on research and innovation
- an inquisitive and proactive regulator
- funding that meets the cost of high quality care
- financing that delivers appropriate funding on a sustainable basis.

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