



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

**Interim Report:
Neglect**

Volume 1

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Royal Commission
into Aged Care Quality and Safety

31 October 2019

His Excellency General the Honourable David Hurley AC DSC (Retd)
Governor-General of the Commonwealth of Australia
Government House
CANBERRA ACT 2600

Your Excellency

In accordance with the Letters Patent issued on 6 December 2018, as amended on 13 September 2019, the Honourable Richard Tracey AM RFD QC and I have made inquiries, and I now submit to you the Interim Report of the Royal Commission into Aged Care Quality and Safety.

Commissioner Tracey and I finalised the text of this Report in late September 2019. Commissioner Tracey died on 11 October 2019.

Yours sincerely

Ms Lynelle Briggs AO
Commissioner

The Honourable Richard Tracey AM RFD QC

The Honourable Richard Tracey AM RFD QC was a Judge of the Federal Court of Australia from 2006 until 2018, President of the Defence Force Discipline Appeal Tribunal from 2009 until 2018, and Judge Advocate General of the Australian Defence Force from 2007 until 2014. Prior to becoming a judge, he taught law in a number of academic roles and worked as a barrister, being appointed Queen's Counsel in 1991. He also served in the Australian Army from 1975 until 2014, achieving the rank of Major-General.

On 6 December 2018, Mr Tracey was appointed Chair of the Royal Commission into Aged Care Quality and Safety. He died on 11 October 2019.

On 14 October 2019, Commissioner the Honourable Tony Pagone QC and Commissioner Lynelle Briggs AO made the following comments at a hearing of the Royal Commission in Melbourne:

Few people ever have the privilege to be a Royal Commissioner but Richard was made for it. He was experienced. He was wise. He was admired. He knew the law like the back of his hand. He was prepared to take a punt if it meant getting a better outcome for older Australians.
– Ms Lynelle Briggs AO, Commissioner

He had, by any measure, a distinguished career as a lawyer, as a jurist and, I must say, from my experiences of him, he was a remarkable friend. He had a selfless drive and energy which he blended with good humour and compassion... His work on this Commission has also been solid, selfless and significant.
– The Hon Tony Pagone QC, Commissioner

Commissioner Tracey's dedication, compassion and wisdom set an example for the future work of the Royal Commission.

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A Shocking Tale of Neglect

It's not easy growing old. We avoid thinking and talking about it. As we age, we progressively shift our focus from work to the other things that give us purpose and joy: our children and grandchildren, our friends, our holidays, our homes and gardens, our local communities, our efforts as volunteers, our passions and hobbies. The Australian community generally accepts that older people have earned the chance to enjoy their later years, after many decades of contribution and hard work. Yet the language of public discourse is not respectful towards older people. Rather, it is about burden, encumbrance, obligation and whether taxpayers can afford to pay for the dependence of older people.

As a nation, Australia has drifted into an ageist mindset that undervalues older people and limits their possibilities. Sadly, this failure to properly value and engage with older people as equal partners in our future has extended to our apparent indifference towards aged care services. Left out of sight and out of mind, these important services are floundering. They are fragmented, unsupported and underfunded. With some admirable exceptions, they are poorly managed. All too often, they are unsafe and seemingly uncaring. This must change.

Australia prides itself on being a clever, innovative and caring country. Why, then, has the Royal Commission found these qualities so signally lacking in our aged care system? We have uncovered an aged care system that is characterised by an absence of innovation and by rigid conformity. The system lacks transparency in communication, reporting and accountability. It is not built around the people it is supposed to help and support, but around funding mechanisms, processes and procedures. This, too, must change.

Our public hearings, roundtable discussions with experts, and community forums have revealed behaviour by aged care service providers that, when brought to public attention, has attracted criticism and, in some cases, condemnation. Many of the cases of deficiencies or outright failings in aged care were known to both the providers concerned and the regulators before coming to public attention. Why has so little been done to address these deficiencies? We are left to conclude that a sector-wide focus on the need to increase funding, a culture of apathy about care essentials, and a lack of curiosity about the potential of aged care to provide restorative and loving care—all of which is underpinned by an ageist mindset—has enabled the aged care system to hide from the spotlight. This must also change.

Left isolated and powerless in this hidden-from-view system are older people and their families. 'This is not a life.' 'This is not my home.' 'Don't let this happen to anyone else.' 'Left in her own faeces, and still no one came.' 'Mum doesn't feel safe.'

This cruel and harmful system must be changed. We owe it to our parents, our grandparents, our partners, our friends. We owe it to strangers. We owe it to future generations. Older people deserve so much more.

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

Confronting the system

Understandably, it is relatively common for older people to avoid thinking about their long-term care needs or to plan for their future because this might signal their decline and eventual death. Most people remain confident that they will be looked after when the time comes.

It is therefore a difficult choice when things begin to go wrong about whether to access aged care or whether to struggle along independently. Very often, older people avoid accepting care for as long as possible. Many families help their loved ones to live independently by providing ongoing support, doing their shopping, driving them to appointments, mowing the lawn, fixing the things that go wrong around the house, supporting them financially, and generally tending to their needs. Other people can buy the support they need.

Nevertheless, there comes a time when some older people are confronted with their declining capability, poor health, failing cognitive function or a crisis involving hospitalisation. A number of people will seek out aged care services either independently or at the urging of family, friends, doctors and hospitals. Unfortunately, it is at this point, when the aged care system should be welcoming and easy to navigate, that the first problems emerge.

People are met with a telephone and internet-based national aged care entry system called My Aged Care that many people in their eighties and nineties find frightening, confronting and confusing. They are then referred for a face-to-face discussion to assess how much care they can receive and whether that will be in their own home or a residential care provider. This is the first of many assessments. Too often they must tell their story over and over again.

Left to fend for themselves at this point, they have to navigate their own way into the system. Older people and their families often find that their choices are limited by a combination of inflexible system design, lack of services near where they live, and cost. In these difficult circumstances, people have a right to expect that they will be given useful information in a helpful way. Unfortunately, useful information is the exception, not the rule.

Accessing home care

It is particularly challenging when an older person is deemed eligible for a Home Care Package, because they must first wait in the national prioritisation queue before a package of services is 'assigned', and then they must find a service provider to deliver their care. That can all take a very long time, especially for those who have higher care and support needs. Once someone is assessed as needing the highest level of care, a Level 4 Home Care Package, they can wait for a year and often longer for the Package to become a reality. Such waiting times would be unacceptable in any other system, but are common in home care today.

The Australian Department of Health, which oversees this system, has no mechanism to follow up with people who are on waiting lists to give them updates, including about whether they have progressed up the waiting list or how long it will be before a Package is available. In the interim, there is a clear and present danger of declining function, inappropriate hospitalisation, carer burnout and premature institutionalisation because necessary services are not provided. We have been alarmed to find that many people die while waiting for a Home Care Package. Others prematurely move into residential care.

By any measure, this is a cruel and discriminatory system, which places great strain on older Australians and their relatives. It is unfair. Older people should receive the home care services they need to live safely at home. Funding should be forthcoming from the Australian Government to ensure the timely delivery of these services. It is shocking that the express wishes of older people to remain in their own homes for as long as possible, with the supports they need, is downplayed with an expectation that they will manage. It is unsafe practice. It is neglect.

The path to residential care

Older Australians' transition from their homes into residential aged care can be very challenging for them and their loved ones. The decision to enter residential care often follows a traumatic event, such as a fall or a sudden decline in health. People feel under pressure to find suitable accommodation for themselves or someone they care for.

We have heard many accounts of older people and their loved ones having to contact service after service to find out if there is a suitable place available. My Aged Care often does not provide helpful information about local services. Perhaps even more worryingly, there is no easily accessible public information about the quality of services or reliable information about whether the services deliver on their advertised promises. Older people and their loved ones do not know what to look for when choosing a home. Choices about where to go are invariably rushed and made on the run, determined by whether or not a bed is available or if a service is close to family or run by a provider thought to be compatible with the older person's wishes or cultural or religious affiliations.

People do not usually enter residential aged care willingly. They often do so with great trepidation. They fear loss of autonomy, of individuality, of control over their own lives. They fear ceasing to be a person with distinct needs and preferences, with an emotional and intellectual life and freedom to do what they want, when they want to do it.

We have heard countless stories about how much people grieve for all they have lost when they arrive in residential care. They become ‘just a resident’, just another body to be washed, fed and mobilised, their value defined by the amount of funding they bring with them. They become infantilised, lose autonomy, and are prevented from making decisions or doing physical things that were routine when they lived at home, on the grounds that they ‘could hurt themselves’. They lose their basic rights to take risks, to choose what to do in their day, to live a life as close as possible to their previous home and community. There is no joy in this.

Their families and friends often feel intense guilt, loss and fear: guilt at not being able to guarantee care at home any longer; loss of the person who, even if living from dementia or otherwise cognitively impaired, is still a unique personality; and fear of how this loved older person or young person living with disability will be treated when there is no one there to look out for them.

For older people who are alone before entering residential aged care, these feelings are magnified by the knowledge that no one will visit them. They are completely reliant on the kindness of strangers. For younger people with disability, their friends stop dropping by and rarely visit over time. It is an isolating and daunting experience. It is not a life.

Given that there is so much evidence about these feelings of loss and abandonment experienced in the aged care system, we are dismayed at the apparent lack of acknowledgement and understanding by those who manage and control the aged care system. As a nation, as a community, we must find a way to ease these transitions and ensure that residential care services are made much more attractive and enjoyable for those in care. This will necessarily require a clear focus on meeting the needs of the people in care, respecting their rights, and building good relationships with them. It will involve finding a way to bring the outside world into residential care homes, or taking those in care out. We will delve deeply into these matters in our Final Report. In the meantime, we encourage the Australian community and the aged care sector to work with people in care to harness their ideas and to develop solutions on the ground.

What happens in care

We have heard substantial direct evidence about what can happen to older people once they move into residential care. The case studies have given us invaluable insights into the vulnerability and isolation of older people in care.

Older people and family members have shown great generosity and courage in recounting painful events that have shocked and dismayed all who have heard about them. We have been told about people who have walked into an aged care residence, frail but in relatively good spirits and mentally alert, only to die a few months later after suffering from falls,

serious pressure injuries and significant pain and distress. We have seen images of people with maggots feeding in open sores and we have seen video and photographic evidence of outright abuse.

These accounts of unkindness and neglect have been difficult to tell and difficult to hear.

Just as striking is the love, dedication and determination of people who are, or have been, a parent, relative, friend, carer or advocate. We have been left with a sense of great pride in the way most ordinary Australians care for their loved ones and overwhelmed by their devotion and commitment.

We have heard about spouses who visit their partners every day to tend to their care and to keep them company. They stop doing other things or give up or reduce their work to do so, and accept the financial and other costs that are imposed on them. Such is their devotion.

At a time in their lives when an older person and their family members and friends should be able to spend peaceful time together, we have heard how these relationships can become subsumed by the battle with staff and managers in aged care services to advocate for basic personal care. We now know these battles go on every day.

Sons and daughters, aghast at seeing the poor state of a parent, insist on calling an ambulance so that they can be admitted to hospital, suspecting or knowing that a fall or other injury has occurred, or that their relative's health is declining. They insist on talking directly to doctors, just as they insist on meeting with senior management at aged care facilities or corporate representatives of the provider, to get answers, explanations and treatment. They pay for extra services, such as physiotherapy. They bring in palliative care clinicians if their family member is nearing the end of their life. They bring in food and feed it to a relative who can no longer eat without help, for fear that not to do so will condemn them to malnutrition. They have even installed hidden cameras in a family member's room to ensure their safety, and been horrified to see occasions of rough treatment and even assault.

Some of these people have been prepared to bear witness to what they have seen, heard, said and done, determined to bring an end to such practices. Their insights are invaluable.

Substandard care

We are concerned that there are no measures available to quantify the extent of substandard aged care. However, the combined impact of the evidence, submissions and stories provided to the Royal Commission leads us to conclude that substandard care is much more widespread and more serious than we had anticipated. We consider substandard care to include care that does not meet the relevant quality standards or other legislative obligations, or which otherwise does not meet community expectations.¹

¹ This is explained in more detail in the Introduction to Volume 2, and is consistent with the guidance provided by the Royal Commission for the November 2018 Service Provider Survey.

The often shocking evidence reveals too many unacceptable practices and an aged care sector that is too often failing to satisfy basic community expectations or legislated requirements.

The major quality and safety issues which have been brought to our attention during this Royal Commission are:

- inadequate prevention and management of wounds, sometimes leading to septicæmia and death
- poor continence management—many aged care residences don't encourage toilet use or strictly ration continence pads, often leaving distressed residents sitting or lying in urine or faeces
- dreadful food, nutrition and hydration, and insufficient attention to oral health, leading to widespread malnutrition, excruciating dental and other pain, and secondary conditions
- a high incidence of assaults by staff on residents and by residents on other residents and on staff
- common use of physical restraint on residents, not so much for their safety or wellbeing but to make them easier to manage
- widespread overprescribing, often without clear consent, of drugs which sedate residents, rendering them drowsy and unresponsive to visiting family and removing their ability to interact with people
- patchy and fragmented palliative care for residents who are dying, creating unnecessary distress for both the dying person and their family.

It is shameful that such a list can be produced in 21st century Australia. At the heart of these problems lies the fundamental fact that our aged care system essentially depersonalises older people. A routine thoughtless act—the cup of coffee placed too far from the hand of a person with limited movement so that they cannot drink it, the call buzzer from someone left unanswered, the meal left uneaten with no effort to help—when repeated day after day, becomes unkindness and often cruelty. This is how 'care' becomes 'neglect'.

More than half the online submissions to us raised issues about substandard care. Forty per cent raised concerns about neglect, 39% about dignity, 37% about personal care, 33% about clinical care, 33% about medication management, 25% about nutrition and malnourishment, 22% about emotional abuse, 16% about physical abuse or assault, 13% about discrimination and 13% about restrictive practices.²

A little over 1000 providers responded to our Service Provider Survey. They self-reported 274,409 instances of substandard care over the five year period to June 2018, including almost 112,000 occasions of substandard clinical care and close to 69,000 occasions

2 Based on issues selected from a list by the person making the submission through the online submission portal.

of substandard medication management. They also reported 79,062 complaints about substandard care. Of these complaints, 15,700 were about personal care, 8800 were about compromises to an older person's dignity, and 7500 were about a lack of choice and control for the people receiving aged care services.

Expert evidence on clinical and personal care has also contributed to our understanding of the extent of substandard care:

- the Dietitians Association of Australia use current research to estimate that 22–50% of people in residential aged care are malnourished³
- an analysis of Aged Care Funding Instrument data reveals much higher than expected rates of incontinence, 75–81% of residents, with the majority in the most dependent category⁴
- recent Australia research reveals that pressure injuries occur in a third of the most frail aged care residents at the end of their lives⁵
- research involving 150 residential aged care facilities⁶ found that 61% of residents were regularly taking psychotropic agents, with 41% prescribed antidepressants, 22% prescribed antipsychotics, and 22% prescribed benzodiazepines⁷
- an Australian Department of Health expert clinical advisory panel estimated that psychotropic medication is only clearly justified in about 10% of cases in which they are prescribed in residential aged care⁸
- there were 4013 notifications of alleged or suspected physical and/or sexual assaults in aged care in 2017–18.⁹

In the face of these horrifying reports and the shocking tale of neglect we have heard throughout this Royal Commission, we will continue to attempt to quantify the level of substandard care in our Final Report.

How does the aged care sector respond?

Not very well.

People living in residential care, or receiving care in their homes, have told us of their feelings of frustration, despair and hopelessness. Their complaints, which should be

3 Exhibit 6-1, Darwin and Cairns Hearing, General Tender Bundle, tab 82, DAA.0001.0001.0079 at 0080-0082.

4 PD Hibbert *et al.* 'CareTrack Aged: the appropriateness of care delivered to Australians living in residential aged care facilities: a study protocol', *BMJ Open*, 2019, 4, online supplementary appendix 1. p 2. file:///C:/users/acrc.allipa/Work%20Folders/Downloads/bmjopen-2019-June-9-6--inline-supplementary-material-1.pdf, viewed 1 October 2019.

5 Exhibit 6-1, Darwin and Cairns Hearing, General Tender Bundle, tab 51, CSH.0001.0001.0032 at 0041.

6 Exhibit 3-61, Sydney Hearing, Statement of Dr Juanita Westbury, 29 April 2019, WIT.0117.0001.0001 at 0008 [15].

7 Exhibit 3-80, Sydney Hearing, Statement of Henry Brodaty, 16 May 2019, WIT.0116.0001.0001 at 0009 [45].

8 Transcript, Brendan Francis Murphy, Sydney Hearing, 14 May 2019 at T1646.3–30.

9 Exhibit 1-37, Adelaide Hearing 1, Department of Health 2017-18 Report on the Operation of the Aged Care Act 1997, RCD.9999.0011.0001 at 0097.

a window into care practices, often go unanswered. Many people have told us that the complaints system is hard to access, slow to act and often effectively unresponsive to the concerns of the complainant.

People become unwilling to complain for fear that care will become worse, as they or their family member will be labelled as ‘difficult’ by the provider. Several submissions have highlighted occasions where the treatment of the older person deteriorated after complaints from family members—with neglect transforming into the withholding of care. It is disturbing that the aged care sector is not sufficiently mature or professional to listen to feedback from those who use and observe its services at close hand, particularly when the regulatory system appears so distant and ineffectual.

Some providers of aged care have appeared before the Royal Commission to be defensive and occasionally belligerent in their ignorance of what is happening in the facilities for which they are responsible. On many occasions when case studies were presented in hearings, providers were reluctant to take responsibility for poor care on their watch. Some providers have shown an unwillingness to accept that they could have, and should have, done better. Others have, rightly, accepted this. Those providers who have demonstrated a commitment to building relationships with people receiving care and their families stood out in sharp relief.

The aged care system lacks fundamental transparency. Witnesses from the Australian Department of Health told us that there is very little information available to the public about the performance of service providers. The number of complaints against them are not published. The number of assaults in their services are not published. The number of staff they employ to provide care are not published. Participation by providers in the collection of a very limited set of performance indicators only became compulsory on 1 July 2019. The Department has said that it will publish differentiated performance ratings of residential aged care providers, but there is still no clarity on what this information will look like.

We have heard evidence which suggests that the regulatory regime that is intended to ensure safety and quality of services is unfit for purpose and does not adequately deter poor practices. Indeed, it often fails to detect them. When it does so, remedial action is frequently ineffective. The regulatory regime appears to do little to encourage better practice beyond a minimum standard. We were flabbergasted to hear that, until recently, it was routine practice for large sections of the reports of accreditation audits of services conducted by the Aged Care Quality and Safety Commission to be generated by computer assisted text. In other words, the same positive words prompted by computers were used over and over again. Computers cannot determine quality; only people can and should do that.

We have heard about an aged care workforce under pressure. Intense, task-driven regimes govern the lives of both those receiving care and those delivering it. While there are exceptions, most nurses, carer workers and allied health practitioners delivering care are doing their best in extremely trying circumstances where there are constraints on their time and on the resources available to them. This has been vividly described by the former and current aged care staff who have given evidence.

The aged care sector suffers from severe difficulties in recruiting and retaining staff. Workloads are heavy. Pay and conditions are poor, signalling that working in aged care is not a valued occupation. Innovation is stymied. Education and training are patchy and there is no defined career path for staff. Leadership is lacking. Major change is necessary to deliver the certainty and working environment that staff need to deliver great quality care.

We have also heard about how the aged care system has not kept up with changing needs and community expectations. The preference for care at home is increasing significantly. Consequently, the complexity of the care needs of people entering residential care is also increasing. The aged care system as a whole has struggled to adapt to these developments, as have specific providers. These changes require different care models, investment in new expertise, reconsideration of funding models and a stronger, closer interface with the acute health care sector.

It is time for a reality check. The aged care sector prides itself in being an 'industry' and it behaves like one. This masks the fact that 80% of its funding comes directly from Government coffers. Australian taxpayers have every right to expect that a sector so heavily funded by them should be open and fully accountable to the public and seen as a 'service' to them.

As a service, aged care is an integral part of our social support system and, as such, it must aim to be the best service that an inventive, clever and compassionate country can provide. It should be delivering aged care services of an exemplary standard, in ways that are responsive to older people's care needs and aimed at delivering the best possible quality of life to them in their later years.

The overall impression we are left with is of a system that is failing, but there are some positive stories emerging from our inquiries. Provider organisations and consumer representative groups have highlighted great quality care and caring environments. We have heard many examples of providers who deliver innovative and effective models of care. Crucially, we have heard about these positive examples not just from the providers themselves, but from the people they care for. There have also been many examples of individual staff members dedicating themselves to providing exemplary and compassionate care, despite the challenges of their working environment. All of these positive examples provide us with confidence that a better aged care system is possible.

However, it seems that these providers and staff are currently succeeding due to their own passion and dedication. The aged care system provides no incentive or encouragement for these achievements. In short, they are succeeding despite the aged care system in which they operate rather than because of it.

The structure of the current system has been framed around the idea of a 'market' for aged care services where older people are described as 'clients' or 'customers' who are able to choose between competitively marketed services. But many older people are not in a position to meaningfully negotiate prices, services or care standards with aged

care providers. The notion that most care is ‘consumer-directed’ is just not true. Despite appearances, despite rhetoric, there is little choice with aged care. It is a myth that aged care is an effective consumer-driven market.

Since the Royal Commission began its work, there have been calls from several quarters for government funding to aged care to be significantly increased, without waiting for our Final Report and recommendations. These interventions are essentially variations on a theme which has haunted this area of government policy for far too long: short-term solutions which will at best temporarily stave off the worst problems and, at worst, produce another set of unintended outcomes requiring further inquiries and reviews and further injections of public funds without addressing the underlying causal factors. These limited interventions are not enough to deliver an aged care system that meets the needs of older people.

Nevertheless, there are some areas identified in this Interim Report where there is a need for urgent action. These are:

- to provide more Home Care Packages to reduce the waiting list for higher level care at home
- to respond to the significant over-reliance on chemical restraint in aged care, including through the seventh Community Pharmacy Agreement
- to stop the flow of younger people with disability going into aged care, and expediting the process of getting those younger people who are already in aged care out.

We see no reason to delay action in these areas.

It is clear that a fundamental overhaul of the design, objectives, regulation and funding of aged care in Australia is required. This will be the central purpose of our Final Report and it also informs our approach to this Interim Report.

This Interim Report

This Interim Report traverses much, but not all, of the work the Royal Commission has done through to September 2019. It is a report in three volumes.

Volume 1 contains the information we have gathered and some of the conclusions we have reached over the course of the hearings held since February, as well as drawing on the research done by the Office of the Royal Commission. It is organised under several themes, which broadly reflect those of the hearings.

Part 1 of Volume 1, which contains the first three chapters, provides context to the Royal Commission’s work. Chapter 1, **The Current System**, gives a brief historical overview of aged care in Australia, followed by a description of the current aged care system. Chapter 2, **The Well-travelled Path**, summarises the plethora of previous inquiries and reviews of the system, including what happened (or didn’t happen) in

the wake of their recommendations. Chapter 3, **Demographic, Social and Economic Pressures**, considers some of the most significant trends affecting aged care.

In Part 2 of Volume 1, Chapter 4, **‘An overwhelming sense of loss’**, tells the aged care story from the perspective of older peoples’ experience of the system, through direct evidence records and submissions.

Part 3 of Volume 1 presents the story around a number of inconvenient truths about the aged care system:

- Chapter 5, **Finding the Door**, describes how people find out about what aged care is available to them and how to access it.
- Chapter 6, **The Lottery**, details the current regime for establishing and managing the waiting list for home care.
- Chapter 7, **‘Elders are our future’**, details the circumstances and challenges involved in providing culturally appropriate, safe and quality aged care to Aboriginal and Torres Strait Islander people.
- Chapter 8, **Restrictive Practices**, describes the use of both physical methods and medications to restrain or pacify people who are living in residential aged care.
- Chapter 9, **Workforce Matters**, identifies some of the problems with recruiting and retaining people to work in aged care.
- Chapter 10, **Falling Through the Gaps**, recounts the plight of younger people who have an acute or chronic illness, have suffered a catastrophic injury or who live with a severe disability, and who are forced into residential aged care because there is nowhere else for them to go.

The chapters in Part 3 provide clear guidance on our thinking to date, but do not include specific recommendations. We will formulate our recommendations on these matters over the remaining months of the inquiry, informed by the comprehensive changes which we will recommend in our Final Report.

The final chapter of Volume 1 outlines the directions our inquiry will take over the next year. We will explore further quality and safety issues, provider perspectives, funding arrangements, governance, leadership and accountability, and options for systemic reform.

Volume 2 of this Interim Report contains detailed overviews of the public hearings we have conducted up to and including the hearing in Darwin and Cairns, including our findings in case studies conducted at those hearings.

Volume 3 contains appendices, including the summaries of the nine community forums the Royal Commission has held throughout Australia since February. We have held forums in metropolitan and regional areas to allow as many people as possible to attend. Some people have travelled considerable distances to come to forums and share their experiences of the aged care system, adding greatly to our knowledge. We are very grateful to everyone who has participated.

Conclusion

The Royal Commission has heard compelling evidence that the system designed to care for older Australians is woefully inadequate. Many people receiving aged care services have their basic human rights denied. Their dignity is not respected and their identity is ignored. It most certainly is not a full life. It is a shocking tale of neglect.

The neglect that we have found in this Royal Commission to date is far from the best that can be done. Rather, it is a sad and shocking system that diminishes Australia as a nation.

Our work over the past year has shown a system that needs fundamental reform and redesign—not mere patching up. The scope and complexity of this task are great. We are strongly of the view that our recommendations must be comprehensive and must reflect all of the evidence. Therefore, this Interim Report sets out what we have learned to date, draws some preliminary conclusions and outlines key areas for our work over the next 12 months.

In due course, we will recommend comprehensive reform and major transformation of the aged care system in Australia. We will chart a new direction for the sector, bringing a clear sense of purpose and of quality, and a renewed focus on compassion and kindness. We are working from the fundamental premise that older people deserve high quality care that protects their wellbeing and dignity and is respectful of ageing. Care needs to be compassionate, empathetic and customised to high standards of quality and safety.

It is a very great honour to be asked to be a Royal Commissioner. That honour brings with it considerable responsibilities and an enormous amount of faith, trust and goodwill from the Australian community. We take our responsibilities very seriously and will do our very best to deliver a Final Report that lives up to the community's expectations.

We do not work alone. We are part of a large team and we would like to thank them all for the important contribution they have made and will continue to make to our work. We appreciate it very much.

We must work together as a nation to ensure that older people are a critical part of our present, a valued part of our community. Older people deserve our respect as valued members of society, with equal rights to a good quality of life and to services that support their needs.

We intend to put older people first and to give them a voice.

As Mrs Barbara Spriggs, the first witness to appear before the Royal Commission, put it:

We need to learn and move forward from our mistakes and develop an aged care system that Australia can be proud of. It needs to be one where we know that our loved ones are given the care, dignity and respect that they deserve.¹⁰

¹⁰ Transcript, Barbara Spriggs, Adelaide Hearing 1, 11 February 2019 at T41.18-20.

Legislation

Accountability Principles 2014 (Cth)

Aged Care Act 1997 (Cth)

Aged Care (Living Longer Living Better) Act 2013 (Cth)

Aged Care Quality and Safety Commission Act 2018 (Cth)

Aged Persons Homes Act 1954 (Cth)

Anangu Pitjantjatjara Yankunytjatjara Land Rights Act 1981 (SA)

Approval of Care Recipients Principles 2014 (Cth)

Budget Savings (Omnibus) Act 2016 (Cth)

Carers Recognition Act 2012 (Vic)

Financial Framework (Supplementary Powers) Regulations 1997 (Cth)

Guardianship Act 1987 (NSW)

Guardianship Regulations 2016 (NSW)

Home and Community Care Act 1985 (Cth)

National Disability Insurance Scheme Act 2013 (Cth)

National Health Act 1953 (Cth)

Parliamentary Privileges Act 1987 (Cth)

Poisons and Therapeutic Goods Regulation 2008 (NSW)

Quality and Safety Commission Act 2018 (Cth)

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

Quality of Care Principles 2014 (Cth)

Residential Aged Care Act 1997 (Cth)

Royal Commissions Act 1902 (Cth)

States Grants (Nursing Homes) Act 1969 (Cth)

Taxation Administration Act 1953 (Cth)

User Rights Principles 2014 (Cth).

Veterans' Entitlement Act 1986 (Cth)

Introduction

Purpose of this report

In Australia, Royal Commissions are the highest form of inquiry on matters of public importance. The Royal Commission into Aged Care Quality and Safety has been established to determine the full extent of the problems in Australia's aged care system and how best to meet the challenges and the opportunities of delivering aged care now and into the future.

This Interim Report provides an update on our progress. It aims to do justice to the stories of the thousands of Australians who have taken the time to write submissions, speak at our community forums, or given evidence at our formal hearings.

The Interim Report sets out our overall impressions of the state of aged care in Australia. Volume 1 includes analysis of some specific issues on which we have received significant evidence, and identifies priority issues that we will examine over the remainder of the Royal Commission. Volume 2 contains an overview of the thematic hearings conducted up to the Darwin and Cairns Hearing in July 2019 and our findings on the case studies examined at those hearings. Volume 3 contains appendices and the record of community forums.

This Interim Report is not a draft of the Final Report. Consistent with our view that reform of aged care must be systemic and transformational rather than reactive and piecemeal, we do not make interim recommendations in advance of our conclusions on overarching systemic reform. However, in chapters 5 to 10 (Part 3), we have included observations and early conclusions on a number of areas, which will be the subject of comprehensive recommendations in the Final Report.

Establishment

The Commissioners and the Letters Patent

The Royal Commission into Aged Care Quality and Safety was established on 8 October 2018 by Letters Patent issued by the then Governor-General of the Commonwealth of Australia, His Excellency General the Honourable Sir Peter Cosgrove AK MC (Retd). The Letters Patent require the Royal Commission to inquire into the quality and safety of care provided in residential aged care facilities and community and flexible aged care settings. They formally appoint the Royal Commissioners and outline the Royal Commission's key areas of inquiry, which we will refer to as our Terms of Reference. The Terms of Reference were developed by the Australian Government, following a consultation process announced by the Prime Minister on 16 September 2018.

The Letters Patent of 8 October 2018 appointed the Honourable Justice Joseph McGrath as Chair and Ms Lynelle Briggs AO as Royal Commissioner. Those Letters Patent were revoked and replaced on 6 December 2018, when Justice McGrath stepped down from his position as Chair. The replacement Letters Patent appointed the Honourable Richard Tracey AM RFD QC as Chair and Ms Briggs as Royal Commissioner.

The Letters Patent of 6 December 2018 required delivery of the Final Report no later than 30 April 2020. On 29 July 2019, the Commissioners wrote to the Prime Minister, requesting an extension of time. On 13 September 2019, the Governor-General, His Excellency General the Honourable David Hurley AC DSC (Retd), issued further Letters Patent. These amending Letters Patent extended the date for delivery of the Final Report until 12 November 2020. The amending Letters Patent also appointed a third Commissioner, the Honourable Tony Pagone QC.

A copy of the Letters Patent of 6 December 2018 and the amending Letters Patent of 13 September 2019 are reproduced at the end of this introduction.

This extension of time gives the Royal Commission the chance to inquire further into a range of matters, including the governance arrangements, leadership and accountability of aged care providers; respite care; the funding and financing of aged care and the impact it has on how care is delivered; options for reform of the aged care system; and how best to deliver good quality and safe aged care services in a sustainable way. Further inquiry into these matters will build on the work we have already undertaken on the quality and safety of aged care. The extension also provides us with a firm basis upon which to propose reform to the existing aged care system and legislative framework.

Commissioner Tracey and Commissioner Briggs prepared this Interim Report, finalising its text in late September 2019. Commissioner Pagone had no role in the preparation of this report.

Commissioner Tracey died on 11 October 2019.

The first steps

Dr James Popple was engaged as Official Secretary to the Royal Commission from 8 October 2018.

On 21 November 2018, following a request for quote process, the Australian Government Solicitor was engaged as the Solicitors Assisting the Royal Commission.

On 31 December 2018, acting under section 6FA of the *Royal Commissions Act 1902* (Cth), the Attorney-General appointed Mr Peter Gray QC, Dr Timothy McEvoy QC, Mr Paul Bolster, Ms Brooke Hutchins and Ms Eliza Bergin as Counsel Assisting the Royal Commission. Further Counsel Assisting were appointed subsequently: Ms Erin Hill, on 29 January 2019; and Mr Peter Rozen QC, Mr Richard Knowles and Ms Zoe Maud on 29 March 2019. Dr McEvoy ceased his role as Senior Counsel Assisting upon his appointment to the Family Court of Australia from 27 March 2019. Mr Gray and Mr Rozen are Senior Counsel Assisting the Royal Commission.

Office accommodation was secured in Adelaide, and staff were engaged to support the work of the Royal Commission. Recruiting a skilled and capable team with relevant professional experience and knowledge was essential. Staff work in diverse areas, including policy, research, counselling for members of the public, engagement, communications, IT, logistics and operations, as well as legal advice. In addition, the Royal Commission contracted Dr Barbara Carney, Dr David Cullen, Mr Roger Fisher, Mr Rod Halstead, Mr Charles Maskell-Knight and Ms Carolyn Smith as senior policy advisers.¹ The Royal Commission also contracted several clinical advisers to provide specific subject-matter expertise.

Given the complexity and sensitivity of the task, seven key methods were adopted:

- public hearings
- notices requiring the production of documents, things, information or statements in writing
- a call for public submissions
- community forums
- expert roundtable discussions
- service visits
- research conducted by both the Royal Commission staff and commissioned from external providers.

¹ Ms Barbara Bennett PSM was also contracted as a senior adviser from January to April 2019.

Initial inquiries

Provider surveys

One of the first activities of the Royal Commission was to invite each approved provider under the *Aged Care Act 1997* (Cth) to make an early written submission in relation to each aged care service or outlet they operate. As part of this process, the Royal Commission asked approved providers to complete a detailed 'Service Provider Survey'.

The request sought information about a number of specific matters and gave providers an opportunity to identify the areas they think need to be changed, and how those areas might be changed.

The Royal Commission extended this invitation on 23 November 2018 to the largest providers and on 30 November 2018 to other providers, with letters sent to all providers. A total of 1029 approved aged care providers responded to the voluntary Royal Commission 'Service Provider Survey', which covered 60% of aged care service providers active as at 30 November 2018.

Submissions

Another early activity of the Royal Commission was developing an online and PDF submission form. We formally opened the invitation for submissions on 24 December 2018. Submissions will remain open until 30 April 2020.

Submissions from individuals and organisations provide information that helps the Royal Commission to identify issues that we should consider, including at public hearings. The opportunity to tell their story can be important and helpful for people who have been through terrible experiences. We realise that making a submission to a Royal Commission, and revisiting traumatic events, can be daunting. We are very grateful to everybody who has taken the time to make a submission or share their story with us.

The invitation to make submissions, initially made through our website (<https://agedcare.royalcommission.gov.au>), has been progressively expanded to include public advertisements, emails to people who have signed up for the Royal Commission's mailing list, and letters to peak bodies and advocacy organisations with a constituency impacted by aged care services.

Submissions can be made online, by phone or email, or through mail. Interpreter services are available for those with a primary language other than English.

Funds have also been allocated to the Australian Government Attorney-General's Department to contract organisations to support older people and people with a disability using aged care services to make submissions. In addition, the Australian Department of Health has funded a number of organisations to facilitate submissions for, or on behalf of, people facing barriers which could prevent their participation in the process.

As of 13 September 2019, we received more than 6139 submissions via the web form (3394), email (1510), telephone (405), forums (86), and hard copy (744).

Enquiries and counselling

The telephone enquiry service, initially outsourced, now operates within the Royal Commission. Callers inquire on a wide range of matters relevant to our inquiry. Some give submissions over the phone. When a caller is, or becomes, distressed, they can be referred to a counsellor for support, funded by the Royal Commission. A witness support and counselling service is available, especially where members of the public are giving evidence about their direct experience.

As of 13 September 2019, we received 3848 telephone calls to the information line (1800 960 711). We have provided these callers with general information, support related to hearings, or counselling support. To this point, we have referred 220 people to our Counselling and Support Team.

Preliminary roundtable discussions

In late November 2018, the Royal Commission held preliminary roundtable discussions with government stakeholders, experts on statistics in aged care, consumer groups, organisations and agencies involved in the aged care sector. These discussions provided early opportunities for us to ask questions about the system to identify challenges and ideas for improvements.

Hearings

The Royal Commission has held public hearings in various capital cities and regional and remote locations across Australia. Although the Royal Commission has the benefit of an Adelaide base, it does not have a purpose-built hearing room. We are very grateful to the following institutions and organisations for their generosity in making court rooms and other facilities available to us for our hearings across Australia:

- Roma Mitchell Commonwealth Law Courts Building, Adelaide
- Lionel Bowen Building (Family Court of Australia), Sydney
- Broome Civic Centre
- Peter Durack Commonwealth Law Courts Building, Perth
- Supreme Court of the Northern Territory
- Cairns Convention Centre
- Mildura Arts Centre
- Harry Gibbs Commonwealth Law Courts Building, Brisbane
- County Court of Victoria
- Owen Dixon Commonwealth Law Courts Building, Melbourne.

The location and theme of each hearing are announced progressively as arrangements are finalised. Details about future hearings are published on the Royal Commission's website and in national, State and Territory, and local newspapers. Hearings will continue to be held into 2020.

Hearings have been, and will continue to be, open to the public and live-streamed on the Royal Commission's website. Transcripts of the hearings are published on the website.

Preliminary Hearing

The preliminary public hearing of the Royal Commission commenced at 10am on 18 January 2019, at Roma Mitchell Commonwealth Law Court Building in Adelaide. There was keen interest from the public. Additional overflow rooms were provided to accommodate people attending.

At the hearing, we set out our approach to our responsibilities as Royal Commissioners, including the conduct of the hearings to follow:

The hallmark of a civilised society is how it treats its most vulnerable people, and our elderly are often amongst our most physically, emotionally, and financially vulnerable. Frail and elderly members of our community deserve to, and should, be looked after in the best possible way, and we intend to do our best to see that it happens.

— The Hon Richard Tracey AM RFD QC, Chair

We will look to the future, canvassing demographic pressures, community expectations, technology, risks and opportunities. We will consider aged people's position in society, what they want and how they are perceived. We will give voice to them.

— Ms Lynelle Briggs AO, Commissioner

Senior Counsel Assisting explained that Commissioners have a number of compulsory powers that can be used for gathering information:

The power to issue notices requiring a person to give information or a statement in writing is a new power. This Royal Commission will be the first Royal Commission to exercise this power. We expect this power will be exercised in preparation for public hearings.

— Mr Peter Gray QC, Senior Counsel Assisting

Public Hearings

Early in the Royal Commission's operation, we decided that each public hearing would focus on a particular theme or themes associated with the Terms of Reference.

At public hearings, we have heard from people receiving aged care, and families and friends of people receiving care, about their direct experiences of aged care. We have increased our understanding of issues through case studies, which have provided us the opportunity for detailed examination of specific providers or instances of substandard care.

The Royal Commission has also heard from a range of expert witnesses, including academics, clinicians, representatives of peak bodies, advocates, service providers and government agencies. We draw on this expert evidence in considering specific issues in Volume 1, and in the hearing summaries in Volume 2. This expert evidence will be further examined in our Final Report.

Table 1 lists hearing locations and dates to the end of October 2019. However, this Interim Report considers in detail evidence from hearings up to and including the Darwin and Cairns Hearing (8–12 July, 15–17 July 2019).



Table 1 - HEARINGS

Location	Date	Theme
Adelaide (Preliminary)	18 January 2019	Operation of the Royal Commission.
Adelaide—1	11-13 February 2019	Key features of the aged care system, quality, safety, complaints system and how the system works in practice.
Adelaide—2	18-22 March 2019	Aged care in the home.
Sydney	6-8 May 2019 13-17 May 2019	Residential care with a focus on people living with dementia.
Broome	17-19 June 2019	Care in remote areas and the care needs of Aboriginal and Torres Strait Islander people and issues of access and inclusion.
Perth	24-28 June 2019	The nature of person-centred care, advance care planning and palliative care services.
Darwin	8-12 July 2019	Aspects of care in residential, home and flexible aged care programs, rural and regional issues and quality of life for individuals in care.
Cairns	15-17 July 2019	Aspects of care in residential, home and flexible aged care programs, rural and regional issues and quality of life for individuals in care.
Mildura	29-31 July 2019	The needs of family, informal and unpaid carers of older Australians, including support services for carers and respite care.
Brisbane	5-9 August 2019	Regulation of aged care with a focus on quality and safety and how the regulatory system operates.
Melbourne—1	9-11 and 13 September 2019	Younger people in residential aged care, with a focus on impact, drivers, appropriateness and how to best support younger people wanting to leave residential care.
Melbourne—2	7-9 October 2019	Diversity in aged care including culturally and linguistically diverse people, LGBTI groups, Aboriginal and Torres Strait Islander people, care leavers, veterans, the homeless and those at risk of homelessness.
Melbourne—3	14-18 October 2019	The aged care workforce, focusing on enhancing capacity and making the sector more attractive and rewarding for employees.

The voices of the community are critically important to the Royal Commission's understanding of the issues relevant to our Terms of Reference. The thousands of submissions we have received and hundreds of accounts given to us at community forums have reinforced this. While every person's story is important, not every personal account is able to proceed to a public hearing. We are especially grateful to all those people who contribute to our hearings. We appreciate the courage people show in telling their stories and providing the Royal Commission with important information about the way the aged care system works in practice and the way it should work in future.

When considering the approach to hearings, Counsel and Solicitors Assisting the Royal Commission recommended that, where appropriate, case studies would be used to illustrate the themes to be examined in the hearings.

Case studies that have the potential to expose the themes being explored at a particular hearing are selected for investigation.

The investigation of case studies for examination at public hearings involves a number of steps, including:

- detailed review of submissions from the public and other information held by the Royal Commission
- interviewing potential witnesses
- issuing notices to relevant entities and comprehensively reviewing the material returned.

Following this process, Counsel and Solicitors select the case studies that proceed to examination at a hearing. In appropriate circumstances, Counsel Assisting invite the Commissioners to make findings about facts and issues arising in these case studies. We expect the Australian Department of Health and the Aged Care Quality and Safety Commission will have regard to the findings we have made and, in appropriate circumstances, take steps to follow up with approved providers.

In addition to case studies and to assist in giving voice to some of those who have provided submissions, the Royal Commission considers it necessary to hear direct accounts from older people, from young people with disabilities, and from those people's families and friends at public hearings. The purpose of this is to allow the Royal Commission and the public to hear directly from people who have experienced the aged care system. Counsel Assisting do not ask the Royal Commissioners to make findings about these individual accounts. However, these accounts are invaluable in helping the Royal Commission to understand a range of issues relevant to the Terms of Reference.

Volume 2 contains hearing overviews and case studies from each hearing, up to and including the Darwin and Cairns Hearing.

Engagement

In addition to holding public hearings and receiving submissions, the Royal Commission has undertaken a series of community forums, roundtable discussions with experts and site visits to aged care and related services. The first of the expert roundtables and the first of the site visits were held in February 2019. The first community forums were held in March 2019. These activities will continue during the life of the Royal Commission.

Community forums

The community forums have provided an opportunity for members of the public to tell their stories or provide their perspective to the Royal Commission in town hall-like public forums.



We have conducted nine community forums as at September 2019 in a mix of metropolitan and regional centres. Forums have been held in Bankstown (Sydney, NSW), Bendigo (Vic), Wollongong (NSW), Maidstone (Melbourne, Vic), Broome (WA), Townsville (Qld), Adelaide (SA), Brisbane (Qld) and Rockhampton (Qld). A community forum in Launceston (Tas) in early October took place after we completed preparation of this Interim Report.

Approximately 20 people have been offered the opportunity to speak at each forum. In total, 165 people have told their stories and around 1900 people have attended the nine forums held up to September 2019. The average attendance for each city and regional location has been about 210 people. Some of those attending have travelled considerable distances from a regional location or interstate, which demonstrates their commitment and passion for reform.

The community forums are very valuable to our inquiry and we appreciate the willingness of people to share their experiences and make suggestions for positive reform. The accounts that people have shared have given a direct and immediate picture of the aged care experience.

The overwhelmingly terrible stories have often been very sad and deeply concerning. They made a lasting impression. We are grateful to everyone who has attended and appreciate the courage people have shown in telling and hearing difficult personal and family stories.

All the speakers at forums have helped to shape our understanding of the reality of aged care in Australia. The deep love and dedication of family and friends of older people was abundantly clear in the stories we heard, but despite their best efforts, the aged care system had still failed them and their loved ones.

A summary of what we heard at the first nine community forums is in Appendix 1 (Volume 3). The Royal Commission's Final Report will include summaries of the Launceston community forum (held on 3 October) and other future forums.

Targeted engagement in specific locations

Royal Commission staff also conducted meetings with members of the public, advocates and service providers in specific locations as part of preparation for hearings. The need for and scope of these activities is identified on a case-by-case basis, depending on the theme of the hearing and particular information gaps requiring attention.

Examples of this engagement included:

- meetings with Aboriginal health services, community organisations, public servants, local researchers and members of the Broome and Bidjardanga communities in Western Australia
- a site visit and meetings with advocacy groups and service providers (government and non-government) in Darwin
- community meetings focused on local issues and informal carers in Mildura
- site visits and meetings with community members in Mudgee and Dubbo.

Roundtable discussions

In addition to the preliminary roundtables described above, we have held six roundtable discussions with invited experts on a range of themes in Sydney, Melbourne and Adelaide, and two roundtables in Canberra with officers from Commonwealth agencies involved in aged care. Roundtable discussions are smaller forums, based on selected themes. Experts in the field share their knowledge and opinions, and also respond to policy issues arising from research and submissions made to the Royal Commission. Attendance at the roundtable discussions is by invitation. The Royal Commission invites participants to expert roundtables to contribute based on their personal knowledge and experience, rather than as representatives of their organisations or sector.

The roundtable discussions form part of an approach that encourages frank and detailed conversations about aged care with those who have both expertise and ideas about specific issues within the Terms of Reference. Where referring to outcomes of roundtable discussions, including in the Interim Report, the Royal Commission will not attribute comments to specific participants. This is to encourage full, frank and spontaneous engagement in the roundtable conversations.

Table 2 - ROUNDTABLE DISCUSSIONS		
Location	Date	Theme
Melbourne	22 November 2018	Preliminary roundtable: young people in residential aged care
Adelaide	27 November 2018	Preliminary roundtable discussions: • Commonwealth agencies • Aged care data holdings • Advocacy groups
Sydney	27 February 2019	Experts: home care
Melbourne	4 March 2019	Experts: dementia
Canberra	29 April 2019	Commonwealth agencies: the aged care system, including proposed reforms and future challenges
Sydney	30 April 2019	Experts: culturally and linguistically diverse community
Sydney	30 April 2019	Experts: lesbian, gay, bisexual, transgender and intersex community
Sydney	2 May 2019	Experts: workforce issues
Adelaide	28 May 2019	Experts: Aboriginal and Torres Strait Islander service delivery
Canberra	1 July 2019	Commonwealth agencies • Younger people in residential aged care • Informal carers

Service provider visits

Visits to aged care service providers have enabled the Royal Commission and its staff to see a range of different care settings and services provided to older Australians. The sites visited have been diverse in size, specialty and innovation in mainstream, residential, home care and respite service settings. Each site visit has been pre-arranged with the provider. The selection of a service for a visit does not reflect any judgement, positive or negative, about the safety and quality of a service.

As of 13 September 2019, Commissioners have conducted 24 service visits in six States and Territories. Appendix 6 in Volume 3 lists the sites visited. By the time the Interim Report is tabled, we will also have visited a service provider in Tasmania.

Research and publications

Research

The Royal Commission is supported by a research program designed to address gaps in current knowledge about aged care. This includes surveys, focus groups, analysis of large administrative data sets, scans of international practice and economic analysis. We intend that most of this research will be completed in the first half of 2020.

Background papers

The Royal Commission has published eight background papers relevant to the Terms of Reference. These background papers are available on the Royal Commission website and are intended to provide critical background information on key issues within aged care in Australia, for the benefit of Commissioners and members of the public. The background papers do not represent a direction or position of the Royal Commission, and any views expressed in these papers are not necessarily the views of the Commissioners.

The following background papers have been published:

- Background Paper 1 – Navigating the maze: an overview of Australia’s current aged care system, Ms Carolyn Smith with assistance from the Office of the Royal Commission, February 2019.
- Background Paper 2 – Medium- and long-term pressures on the system: the changing demographics and dynamics of aged care, Dr David Cullen with assistance from the Office of the Royal Commission, May 2019.
- Background Paper 3 – Dementia in Australia: nature, prevalence and care, the Office of the Royal Commission, May 2019.
- Background Paper 4 – Restrictive practices in residential aged care in Australia, the Office of the Royal Commission, May 2019.
- Background Paper 5 – Advance care planning in Australia, the Office of the Royal Commission, June 2019.
- Background Paper 6 – Carers of older Australians, the Office of the Royal Commission, July 2019.
- Background Paper 7 – Legislative framework for Aged Care Quality and Safety regulation, the Office of the Royal Commission, August 2019.
- Background Paper 8 – A history of aged care reviews, the Office of the Royal Commission, October 2019.

‘Moving targets’

Since the Royal Commission began work, the Australian Government has made several announcements of new expenditure or new policies in aged care.

As part of the 2018-19 Federal Budget, the Government announced the ‘More Choices for a Longer Life’ package. This included 42 measures on ageing and aged care, including some measures in response to previous reviews. The Government has continued to implement these measures since announcing the Royal Commission.

There have also been a number of more recent policy announcements, notably:

- an additional \$320 million for residential aged care, announced in February 2019
- 10,000 new Home Care Packages, also announced in February 2019
- changes to policy on the use of both medications and physical means to ‘restrain’ people living in residential aged care
- a plan to establish a national network of specialised dementia units
- new research projects in the sphere of dementia.

While these more recent announcements, especially those aimed at improving the supply of home-based and residential care, have been welcomed by providers and advocacy groups, the Royal Commission is obliged to observe that this series of ‘moving targets’ makes our work more difficult. As mentioned in our foreword, we consider the urgent areas for Government action in advance of our Final Report are the waiting list for home care, the use of chemical restraint, and younger people in residential aged care.

Our remit is to conduct the most wide-ranging inquiry into Australia’s aged care system in the last 40 years, using all the powers at our disposal. We will develop recommendations that go to the heart of the many longstanding problems in aged care. It is therefore highly desirable that we do so without having to take account of further, relatively minor, policy shifts.

Timing of the Interim Report

This Interim Report primarily draws on hearings conducted between February and July 2019, and where possible also draws on evidence heard up until September 2019. Chapter 10, which reflects on the urgent need to address the plight of younger people with a disability living in residential aged care, draws on the Melbourne Hearing of 9-11 and 13 September 2019. This issue has been elevated to the Interim Report due to its clear urgency, and because our inquiries on this issue are substantially complete. In contrast, our inquiries on the issue of aged care for older people will continue over the life of the Royal Commission.

To meet publication deadlines, the substantive text was finalised in late September 2019. Case study evidence summarised in Volume 2 is limited to material heard no later than July 2019, to ensure that all parties concerned have had an opportunity to respond to the evidence heard and submissions made. Unless otherwise stated, information about the Royal Commission's other activities reflect developments up to mid-September 2019.



ELIZABETH THE SECOND, by the Grace of God Queen of Australia and Her other Realms and Territories, Head of the Commonwealth

TO

The Honourable Richard Ross Sinclair Tracey AM RFD QC, and
Ms Lynelle Jann Briggs AO

GREETING

RECOGNISING the contribution of older Australians to society, and that older Australians deserve high quality care in a safe environment that protects their wellbeing and dignity.

AND the importance of building a national culture of respect for ageing and older persons.

AND that Australia's population is ageing and the proportion and number of people accessing and needing care is increasing.

AND the many positive examples of high quality care within the Australian aged care sector which engages thousands of dedicated people providing aged care services every day, complemented by the important contribution of families and volunteers.

AND that as a community all Australians expect high standards of quality and safety from our aged care services, and it is important that the Australian Government has the best regulatory and policy framework to provide a sustainable aged care system that meets the needs of older Australians in the future.

AND that it is important that frail, older people needing care should receive services that reflect and address their care needs.

AND that the Commonwealth provides funding to, and regulates, providers of aged care services.

AND that some people residing in aged care facilities, including younger people, or otherwise receiving aged care services, have disabilities and Australia has undertaken relevant international obligations, including to take

ENTERED ON RECORD by me in Register of Patents No. 53, page 48, on 6 December 2018

Secretary to the Federal Executive Council

Just Carr

all appropriate legislative, administrative and other measures for the implementation of the rights of people with disabilities.

NOW THEREFORE We do, by Our Letters Patent issued in Our name by Our Governor-General of the Commonwealth of Australia on the advice of the Federal Executive Council and under the Constitution of the Commonwealth of Australia, the *Royal Commissions Act 1902* and every other enabling power, appoint you to be a Commission of inquiry, and require and authorise you, to inquire into the following matters:

- (a) the quality of aged care services provided to Australians, the extent to which those services meet the needs of the 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;
- (b) how best to deliver aged care services to:
 - (i) people with disabilities residing in aged care facilities, including younger people; and
 - (ii) the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services;
- (c) the future challenges and opportunities for delivering accessible, affordable and high quality aged care services in Australia, including:
 - (i) in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and
 - (ii) in remote, rural and regional Australia;
- (d) what the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe;
- (e) how to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters;
- (f) how best to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure;
- (g) any matter reasonably incidental to a matter referred to in paragraphs (a) to (f) or that you believe is reasonably relevant to the inquiry.

AND We direct you to make any recommendations arising out of your inquiry that you consider appropriate, including recommendations about any policy, legislative, administrative or structural reforms.

AND, without limiting the scope of your inquiry or the scope of any recommendations arising out of your inquiry that you may consider appropriate, We direct you, for the purposes of your inquiry and recommendations, to have regard to the following matters:

- (h) all forms of Commonwealth-funded aged care services, whatever the setting or environment in which those services are delivered;
- (i) all aspects of the quality and safety of aged care services, including but not limited to the following:
 - (i) dignity;
 - (ii) choice and control;
 - (iii) clinical care;
 - (iv) medication management;
 - (v) mental health;
 - (vi) personal care;
 - (vii) nutrition;
 - (viii) positive behaviour supports to reduce or eliminate the use of restrictive practices;
 - (ix) end of life care;
 - (x) systems to ensure that high quality care is delivered, such as governance arrangements and management support systems;
- (j) the critical role of the aged care workforce in delivering high quality, safe, person-centred care, and the need for close partnerships with families, carers and others providing care and support;
- (k) the wide diversity of older Australians and the barriers they face in accessing and receiving high quality aged care services. This should take into account the increasing incidence of chronic and complex conditions;
- (l) the interface with other services accessed by people receiving aged care services, including primary health care services, acute care and disability services, and relevant regulatory systems. This should take

into account how people transition from other care environments or between aged care settings;

- (m) examples of good practice and innovative models in delivering aged care services;
- (n) the findings and recommendations of previous relevant reports and inquiries.

AND We further declare that you are not required by these Our Letters Patent to inquire, or to continue to inquire, into a particular matter to the extent that you are satisfied that the matter has been, is being, or will be, sufficiently and appropriately dealt with by another inquiry or investigation or a criminal or civil proceeding.

AND, without limiting the scope of your inquiry or the scope of any recommendations arising out of your inquiry that you may consider appropriate, We direct you, for the purposes of your inquiry and recommendations, to consider the following matters, and We authorise you, as you consider appropriate, to take (or refrain from taking) any action arising out of your consideration:

- (o) the need to establish mechanisms to facilitate the timely communication of information, or the furnishing of evidence, documents or things, in accordance with section 6P of the *Royal Commissions Act 1902* or any other relevant law, including, for example, for the purpose of enabling the timely investigation and prosecution of offences;
- (p) the need to ensure that evidence that may be received by you that identifies particular individuals as having been subject to inappropriate treatment is dealt with in a way that does not prejudice current or future criminal or civil proceedings or other contemporaneous inquiries;
- (q) the need to establish appropriate arrangements in relation to current and previous inquiries, in Australia and elsewhere, for evidence and information to be shared with you in ways consistent with relevant obligations so that the work of those inquiries, including, with any necessary consents, the testimony of witnesses, can be taken into account by you in a way that avoids unnecessary duplication, improves efficiency and avoids unnecessary trauma to witnesses;
- (r) the need to establish, as you see fit and having regard to the date by which you are required to submit your final report, appropriate arrangements for evidence and information to be shared with you by people about their experiences, including people receiving aged care services, their families, carers and others who provide care and support, recognising that some people will need special support to share their experiences.

AND We appoint you, the Honourable Richard Ross Sinclair Tracey AM RFD QC, to be the Chair of the Commission.

AND We declare that you are a relevant Commission for the purposes of sections 4 and 5 of the *Royal Commissions Act 1902*.

AND We declare that, in exercising your powers under Part 2 of the *Royal Commissions Act 1902*, you are to inquire into the matters falling within the scope of paragraphs (a) to (g) only to the extent that Commonwealth constitutional power extends to those subjects of inquiry.

AND We declare that you are a Royal Commission to which item 5 of the table in subsection 355-70(1) in Schedule 1 to the *Taxation Administration Act 1953* applies.

AND We declare that in these Our Letters Patent:

aged care services means services provided by any of the following:

- (a) approved providers within the meaning of the *Aged Care Act 1997*;
- (b) entities to which a grant is payable under Chapter 5 of the *Aged Care Act 1997*;
- (c) entities to which funding is payable under a program relating to aged care specified in Schedule 1AA or 1AB to the *Financial Framework (Supplementary Powers) Regulations 1997*;
- (d) entities that receive funding for the purposes of the Veterans' Home Care Program established under the *Veterans' Entitlements Act 1986*.

AND We:

- (s) require you to begin your inquiry as soon as practicable; and
- (t) require you to make your inquiry as expeditiously as possible; and
- (u) require you to submit to Our Governor-General an interim report that you consider appropriate not later than 31 October 2019; and
- (v) require you to submit to Our Governor-General a final report of the results of your inquiry, and your recommendations, not later than 30 April 2020.

IN WITNESS, We have caused these Our Letters to be made Patent.

Paul de Jersey AC

WITNESS ~~General the Honourable Sir Peter Cosgrove AK MC~~
(Ret'd), ~~Governor-General~~ of the Commonwealth of Australia,

Administrator of the Government

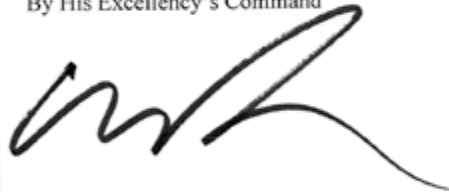
Dated *6th December* 2018



~~Governor-General~~

**Administrator of the Government
of the Commonwealth of Australia**

By His Excellency's Command



Attorney-General



ELIZABETH THE SECOND, by the Grace of God Queen of Australia and Her other Realms and Territories, Head of the Commonwealth

TO

The Honourable Richard Ross Sinclair Tracey AM RFD QC,

Ms Lynelle Jann Briggs AO, and

The Honourable Gaetano Tony Pagone QC

GREETING

WHEREAS, by Letters Patent issued in Our name and entered in the Register of Patents on 6 December 2018, We appointed you:

- (a) The Honourable Richard Ross Sinclair Tracey AM RFD QC; and
- (b) Ms Lynelle Jann Briggs AO;

to be a Commission of inquiry, required and authorised you to inquire into certain matters, and required you to submit to Our Governor-General a final report of the results of your inquiry, and your recommendations, not later than 30 April 2020;

AND WHEREAS it is desired to amend Our Letters Patent;

NOW THEREFORE We do, by these Our Letters Patent issued in Our name by Our Governor-General of the Commonwealth of Australia on the advice of the Federal Executive Council and under the Constitution of the Commonwealth of Australia, the *Royal Commissions Act 1902* and every other enabling power, amend those Letters Patent:

- (c) by appointing you, the Honourable Gaetano Tony Pagone QC, to be an additional member of this Commission of inquiry; and
- (d) so that those Letters Patent apply to you in a corresponding way to the way those Letters Patent apply to Ms Lynelle Jann Briggs AO, subject to paragraph (e); and

ENTERED ON RECORD by me in Register of Patents No. 54, page 64, on 13 September 2019

Deborah M. Grogan
Secretary to the Federal Executive Council

- (e) by inserting the following paragraphs after the paragraph “AND We appoint you, the Honourable Richard Ross Sinclair Tracey AM RFD QC, to be the Chair of the Commission.” in those Letters Patent:

“AND We appoint you, the Honourable Gaetano Tony Pagone QC to act as the Chair of the Commission during any period, or during all periods, when the Honourable Richard Ross Sinclair Tracey AM RFD QC is absent from duty or from Australia or is, for any reason, unable to perform the duties of the Chair.

AND We declare that while you, the Honourable Gaetano Tony Pagone QC, are acting as the Chair of the Commission:

- (ra) you have and may exercise all the powers, and must perform all the functions and duties, of the Chair of the Commission; and
 - (rb) the *Royal Commissions Act 1902*, or any other Act, applies in relation to you as if you were the Chair of the Commission.”; and
- (f) by omitting from paragraph (v) of the Letters Patent “30 April 2020” and substituting “12 November 2020”.

IN WITNESS, We have caused these Our Letters to be made Patent.

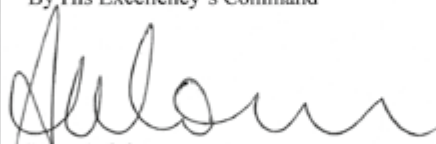
WITNESS General the Honourable David Hurley AC DSC
(Retd), Governor-General of the Commonwealth of Australia.

Dated 13 September 2019



Governor-General

By His Excellency's Command



Prime Minister

Part 1

The Road to Reform

1. The Current System

With older people, we bracket them off into the aged care system which, I might say, apart from prisoners is the only institutionalised system we still have left...we've expected that when people go to residential aged care, somehow everything that they have as needs will be looked after by that facility. If that's our expectation, that's not what government is funding. That's not what it's actually requiring of them to do.¹

Introduction: What is aged care?

The experience of ageing is varied, affecting every person at different ages and in different ways. Normal ageing involves a number of physical, cognitive and social changes, some of which can be anticipated and managed, some requiring support and others involving care, especially when capacity declines or when one or more chronic diseases add to the complexity of a person's needs. A small proportion of older people are completely dependent on others but, generally, many older people need different types of support at different times and for differing periods.

To understand fully Australia's system of providing services and support to older people, it has been necessary for the Royal Commission to explore how the system has evolved over the past century or more. This chapter gives a brief overview of developments in aged care since Australia's Federation in 1901, before going on to describe the current system, examining the type of support people access, how it is funded, and the regulation of safety and quality.

Aged care is the network of all support provided to people aged 65 years and over. This ranges from informal support—the help of spouses, other family members and friends—to formal support provided for, or subsidised by, governments and other organised systems.²

Formal aged care in Australia has evolved to provide services to those who can no longer live independently and care for themselves. The Australian aged care system provides those whose capacity has been diminished by physical or mental disability or frailty with support, including:

- assistance with everyday living activities such as cleaning, laundry, shopping, meals and social participation
- help with personal care such as help with getting dressed, eating and going to the toilet

1 Transcript, Ian Yates AM, Adelaide Hearing 1, 11 February 2019 at T58.6-20.

2 D Cullen, *Historical Perspectives: The evolution of the Australian Government's involvement in supporting the needs of older people*, 2003, p 1.

- help with health care, including nursing, physiotherapy and dietetics
- accommodation.³

Aged care can be provided in a person's own home, in the community, in group homes or in residential facilities that are purpose-built.

A brief history of aged care in Australia

Prior to the establishment of a formal aged care system, older Australians were cared for by their families. Older people without family support had few options except to live in institutions, generally provided by the Australian colonies and then State Governments. These were older people who did not have the capability, funds or circumstances to provide fully for their own care. They relied on the state to support them when they could no longer do so themselves due to illness, frailty or cognitive decline. Institutions like asylums and hospitals were the main source of accommodation for these poorer, frail older people.⁴

The involvement of governments in supporting older people is a result of the intersection of three key policy areas: age pensions, housing, and health care.⁵ Until Federation, the colonies had responsibility for the limited support available, including income, health care and housing. Since Federation, the Commonwealth has increasingly become involved in providing direct support for older people, although the States and Territories retain significant responsibilities in health care and public housing.

From 1909, the Commonwealth used its constitutional powers to assume responsibility for paying age and service pensions. Until World War Two, income support was the primary contribution the Australian Government made to older Australians. During the war, and in the decade following, the Commonwealth started to subsidise health care—such as through the introduction of the Pharmaceutical Benefits Scheme to provide affordable medicines to all Australians, including older people.

The Commonwealth firstly became involved in subsidising accommodation for poorer older people after the passage of the *Aged Persons Homes Act 1954* (Cth). This legislation subsidised religious and charitable organisations to build homes for older people. Over time, the Australian Government went on to provide rental assistance to older people on lower incomes and to enter into various partnerships with State and Territory Governments to deliver affordable housing options.

3 Productivity Commission, *Caring for Older Australians, Productivity Commission Inquiry Report No 53, Volume 1*, 2011, pp 5, 13, 16.

4 This brief history of aged care draws primarily from: D Cullen, *Historical Perspectives: The evolution of the Australian Government's involvement in supporting the needs of older people*, 2003, pp 1–85 unless otherwise cited.

5 Department of Health and Ageing, *Submission to the Productivity Commission Inquiry Caring for Older Australians*, 2010, p 41.

The Aged Persons Homes Act resulted in the introduction of a two-tier aged care system in the 1960s: nursing home care (high-level care) and hostel care (low-level care). Under this structure, and with substantial capital funding by the Commonwealth, the aged care system, administered by the States, grew significantly over the next 20 years.

While State Governments continued to provide some care, funding was more usually provided to religious and charitable organisations to provide care to older people. Not-for-profit and, over time, for-profit organisations have become key features of the aged care system, with the Australian Government's role more to fund and regulate them rather than to deliver care directly.

In 1963, State Governments, as well as for-profit and not-for-profit or community organisations, were initially given subsidies from the Commonwealth for care services through the *National Health Act 1953* (Cth). This new form of financing, known as the Nursing Home Benefit, resulted in an immediate and dramatic growth in nursing homes, with the majority of growth being in the for-profit sector. This growth outstripped the growth in the population of older people, and had the effect of shifting financial responsibility for frail older people from hospitals and asylums (States) to nursing homes (Commonwealth).

The Australian Government faced cost pressures in this program from the late 1960s and had to take action to address concerns that providers were selecting those residents with lower needs who did not need to be in care permanently. In setting higher subsidies more generally, the Government also put a ceiling on the fees that could be charged to older people (particularly to pensioners) and which could be topped up by the Government. It also introduced a test for subsidies based on care needs. This created a tension between the Government and for-profit providers concerning the provider profitability.

Commonwealth funding for aged care infrastructure continued in 1969 under the *States Grants (Nursing Home) Act 1969* (Cth). Under this legislation, the Commonwealth granted funds to the States to build nursing homes instead of subsidising care in those nursing homes. This funding further encouraged the rapid growth of nursing homes across Australia—a cheaper alternative to hospitals.

More personalised services like Senior Citizens Centres, which provided group activities, and Meals on Wheels, which delivered prepared meals to people at home, were introduced in the late-1960s and early-1970s, with the aim of reducing the need for residential care. The Australian Government also offered funding to providers, other than those from private enterprise, to construct more hostels. This encouraged not-for-profit organisations to provide aged care by funding any deficits in their operating expenses.⁶

6 Australian Department of the Parliamentary Library, *Residential care for the aged: An overview of Government policy from 1962 to 1993*, 1993, pp 6–10.

In 1972, the National Health Act was amended to include the first domiciliary nursing care benefits. These were introduced to provide income for carers who were responsible for older relatives—this benefit was the precursor to today’s carer payment.⁷

In the mid-1980s, there were major changes to aged care. By this time, both major political parties recognised the need for greater direct involvement by the Australian Government and more stringent management of funding. Issues of accessibility, affordability, quality and cost containment were at the forefront of policy development. The influential McLeay Report, released in 1982, recommended rebalancing the system towards more care at home.⁸ The *Home and Community Care Act 1985* (Cth) was passed to support a program—jointly funded by the Commonwealth with the States and Territories, and administered by the States and Territories—that provided care in the home and community by making grants for community-based services for people of all ages.⁹ The program provided older people with basic support services as well as allied health and nursing care. A form of ‘packaged care’ also evolved under this program, with a case manager appointed to coordinate the services provided at home for each older person accepted into the program. This would become the basis for the Community Aged Care Packages program.

At the same time, the Senate inquired into and reported on aged care and private hospitals, among other things, in Australia. This became known as the Giles Report, as the Chair of the committee was Senator Patricia Giles.¹⁰ The Giles Report put forward the idea of unifying the two-tier residential system. Rather than separate nursing homes and hostels, the committee that led the Giles Report believed that it would be more efficient and easier for there to be residential aged care facilities with providers able to offer a full range of aged care services in one place.¹¹ The *Nursing homes and hostels review* of 1986 recommended eligibility assessments that limited people’s entry into residential care, standards aimed at encouraging better quality in aged care and monitoring of those standards.¹²

7 Australian Department of the Parliamentary Library, *Residential care for the aged: An overview of Government policy from 1962 to 1993*, 1993, Canberra, p 7; D Cullen, *Historical Perspectives: The evolution of the Australian Government’s involvement in supporting the needs of older people*, 2003, p 53.

8 House of Representatives Standing Committee on Expenditure, *In A Home Or At Home: Accommodation And Home Care For The Aged – A Follow-Up Report*, Parliamentary Paper No. 292, 1984, p 47.

9 Exhibit 1-3, Adelaide Hearing 1, Statement of Ian Yates, 31 January 2019, WIT.0006.0001.0001 at 0004, 0005.

10 Senate Select Committee on Private Hospitals and Nursing Homes, *Private nursing homes in Australia: their conduct, administration and ownership*, Parliament of Australia, Report No. 159, 1985.

11 Senate Select Committee on Private Hospitals and Nursing Homes, *Private nursing homes in Australia: their conduct, administration and ownership*, Parliament of Australia, Report No. 159, 1985.

12 Department of Community Services and Health, *Nursing homes and hostels review*, Australian Government Publishing Service, 1986; H Kendig and S Duckett, *Australian directions in aged care: the generations of policies for generations of older people*, Australian Health Policy Institute at the University of Sydney, 2001, pp 1112.

The Australian Government adopted some of the recommendations of the Giles Report, but progress towards a truly unified residential aged care system was slow. Funding models continued to support a distinction between nursing homes and hostels, and capital grants to build separate types of accommodation continued well into the 1990s. Not until the changes enacted under the *Aged Care Act 1997* (Cth) did a unified system emerge. This legislation sought to improve the standard of residential accommodation; standardised funding arrangements for both funds provided by Government and contributions made by residents; and linked the quality of care to government funding through the introduction of obligations on providers to meet minimum Standards of Care that were subject to audit.

The early 2000s saw a renewed focus by all levels of government on home and community care. Packages providing more intensive support for people with higher care needs were introduced through the Extended Aged Care at Home and the Extended Aged Care at Home Dementia programs.¹³ Despite these attempts at streamlining and rationalising the system, by about 2010 questions began to grow about its longer-term sustainability. The Australian Government tasked the Productivity Commission with inquiring into Australia's aged care system. These questions were fuelled by an increasing demand for home-based services, with attention being brought to bear on the growing proportion of the population aged over 65 years.¹⁴

In 2010, the Australian Government negotiated with the States and Territories that, as part of the National Health Reform Agreement, the Commonwealth would assume full responsibility for the Home and Community Care program. This eventually led to the Australian Government assuming full responsibility for funding and regulating all home and residential aged care services—with the transition of the Western Australian Home and Community Care program on 1 July 2018—although some State Governments still operate residential aged care services. Health care for older people remains a shared responsibility between the Commonwealth and the States and Territories.¹⁵

Now that it had control of the aged care system, and in response to some of the Productivity Commission's recommendations in the 2011 report of the *Caring for older Australians* inquiry, the Australian Government embarked on another round of changes to funding, programs and administration. These included the expansion of programs delivered in people's homes and changes to means testing for home and residential aged care. A single entry point for people who needed to access the system was also established.

13 Exhibit 1-3, Adelaide Hearing 1, Statement of Ian Yates, 31 January 2019, WIT.0006.0001.0001 at 0004-0005 [18].

14 Australian Government, *Australia to 2050: future challenges*, Intergenerational Report – Overview, 2010, p 4.

15 Exhibit 2-86, Adelaide Hearing 2, Statement of Professor Swerissen, 15 March 2019, WIT.0085.0001.0001 at 0012 [77].

Many of these changes to the aged care system were established by a package of legislation entitled *Living Longer Living Better*, introduced into Parliament in 2013. Since that time, there have been further tweaks to the system by way of various policy changes, and rebalancing of the system towards home care, but the broad architecture of the system in 2019 dates back to the 1997 changes. The sector continues to bed down the changes to care and support in the home that were introduced in response to the findings of the Productivity Commission's 2011 review. This has included moving the Home and Community Care program into the newly created Commonwealth Home Support Programme, and the introduction of consumer direction in Home Care Packages.

A 2017 review, mandated by the *Aged Care (Living Longer Living Better) Act 2013* (Cth), undertaken by David Tune AO PSM, concluded that progress had been made in establishing a more consumer-driven and sustainable aged care system. This review also recognised that further change was required in information, assessment, consumer choice, means testing and equity of access.¹⁶

Care for older people

Many older people continue to live in the community without aged care services, despite some decline in their physical and cognitive health. They are mostly independent, or rely on family and friends, to varying degrees, to assist them. If their needs reach a point where formal aged care is required, they have the option to pay for it privately or seek government-subsidised care, or to do a mix of both.

In fact, at the last Census, 95% of Australians aged 65 years and over lived in their own home. Of this group, 25% lived alone. The likelihood of a person living alone increases with age, particularly for women. The 65 to 74-year age group is most likely to live with a spouse or partner (68%), while those aged 85 years and older are more likely to live alone (35%). Of the older people who lived alone, 88% had been visited by family members or friends in the last three months and 84% had visited friends and family.¹⁷ Not all older people will need care and support beyond that provided by their family and friends.

¹⁶ D Tune, *Legislated Review of Aged Care 2017*, 2017, p 12.

¹⁷ Data from the Australian Bureau of Statistics, *Census of Population and Housing*, Stories from the Census 2016, 2017 quoted in the Australian Institute of Health and Welfare, *Australia's Welfare 2017*, Australia's welfare series No. 13. AUS 214. 2017.

Informal aged care

Most support for older Australians is provided by unpaid or informal carers. Yet this is the least visible form of support.¹⁸ The Australian Bureau of Statistics 2015 Survey of Disability, Ageing and Carers found that 73% of older people who needed assistance received help from an informal carer.¹⁹ In that survey, older people most frequently reported needing assistance with self-care, household chores, getting to places beyond walking distance, communicating with others, reading and writing, cognitive or emotional tasks, and health care. Typically, informal carers provide older people with support to communicate, read and write, perform domestic chores, and help them manage at home. Informal carers also play a major role in coordinating and facilitating formal aged care services. Social connection, communicating and interacting with others are important parts of the informal support provided to older people as it counters their risk of social isolation.²⁰

In 2015, Deloitte Access Economics estimated the commercial value of informal care at more than \$60.3 billion per annum.²¹ It also predicted that demand for informal care would significantly outstrip supply in 10 years. While family members and friends will continue to play a central role in providing aged care, changing demographics and social norms are likely to see a continuation in families, governments and other sectors sharing these responsibilities, but possibly in different ways.²² There is a need for more effective partnerships between informal carers and formal care providers, to ensure access to quality aged care for all who need it.

18 Exhibit 1-4, Adelaide Hearing 1, Statement of Professor John McCallum, 31 January 2019, WIT.0004.0001.0001 at 0006.

19 Data from the Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: summary of findings 2015*, ABS cat. No. 4430.0. Canberra: Australian Bureau of Statistics, 2016, quoted in the Australian Institute of Health and Welfare, *Australia's Welfare 2017*, 2017, Australia's welfare series No. 13. AUS 214.

20 Data from the Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: summary of findings 2015*, ABS cat. No. 4430.0. Canberra: Australian Bureau of Statistics, 2016, quoted in the Australian Institute of Health and Welfare, *Australia's Welfare 2017*, 2017, Australia's welfare series No. 13. AUS 214.

21 Deloitte Access Economics, *The economic value of informal care in Australia in 2015*, Carers Australia, 2015, p iii.

22 World Health Organization, *Fact File: Misconceptions on ageing and health*, Ageing and life-course, 2019, <https://www.who.int/ageing/features/misconceptions/en/>, viewed 22 July 2019.

Formal aged care

Formal aged care has two key variables: the intensity of the needed care and the location in which services are delivered. Locations include the person's home, in the community, or in purpose-built facilities. Care extends across:

- basic, entry-level support which is generally delivered as a 'one-off' or 'as required' service for either short sustained periods or over longer periods at low frequencies. The delivery of meals and provision of domestic assistance, home nursing and respite care are typical
- coordinated care at home, which is more structured and intense assistance and usually involves case management
- care in a residential setting that is intensive and helps people with severe physical or cognitive problems, or general frailty, care for themselves with considerable assistance. This is generally provided in purpose-built accommodation.²³

There is also respite care, provided in a variety of residential and community settings for short stays of up to 63 days annually, which is aimed at giving carers a break.²⁴ Finally, there are also several types of more flexible care available to older people and their carers that extend across the spectrum, from home support to residential aged care.²⁵

Figure 1.1 illustrates the intensity and types of aged care services available to older Australians. More than 1.2 million Australians accessed aged care services from mainstream programs in 2017–18. They included:

- 847,534 people who received basic services provided through the Commonwealth Home Support Programme at some time during the year
- 116,843 people who received support through a Home Care Package at some time during the year
- 241,723 people who received permanent residential aged care at some time during the year.²⁶

While the system is designed on the basis that it provides a continuum of care as a person's needs increase, older people in Australia do not necessarily progress through the system in this linear fashion. Each person's life experience is unique and therefore there is no 'typical' aged care profile. People will need a mix of services as their health and strength waxes and wanes over time.

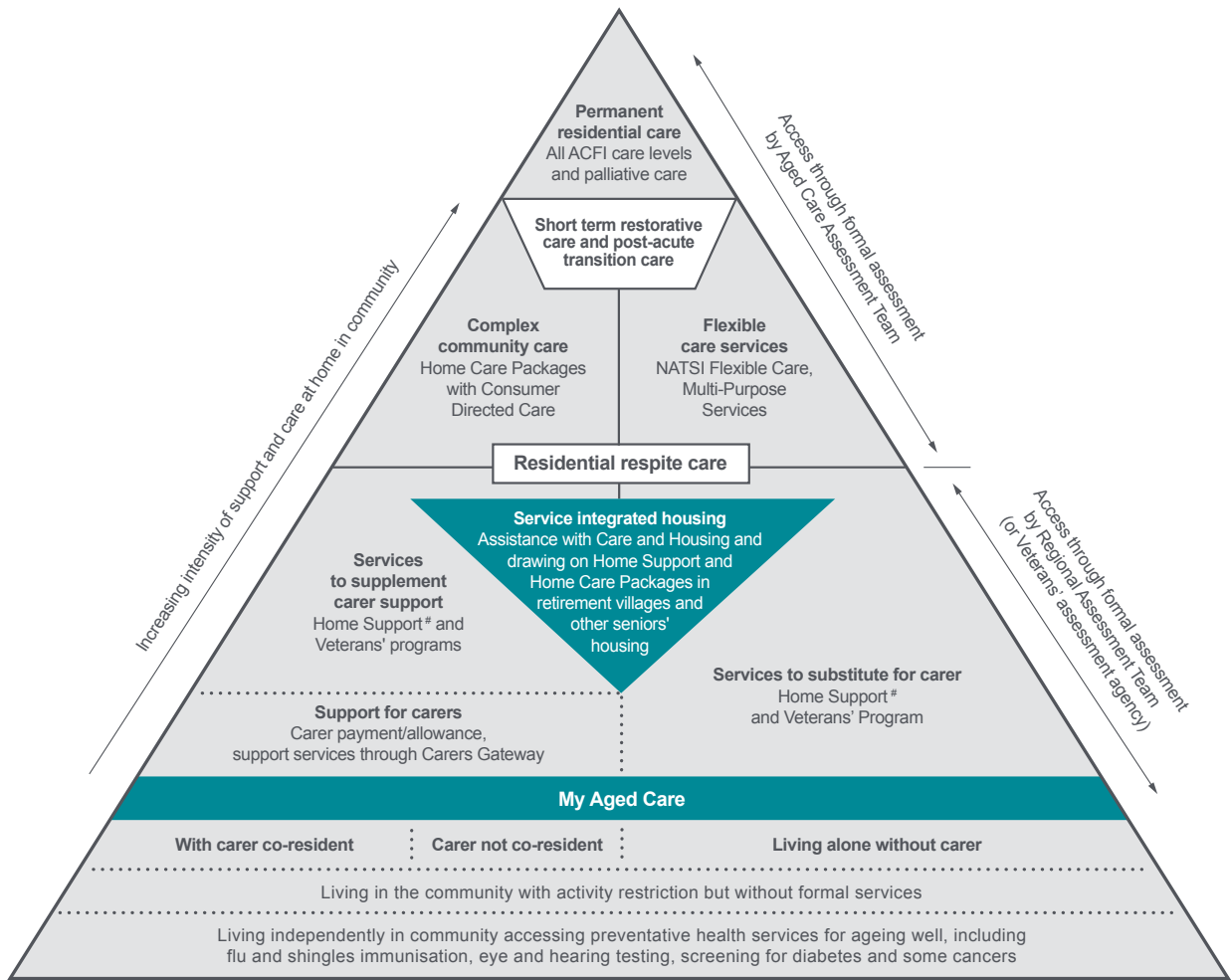
23 Department of Health and Ageing, *Submission to the Productivity Commission Inquiry Caring for Older Australians*, 2010, pp 10–11.

24 Aged Care Financing Authority, *Report on respite for aged care recipients*, 2018, p 14.

25 Department of Health, *2017–18 Report on the Operation of the Aged Care Act 1997*, 2018, p 2.

26 Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, Annual Report, 2019, pp 7, 11.

Figure 1.1: Intensity and type of aged care



Home Support (CHSP) provides domestic assistance, personal care, nursing, allied health, social support, planned respite, transport, home maintenance and gardening, modifications, equipment and meals.

Source: First developed by Professor Anna Howe and published in A Howe, 'Changing the balance of care: Australia and New Zealand' in OECD, *Caring for frail elderly people: policies in evolution*, 1996. Revised in 2019 with advice from Anna Howe via personal communication with the Royal Commission, 2019.

Current programs in Australia's aged care system

My Aged Care

To access subsidised aged care, people must use the Australian Government's single-entry point, a call centre and website known as 'My Aged Care'. My Aged Care provides information on aged care, refers older people for eligibility assessments and provides information that helps them find appropriate services in their local area. My Aged Care was introduced after advocacy from consumer groups and on recommendation from the Productivity Commission in its 2011 report.²⁷ There had long been calls to improve the confusing, numerous and often contradictory entry points to the aged care system.

Eligibility for support

When an older person, or their family member or carer, wants to register their interest in aged care, they have an initial conversation with staff members in the national My Aged Care call centre.²⁸ A My Aged Care staff member asks questions about the person's health, current support and how they are managing at home. The staff member decides whether the person needs to be referred for an aged care assessment.²⁹ If the person requires basic support services, My Aged Care will arrange a visit from a Regional Assessment Service. For those with more complex care requirements, My Aged Care will arrange for a comprehensive assessment by an Aged Care Assessment Team. Both forms of aged care assessment are conducted face-to-face and focus on the person's eligibility for care.³⁰

Care at home and in the community

Basic support at home

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 of people accessing care over a decade, found 76% used this program before any other aged care program.³¹ In 2017–18, about 45% of people accessing the program lived alone.³² The average age of people receiving home support was 79.1 years.³³

27 Productivity Commission, *Caring for Older Australians*, Productivity Commission Inquiry Report No 53, Volume 1, 2011, p LXVIII.

28 Exhibit 2-89, Adelaide Hearing 2, Statement of Fiona Kathryn Buffinton, 11 March 2019, WIT.0058.0001.0001 at .0007 [25].

29 Exhibit 2-89, Adelaide Hearing 2, Statement of Fiona Kathryn Buffinton, 11 March 2019, WIT.0058.0001.0001 at .0007 [25].

30 Department of Health, *Streamlined Consumer Assessment for Aged Care*, Discussion Paper, 2018, pp 4-5.

31 Australian Institute of Health and Welfare, *Pathways in Aged Care*, GEN Aged Care Data, updated: 9 August 2019, <https://www.gen-agedcaredata.gov.au/Topics/Pathways-in-aged-care>, viewed 18 July 2019.

32 Department of Health, *Fact Sheet: Commonwealth Home Support Programme (CHSP) aged care services*, 2018, pp 1-2.

33 Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, Annual Report, 2019, p 36.

The Commonwealth Home Support Programme is designed to provide relatively small amounts of support to a large number of older people.³⁴ Most eligible people access only one or two of the 17 available support services, based on advice from Regional Assessment Services.³⁵ The services are:

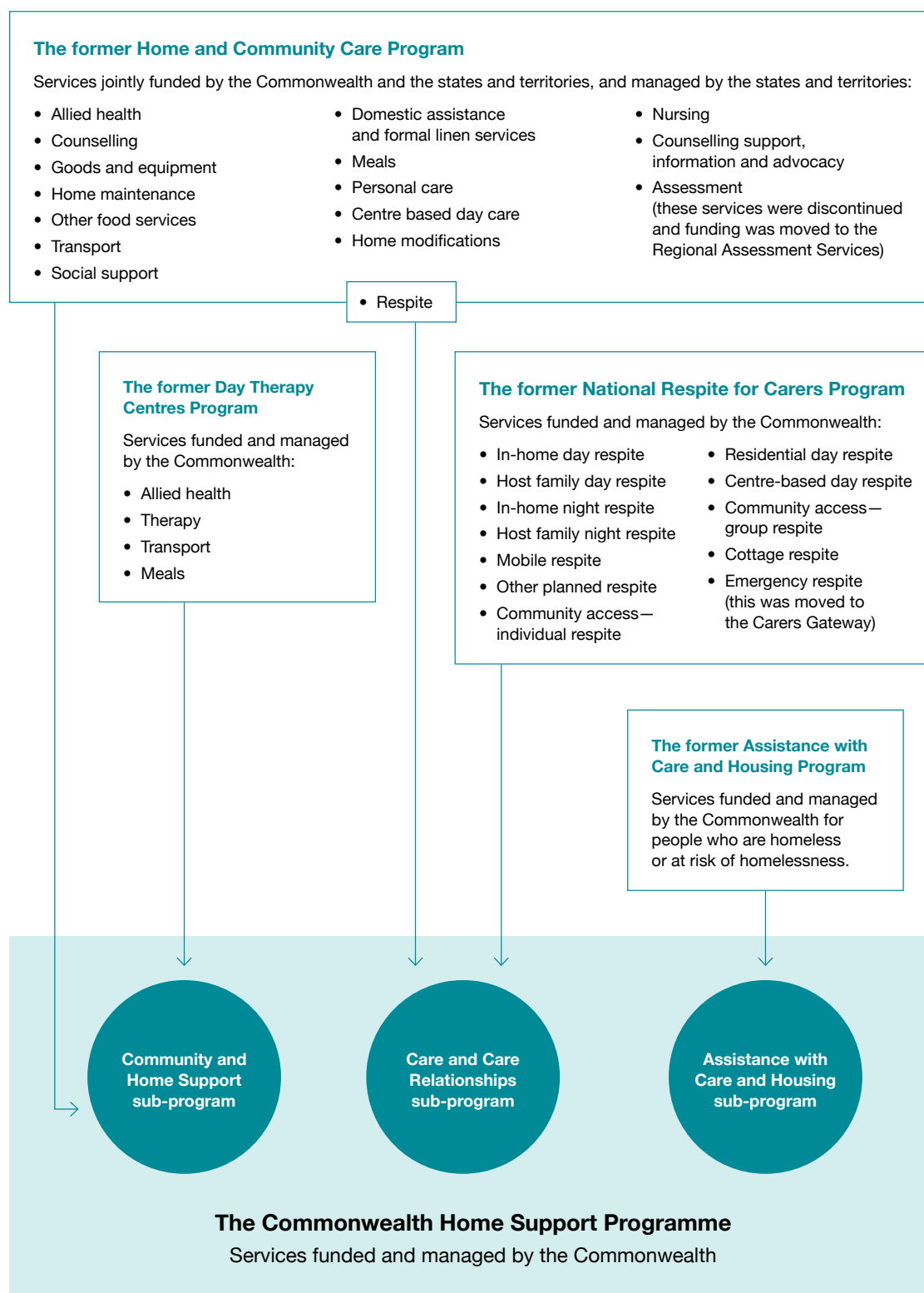
- allied health and therapy services
- domestic assistance
- goods, equipment and assistive technology
- home maintenance
- home modifications
- meals and other food services
- nursing
- personal care
- social support for an individual or group
- specialised support services
- transport
- centre-based respite, flexible respite and cottage respite
- assistance with care and housing (for people who are homeless or facing homelessness).

Figure 1.2 shows how this program consolidated Commonwealth-funded entry level assistance in the home, which helped people remain independent, with the National Respite for Carers Program and Day Therapy Centres Program. It continues to provide funding for one-off, occasional or time-limited support services.

34 Department of Health, *Commonwealth Home Support Programme*, Program Manual, 2018, p ii.

35 Department of Health, *Fact Sheet: Commonwealth Home Support Programme (CHSP) aged care services*, 2018, pp 1-2, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/Factsheet-PDFs-and-thumbnail/CHSP-Fact-Sheet-2017-18.pdf?ext=.pdf, viewed 25 August 2019.

Figure 1.2: Mapping of Commonwealth Home Support Programme



Source: Department of Health, *Mapping of former services to Commonwealth Home Support Programme Structure*, 2015, https://agedcare.health.gov.au/sites/default/files/documents/11_2015/chsp_taxonomy_-_november_2015.pdf, viewed 25 August 2019.

People most commonly access assistance with housekeeping (domestic assistance), followed by allied health and therapy services, transport to places out of walking distance and meals delivered to their home.³⁶ Not all providers deliver all services and older people may need to contact several different providers to get everything they need.

Most of the 1456 providers³⁷ delivering the Commonwealth Home Support Programme in 2017-18 had been delivering similar services under former aged care programs that were provided by the States and Territories up until 30 June 2012, or 30 June 2015 for Victoria and 30 June 2018 for Western Australia.³⁸

More coordinated care at home

Home Care Packages provide a more structured and comprehensive bundle of home-based care and support for older people with more complex needs. Packages differ from those services provided under the Commonwealth Home Support Programme, as they are individually tailored. However, a Package can, and often does, contain many of the same sorts of services as are available under the Commonwealth Home Support Programme.

In 2015, the Government announced that the two home-based programs—the Commonwealth Home Support Programme and the Home Care Packages Program—would be combined from mid-2018.³⁹ In May 2019, it was announced that they will continue to operate under separate program and user contribution arrangements until at least July 2022.⁴⁰ Although welcomed by providers, this delay from the original transition date of 2018 to 2022 increases complexity for older people and their families, and fails to create a seamless system of care provision in the home.

The Home Care Packages Program offers packages of care at one of four levels—known as Level 1, 2, 3 or 4 Packages—with the higher levels attracting greater government funding for more care (varying from \$8785.55 for a Level 1 to \$50,990.50 for a Level 4 per annum).⁴¹ Figure 1.3 shows the current number of people with a Home Care Package by level compared with the number of people that accessed a new Package in the June 2019 quarter. There are more Level 2 and 4 Packages, as these were historically the Community Aged Care Packages and the Extended Aged Care at Home packages respectively.

36 Exhibit 2-89, Adelaide Hearing 2, Statement of Fiona Kathryn Buffinton, 11 March 2019, WIT.0058.0001.0001 at 0005 [18].

37 Exhibit 2-89, Adelaide Hearing 2, Statement of Fiona Kathryn Buffinton, 11 March 2019, WIT.0058.0001.0001 at 0005 [20] – note: there were 91 providers delivering HACC services in Western Australia that are included in this count.

38 Exhibit 2-89, Adelaide Hearing 2, Statement of Fiona Kathryn Buffinton, 11 March 2019, WIT.0058.0001.0001 at 0006 [21].

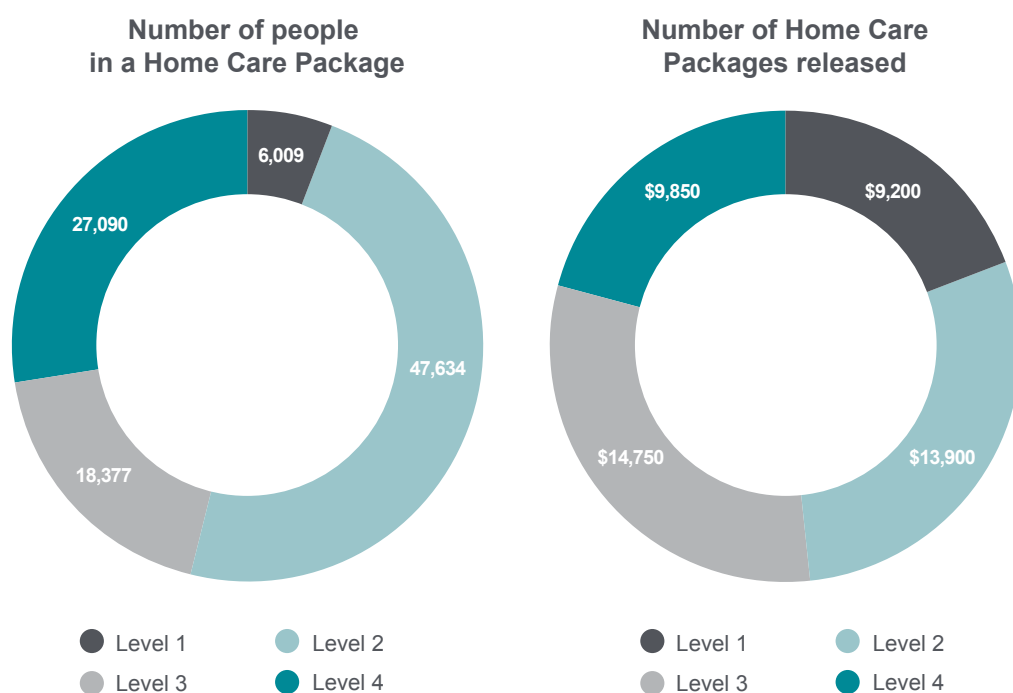
39 The Hon Mitch Fifield, *Certainty for Commonwealth Home Support Programme*, Media Release, updated: 15 June 2015, <https://formerministers.dss.gov.au/15468/certainty-for-commonwealth-home-support-programme/>, viewed 13 February 2019.

40 Department of Health, *Portfolio Budget Statements 2019-20: Budget Related Paper No. 1.9*, Health Portfolio, 2019, p 121.

41 Department of Health, *Aged Care Subsidies and Supplements: New Rates of Daily Payments from 1 July 2019*, 2019, https://agedcare.health.gov.au/sites/default/files/documents/06_2019/aged_care_subsidies_and_supplements_new_rates_of_daily_payments_from_1_july_2019.pdf, viewed 26 September 2019.

There are fewer Level 1 and 3 Packages as these were new additions in 2013. The Australian Government has been recently focused on growing the numbers of Level 3 and 4 Packages.⁴²

Figure 1.3: Home Care Packages 2018–19



Source: Department of Health, *Home Care Package Program*, Data Report 4th Quarter 2018–19, 2019, p 7, 14.

The average age of people taking up a Package was 80.8 years in 2017–18 and the number of people receiving a Package at 30 June 2018 was 91,847.⁴³ This was an increase of 20,424 (or 28.6%) from 30 June 2017.⁴⁴

Home Care Packages were the first component of the formal aged care system to become what is now described by the Australian Department of Health as ‘consumer-directed’. From mid-2015, the Australian Government has required that people receiving a Package be involved in decisions about their care, be respected and treated with dignity. This consumer direction is supposed to give people choices about the services they need, based on the professional advice of an assessor or provider.

42 Exhibit 1-23, Adelaide Hearing 1, Statement of Glenys Beauchamp, 4 February 2019, WIT.0022.0001.0001 at 0028 [119].

43 Department of Health, *2017–18 Report on the Operation of the Aged Care Act 1997*, 2018, p 29.

44 Department of Health, *2017–18 Report on the Operation of the Aged Care Act 1997*, 2018, p 29.

Services that may form part of a Home Care Package can include:

- personal services, such as help with showering or bathing, dressing and mobility
- 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, attending doctor's visits or social activities.
- clinical care, 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: coordinating care and services that will help consumers achieve the goals identified at the commencement of their Package.⁴⁵

The services a person will receive depends on the amount of money they have been allocated which in turn reflects the level of package for which a person is eligible.

The number of providers of Home Care Packages has nearly doubled since 2017, when Packages started being allocated to the older person instead of the provider.⁴⁶ This is because providers no longer have to compete for Home Care Packages through the Aged Care Approvals Round—a competitive tender process run by the Australian Department of Health—where a large number of applications were received for a limited number of packages. With the Package now going directly to the person, providers must only apply to be an 'approved provider' before they can advertise to potential clients.⁴⁷ The total number of Home Care Packages, nevertheless, remains tightly constrained by the Government.

Large numbers of older people who have been assessed as eligible for care are not able to access a Package in a timely way. The average length of time waiting for a Package is just over one year for half of the people on a Level 4 Package, and can be around three years for a quarter of people.⁴⁸ The Royal Commission has been told that unmet demand for home care is long-standing but was not quantified or visible until the implementation of the National Prioritisation Queue in 2017.⁴⁹ That does not in any way excuse the problem. Government policy is lagging well behind older people's collective needs for care. Given the long waiting periods for Packages, some people are being effectively forced to choose the option to access a lesser amount of care while they wait for their eligible level. This may include a lower level (such as a Level 2 Package), or the Commonwealth Home Support Programme.⁵⁰

45 Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, Annual Report, 2019, p 45.

46 Department of Health, *2017–18 Report on the Operation of the Aged Care Act 1997*, 2018, p 29.

47 Exhibit 2-78, Adelaide Hearing 2, Statement of Graeme Barden, 20 March 2019, WIT.1066.0001.0001 at 0003.

48 Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, Annual Report, 2019, p 38.

49 Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, Annual Report, 2019, p 34.

50 Department of Health, *Streamlined Consumer Assessment for Aged Care*, Discussion Paper, 2018, p 11.

Residential aged care

When a person is assessed as having a condition of frailty or disability requiring continuing personal care, they may be eligible for residential aged care. An Aged Care Assessment Team will make a recommendation on the best care setting for the person—whether this is in their home, a residential aged care facility or other location. Residential aged care can be provided on either a permanent or a temporary (respite) basis, with 24-hour support and accommodation, covering:

- assistance with everyday living activities such as cleaning, laundry, shopping and meals
- help getting dressed, grooming, eating and going to the toilet
- clinical care such as wound and catheter care, medication administration and pain management.

People entering residential aged care have the highest average age—83.4 years—of any of the three mainstream programs.⁵¹ In 2017–18, 241,723 people received permanent residential aged care at some time during the year, an increase of 2344 from 2016–17.⁵² A further 61,993 people received residential respite care.⁵³

As of 30 June 2018, there were 6045 people aged under 65 years living in residential aged care.⁵⁴ It is a matter of long-standing public policy interest and community concern that the disability service system is not providing appropriate support and services for these younger people and that they are inappropriately being admitted to aged care.

In 2017–18, there were 886 providers of residential aged care approved under the Aged Care Act. This means that the organisation has been determined as suitable to provide residential aged care by the Australian Department of Health. Approved providers ranged from small businesses to large national enterprises, with 56% of services provided by not-for-profit service providers. Much of the growth in aged care supply in recent years, however, has been in the growth of for-profit providers.⁵⁵ While the number of for-profit providers has remained stable, the number of places supplied by each for-profit provider has increased, indicating some consolidation in the aged care sector.⁵⁶ In 2017–18, most providers still operated only one aged care service, with only 21 providers operating more than 20 facilities.⁵⁷

51 Exhibit 1-23, Adelaide Hearing 1, Statement of Glenys Beauchamp, 4 February 2019, WIT.0022.0001.0001 at 0007 [35].

52 Department of Health, *2017–18 Report on the Operation of the Aged Care Act 1997*, 2018, p 43.

53 Department of Health, *2017–18 Report on the Operation of the Aged Care Act 1997*, 2018, p 37.

54 Productivity Commission, *Report on Government Services 2019: Services for people with disability*, 2019, table 15A.52.

55 Aged Care Financing Authority, *Sixth report on the Funding and Financing of the Aged Care Sector*, 2018, p 80.

56 Deloitte Access Economics, *Australia's aged care sector: economic contribution and future directions*, Aged Care Guild, 2016, p 3.

57 Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, Annual Report, 2019, p 63.

Alternative options

Eligibility for subsidised aged care may also cover some alternative options. These programs are designed to respond to the differing care needs of older people and can be provided in a facility or at home. They are:

- Transition Care—short-term care after a period in hospital
- Short-Term Restorative Care—early interventions that are aimed at slowing or reversing decline in function, characterised by time-limited, goal orientated and multidisciplinary interventions
- Multi-Purpose Services—a mix of aged care and health services tailored to meet local community needs, in rural and remote communities
- National Aboriginal and Torres Strait Islander Flexible Aged Care Program services—culturally appropriate care for Aboriginal and Torres Strait Islander communities.

There are also two alternative programs available for veterans in their own homes: Veterans' Home Care and the Community Nursing Program.

Funding and financing Australia's aged care

The formal aged care system is funded through a combination of universal taxation and means-tested user contributions (or fees). Most aged care consumers contribute to the cost of their care.⁵⁸ User contributions represented one-fifth of the total expenditure across the major aged care programs in 2017–18, and Government spending made up the rest.⁵⁹ This raises issues of affordability and sustainability. These are issues that the Royal Commission will consider in depth in future hearings and our Final Report.

Australian Government expenditure for aged care totalled \$18.1 billion in 2017–18.⁶⁰ Funding of \$12.2 billion was directed to residential aged care and \$4.9 billion was split between Home Care Packages, the Commonwealth Home Support Programme and several other programs providing support at home.⁶¹ The remainder of funding went to a range of other functions, including several smaller aged care programs as well as assessment, information and aged care quality.⁶²

58 Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, Annual Report, 2019, p 13.

59 Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, Annual Report, 2019, p. 6, 11, https://agedcare.health.gov.au/sites/default/files/documents/08_2019/acfa-seventh-report-2019-acc.pdf, viewed 25 September 2019. Calculation based on revenue of \$22.6 billion, with \$18.1 in Australian Government funding.

60 Department of Health, *2017–18 Report on the Operation of the Aged Care Act 1997*, 2018, p 8.

61 Australian Institute of Health and Welfare, *Aged Care Data Snapshot 2018 – 6th release*, 2018, data from the Australian Government Department of Health, Canberra, [https://www.gen-agedcaredata.gov.au/www_ahwgen/media/Data-Snapshot/Aged-Care-Data-Snapshot-2018-6th-release-\(final\).xlsx](https://www.gen-agedcaredata.gov.au/www_ahwgen/media/Data-Snapshot/Aged-Care-Data-Snapshot-2018-6th-release-(final).xlsx), viewed 25 September 2019. The other home support programs are: the Commonwealth's contribution to the WA HACC program; and the DVA administered Veterans' Home Care and Home Nursing programs.

62 For example, Multi-Purpose Services, the National Aboriginal and Torres Strait Islander Flexible Aged Care Program, and Transition Care.

There has been a consistent focus on rebalancing the formal aged care system towards home care over the last decade because older people have expressed the desire to live in their own homes for as long as possible. There has even been additional expenditure on Home Care Packages announced before and during this Royal Commission, reflecting demand pressures.

Australian Government funding for residential aged care comprises:

- a basic care subsidy for personal and nursing care
- supplements paid to support aspects of care that incur higher costs—for example, for needs such as enteral feeding, oxygen, and for the care of special needs groups
- the maximum rate of accommodation supplement for those residents who cannot afford to pay their accommodation costs.⁶³

The majority of residential care funding is made up of the basic care subsidy. For permanent residential care, this is determined by providers appraising the care needs of their residents by applying the Aged Care Funding Instrument. The Aged Care Funding Instrument assesses the care needs of permanent residents by allocating funding around the three main areas that differentiate relative care needs among residents—rating from nil, low, medium or high in each of the three domains of activities of daily living, behaviour, and complex health care.⁶⁴ As at 1 July 2019, subsidies provided under the Funding Instrument ranged from \$0 per day for those with the lowest care needs (nil in all three domains) to \$219.62 per day for those with the highest care needs (high in all three domains).⁶⁵

Total personal or private contributions amounted to \$3.8 billion towards the costs of living expenses and care in residential aged care in 2017–18 with a further \$780 million for accommodation costs. User payments comprised more than a quarter of the total funding in residential care.⁶⁶

Compared with the two main aged care programs provided at home, residential aged care is much more expensive for the person going into care because they are asked to contribute to their daily living expenses, to their care and for their accommodation.⁶⁷ People contribute the equivalent of 85% of the single age pension for daily living expenses, such as meals, laundry, utilities and toiletries. This is calculated as a daily fee of \$51.63. A means-tested care fee also applies for part-pensioners and wholly self-funded retirees, up to a maximum of \$27,754.52 per annum.⁶⁸

63 Department of Health, *2017–18 Report on the Operation of the Aged Care Act 1997*, 2018, pp 45–46.

64 Department of Health, *Aged Care Funding Instrument (ACFI) Reports*, updated: 13 September 2019, www.agedcare.health.gov.au/tools-and-resources/aged-care-funding-instrument-acfi-reports, viewed 19 September 2019.

65 Department of Health, *Schedule of subsidies and supplements from 1 July 2019*, 2019, p 3.

66 Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, Annual Report, 2019, p 13.

67 Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, Annual Report, 2019, p 22.

68 Department of Health, *Schedule of Fees and Charges for Residential and Home Care: From 20 September 2019*, 2019, https://agedcare.health.gov.au/sites/default/files/documents/09_2019/schedule_of_fees_and_charges_for_residential_and_home_care_from_20_september_2019.pdf, accessed 26 September 2019

Whether or not a person is required to contribute to their accommodation costs depends on their income and assets. For example, home ownership could result in payment of a refundable accommodation deposit (or the equivalent daily payment). This was, on average, \$331,117 in 2017–18, but it can be much more, depending on the room on offer or the location of the residential care home. For those people with no assets, a contribution of up to \$57.14 per day is made by the Government on their behalf to the provider for accommodation.⁶⁹

In home care, user contributions make up less of the total funding available. In 2017–18, older people contributed \$122 million to the Home Care Packages program, representing around 6% of the total program funding.⁷⁰ User contributions in home care include up to \$10.54 as a daily fee. An income tested care fee also applies for part pensioners and self-funded retirees up to a maximum of \$11,101.81 per annum. In 2017–18, a total of \$219.5 million in user contributions was reported for the Commonwealth Home Support Programme, representing less than 10% of the total program.⁷¹

Aged care quality and safety

Australians want older people to have access to safe and high quality aged care. An effective regulatory system will deter, detect and respond appropriately to actions that have the potential to cause harm or which do not keep older people safe. The primary purpose of aged care regulation is to protect and enhance the health, safety and wellbeing of people receiving care. Regulation in aged care should consistently provide assurance that the most frail and vulnerable people in the community are protected while in care.

Quality framework

The regulatory framework that applies to aged care safety and quality in Australia is multi-layered and complex. It includes:

- approval of providers as suitable to provide care
- assessment of people as eligible to receive care
- funding and financing arrangements
- accreditation and quality review processes
- enforcement and sanctions
- complaints processes
- advocacy and community visitors.

69 Department of Health, *Schedule of subsidies and supplements from 1 July 2019*, 2019, p 5; My Aged Care, *Fee estimator*, updated: 2019, <https://www.myagedcare.gov.au/fee-estimator>, verified 25 September 2019.

70 Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, Annual Report, 2019, pp 7, 69.

71 Department of Health, *CHSP Fees Clients and HC Final*, 11 March 2019, CTH.1000.0002.5735.

Until 2019, the aged care regulatory framework was primarily administered by three Australian Government agencies: the Australian Department of Health, the Australian Aged Care Quality Agency and the Aged Care Complaints Commissioner.

An independent 2017 review, carried out by Ms Kate Carnell AO and Professor Ron Paterson ONZM following the revelations of abuse and neglect at the Oakden Older Persons Mental Health Facility in South Australia, recommended a number of changes to the aged care regulatory system, including establishment of an independent Aged Care Quality and Safety Commission. That review, titled *Review of National Aged Care Quality Regulatory Processes* (and referred to as the Carnell-Paterson review), explored the regulation of aged care. The Australian Government announced broad support for the recommendations of the Carnell-Paterson review, and established the Aged Care Quality and Safety Commission. The Government has yet to respond to all recommendations and has indicated that it will not pursue all of them.⁷²

The Aged Care Act and the *Aged Care Quality and Safety Commission Act 2018* (Cth) provide the legislative framework for aged care regulation. Subordinate to the Aged Care Act is a complex suite of legislative instruments known as Principles that contain detail about the operation and regulation of the aged care system.⁷³ The Principles—such as the *Accountability Principles 2014* (Cth), *User Rights Principles 2014* (Cth) and *Quality of Care Principles 2014* (Cth)—specify certain obligations, including the care and services that must be provided to older people in aged care. The Principles, as well as other regulatory documents, also contain certain standards against which compliance is measured.⁷⁴

These regulatory arrangements apply to all providers that have been approved to operate under the Aged Care Act—that is, providers of residential aged care and Home Care Packages. Those not operating under the Aged Care Act—providers of the Commonwealth Home Support Programme and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program—are subject to different processes for compliance, although the services are covered by the Quality Principles and relevant Standards.⁷⁵

72 The Hon Ken Wyatt AM, MP, *Powerful New Reforms to Ensure Safe, Quality Aged Care*, Media Release, 18 April 2018.

73 *Aged Care Act 1997* (Cth) s 96-1.

74 Exhibit 1-38, Adelaide Hearing 1, Statement of Janet Mary Anderson, 4 February 2019, WIT.0023.0001.0001at 0005, 0006 [24].

75 Exhibit 1-23, Adelaide Hearing 1, Statement of Glenys Beauchamp, 4 February 2019, WIT.0022.0001.0001 at 0004, 0005 [21]-[23].

The Australian Department of Health has responsibility for aged care policy, funding and administration, as well as some regulatory functions, including approval of providers, enforcement of providers' responsibilities and the issuing of sanctions.⁷⁶ The Aged Care Quality and Safety Commission commenced operations on 1 January 2019 taking on the roles previously performed by the Australian Aged Care Quality Agency and the Aged Care Complaints Commissioner.⁷⁷ Its functions are to:

- protect and enhance the safety, health, wellbeing and quality of life of aged care consumers
- promote the provision of quality care and services in aged care
- provide consumer engagement
- receive/investigate complaints
- provide regulatory functions
- provide education.⁷⁸

The focus of the Aged Care Quality and Safety Commission is on compliance with the Standards within individual aged care services. The Australian Department of Health's role is focused on compliance at the broader level of approved providers. In managing non-compliance, the Department's focus is to return the provider to compliance as soon as possible.⁷⁹

Residential aged care quality and safety

The current regulatory model for residential aged care is centred on an accreditation system that involves the cyclical review of approved providers against minimum standards.⁸⁰ Prior to 30 June 2019, residential care providers were assessed against four Accreditation Standards. A single set of Aged Care Quality Standards was put in place from July 2019. It comprises eight Quality Standards, with each Quality Standard including a statement of the outcome for the consumer, expectations of the provider and requirements to be achieved.⁸¹ These Quality Standards replaced the Accreditation Standards for residential aged care and the Home Care Standards for packages and the Commonwealth Home Support Programme, creating a single quality and safety standards regime.

76 From 1 January 2020, subject to the passage of legislation, the Aged Care Quality and Safety Commission will also take on the provider approval and compliance functions of the Department of Health.

77 The Hon Ken Wyatt AM, MP, *New Commission, new era for aged care quality and safety*, Media Release, 2 January 2019.

78 *Aged Care Quality and Safety Commission Act 2018* (Cth) s 16.

79 K Carnell and R Paterson, *Review of National Aged Care Quality Regulatory Processes*, 2017, p 19.

80 Exhibit 1-23, Adelaide Hearing 1, Statement of Glenys Beauchamp, 4 February 2019, WIT.0022.0001.0001 at 0018, 0019 [81]-[84]; Exhibit 1-38, Adelaide Hearing 1, Statement of Janet Mary Anderson, 4 February 2019, WIT.0023.0001.0001 at 0005, 0013 [24]-[58].

81 *Quality of Care Principles 2014* (Cth), made under the *Aged Care Act 1997* (Cth) s 96-1.

Assessments of provider performance against the standards by the Aged Care Quality and Safety Commission are currently presented as a simple ‘met’ or ‘not met’ rating, with assessors visiting the facility to conduct assessments and follow-up site audits. From 2011, assessment contact visits to residential aged care facilities had to be unannounced and from 1 July 2018 this was extended to site audits.⁸² Where the Aged Care Quality and Safety Commission finds that a provider is not meeting one of more of the standards:

- the Aged Care Quality and Safety Commission may decide that failure to meet the standards has placed or may place the safety, health or wellbeing of older people in care at serious risk (often referred to as a serious risk finding) and, if so, not accredit or not re-accredit a service, and may also revoke accreditation⁸³
- the Australian Department of Health may also act where it finds there is an immediate and severe risk to the health, safety or wellbeing of older people in care or where a service does not rectify its non-compliance; this can include issuing a notice of non-compliance or imposing sanctions.⁸⁴

Findings of non-compliance with the standards are relatively unusual. Since 2013, serious risk findings and sanctions have been rare, but have increased rapidly in the last two financial years. Between July 2013 and June 2017, the Australian Aged Care Quality Agency made only 41 serious risk findings and revoked the accreditation for only three providers.⁸⁵ In contrast, there were 61 serious risk findings and 12 revocations in 2017–18 alone, the year after the Oakden scandal came to light.⁸⁶ In 2018–19, there were nine revocations and there was a major increase in serious risk findings to 168 across the year.⁸⁷ There were 2725 residential care facilities across Australia at 30 June 2019.⁸⁸

82 A Grove, *Changes to quality and compliance visits for nursing homes*, Parliament of Australia, 12 February 2018, https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/FlagPost/2018/February/nursing_home_quality_and_compliance_visits, verified 25 September 2019.

83 Exhibit 1-38, Adelaide Hearing 1, Statement of Janet Anderson, WIT.0023.0001.0001 at 0009 [36-40].

84 Exhibit 1-23, Adelaide Hearing 1, Statement of Glenys Beauchamp, 4 February 2019, WIT.0022.0001.0001 at 0021 [99-100].

85 Exhibit 1-38, Adelaide Hearing 1, CTH.0001.4000.2192, *Regulatory and Complaints Statistics 2013-2018*.

86 Australian Aged Care Quality Agency, *Annual Report 2017–18*, 2018, https://www.agedcarequality.gov.au/sites/default/files/media/aacqa_annual_report_2017-18.pdf, viewed 26 September 2019, pp 25, 28.

87 Exhibit 8-27, Brisbane Hearing, Brisbane General Tender Bundle, Tab 146, CTH.0001.1000.8094, *Aged Care Regulation in Quality – Activity and Actions* (accurate as at 18 July 2019), excluding 10 serious risk findings for home care issued during this period as identified in Aged Care Quality and Safety Commission, *Sector Performance Data*, Australian Government, 2019, <https://www.agedcarequality.gov.au/sector-performance>, 1 July to 31 December 2018 (Tables 10 and 11), January to 30 March 2019 (Tables 10 and 11), April to 30 June 2019 (Tables 10 and 11), viewed 30 September 2019.

88 Aged Care Quality and Safety Commission, *Sector Performance Data*, Australian Government, 2019, <https://www.agedcarequality.gov.au/sector-performance>, 1 April to 30 June 2019, p 1, viewed 26 September 2019.

Across the four years from July 2013 to June 2017, the Australian Department of Health issued 33 notices of decision to impose sanctions.⁸⁹ In 2017–18 alone, after the Oakden scandal, the Department issued 25 sanctions, and this substantially increased again in 2018–19 to 51 sanctions.⁹⁰ These substantial changes over time warrant close attention.

The Aged Care Act also requires approved providers of residential aged care to report allegations or suspicions of physical or sexual assault to police and the Australian Department of Health as soon as reasonably practicable and within 24 hours.⁹¹ There is a discretion given to the provider not to report where the alleged perpetrator is a resident with a cognitive or mental impairment and the provider has put in place care arrangements to manage behaviour within 24 hours.⁹²

Quality and safety in home and community care

Once approved or contracted by the Commonwealth, a provider can supply home care or home support services prior to any quality review process being undertaken by the Aged Care Quality and Safety Commission. A quality review is undertaken at some point after the service has commenced operations, and providers may operate for many months before they are subjected to such a quality review.⁹³

As at 30 June 2019, a total of 159 approved providers had not had a quality review for any of their active care at home services.⁹⁴ Over the three-year period from 30 June 2014 to 1 July 2018, the chance of a home care service failing a quality Standard was less than 1%.⁹⁵ Only a small number of providers of care in the home are ever sanctioned for non-compliance—only two home care providers were sanctioned in 2018–19.⁹⁶

89 Exhibit 8-27, Brisbane Hearing, Brisbane General Tender Bundle, Tab 146, CTH.0001.1000.8094, *Aged Care Regulation in Quality – Activity and Actions* (accurate as at 18 July 2019), excluding three sanctions for home care issued during this period as identified in Exhibit 8-27, Brisbane Hearing, Brisbane General Tender Bundle, Tab 147 CTH.0001.1000.7914, *Department of Health's Response to NTG-0280 Categories 1,2,6, 8 and 10*, Annexure B.

90 Exhibit 8-27, Brisbane Hearing, Brisbane General Tender Bundle, Tab 146, CTH.0001.1000.8094, *Aged Care Regulation in Quality – Activity and Actions* (accurate as at 18 July 2019) excluding two sanctions in 2018-19 and one in 2017-18 for home care as identified in Exhibit 8-27, Brisbane Hearing, Brisbane General Tender Bundle, Tab 147 CTH.0001.1000.7914, *Department of Health's Response to NTG-0280 Categories 1,2,6, 8 and 10*, Annexure B.

91 *Aged Care Act 1997* (Cth) s 63-1AA.

92 *Accountability Principles 2014* (Cth), s 25(2), s 52-53.

93 Exhibit 8-27, Brisbane Hearing, Brisbane General Tender Bundle, Tab 7 CTH.0001.4001.9469, *Department of Health's Response to NTG-0281*.

94 Exhibit 8-27, Brisbane Hearing, Brisbane General Tender Bundle, Tab 7 CTH.0001.4001.9469, *Department of Health's Response to NTG-0281*.

95 Calculations based on: home care assessment contact and quality review data in Exhibit 8-27, Brisbane Hearing, Brisbane General Tender Bundle, Tab 7 CTH.0001.4001.9469, *Department of Health's Response to NTG-0281*; and sanctions data in Exhibit 8-27, Brisbane Hearing, Brisbane General Tender Bundle, Tab 147 CTH.0001.1000.7914, *Department of Health's Response to NTG-0280 Categories 1,2,6, 8 and 10*, Annexure B.

96 Tab 147 CTH.0001.1000.7914, *Department of Health's Response to NTG-0280 Categories 1, 2, 6, 8 and 10*, Annexure B. See also: A Donnellan, *Home care industry faces crack down amid concerns over quality of providers*, ABC News, 8 January 2019, <https://www.abc.net.au/news/2019-01-08/home-care-industry-faces-crackdown/10697638>, verified 25 September 2019.

In 2011, the Productivity Commission observed that as the number of people wanting to be cared for at home increased, the regulation of this care would become increasingly important and would be challenging for the Government.⁹⁷ Commonwealth witnesses have acknowledged in Royal Commission hearings that the regulation of care in the home is less developed than the regime that applies to residential care.⁹⁸

The place of the individual in the aged care system

The origins of the current residential aged care regulatory framework date back to changes to residential care in the mid-1980s and late-1990s. Those changes are seen by some as having led to substantial improvements in the quality of care.⁹⁹ Quality arrangements for care delivered in the home are much less onerous than those in residential aged care and have varied significantly both within and across programs.¹⁰⁰ The Aged Care Quality and Safety Commission says that the new Aged Care Quality Standards ‘reflect the level of care and services the community can expect from organisations that provide Commonwealth subsidised aged care services’.¹⁰¹ It argues that the stronger focus on consumer outcomes in the new Standards represents a shift toward a more person-centred approach in aged care.

The Charter of Aged Care Rights has also been updated, with effect from 1 July 2019.¹⁰² The Charter aims to build an understanding of the rights of people receiving aged care, and to provide protections for those rights. The new Charter replaced four separate charters that were slightly different depending on the program people accessed. Providers must comply with the Charter, in addition to the Standards. Sanctions can be imposed on an approved provider if it is found to have acted in a way that is inconsistent with any of the rights that are specified in the Charter.¹⁰³

97 Productivity Commission, *Caring for Older Australians*, Productivity Commission Inquiry Report No 53, Volume 2, 2011, p 186.

98 Exhibit 2-89, Adelaide Hearing 2, Statement of Fiona Kathryn Buffinton, 11 March 2019, WIT.0058.0001.0001 at 0009, 0010 [26]-[29]; Exhibit 1-23, Adelaide Hearing 1, Statement of Glenys Beauchamp, 4 February 2019, WIT.0022.0001.0001 at 0020 [94].

99 L Gray, D Cullen and H Lomas, *Regulating long-term care quality in Australia*, Regulating Long-Term Care Quality: An International Comparison, 2014, p 158.

100 L Gray, D Cullen and H Lomas, *Regulating long-term care quality in Australia*, Regulating Long-Term Care Quality: An International Comparison, 2014, p 163.

101 Aged Care Quality and Safety Commission, *About the Aged Care Standards*, updated: 9 September 2019, <https://www.agedcarequality.gov.au/standards/guidance-introduction>, viewed 17 September 2019.

102 *User Rights Principles 2014* (Cth) sch 1.

103 *Aged Care Act 1997* (Cth) ss 56-1(m), 65-1.

An important aspect of the Charter is to ensure people know they can complain to their provider or to the Aged Care Quality and Safety Commission. Complaints and concerns can be raised about providers of any Commonwealth-funded residential or respite care, Home Care Packages, Commonwealth Home Support Programme services and flexible care, and can be raised openly, anonymously or confidentially. The Aged Care Quality and Safety Commission is required to respond to each issue in a complaint and can commence a resolution process.¹⁰⁴ The Royal Commission has heard much to show that, in practice, the complaints system is difficult to access and can be unresponsive to the concerns of complainants. Worst, we heard that people fear reprisals against those who complain by withdrawing care or otherwise mistreating the person receiving care.

In 2018–19, there were 7828 formal complaints, an increase of 35% from 2017–18. There were 5748 complaints about residential care, which accounted for 73% of all complaints.¹⁰⁵ A breakdown of complaints for the last quarter of 2018–19, shows that for residential aged care the issues most commonly subject to complaint were medication administration and management (308), falls prevention and management (213), personal and oral hygiene (190), personnel numbers/ratio (187) and continence management (139).¹⁰⁶ In home care across the last quarter in 2018–19, the issues most commonly subject to complaint were fees and charges (112), consistent client care (89), lack of consultation (74), management of finances (57) and complaints about domestic assistance (51).¹⁰⁷

104 Exhibit 1-38, Adelaide Hearing 1, Statement of Janet Mary Anderson, 4 February 2019, WIT.0023.0001.0001 at 0007 [29]–[30].

105 Exhibit 8-27, Brisbane Hearing, Brisbane General Tender Bundle, Tab 146 CTH.0001.1000.8094, *Aged Care Regulation in Quality – Activity and Actions*, p 1 (accurate as at 18 July 2019).

106 Aged Care Quality and Safety Commission, *Sector Performance Data*, Australian Government, 2019, <https://www.agedcarequality.gov.au/sector-performance>, 1 April to 30 June 2019, Table 23, viewed 26 September 2019.

107 Aged Care Quality and Safety Commission, *Sector Performance Data*, Australian Government, 2019, <https://www.agedcarequality.gov.au/sector-performance>, 1 April to 30 June 2019, Table 24, viewed 26 September 2019.

Conclusion

Since Federation, the history of aged care in Australia has seen the progressive movement of the Australian Government into the field and its eventual assumption of full policy, funding and regulatory responsibility. Over the last four decades, there have been many changes to the Australian aged care system, some very large, some incremental. The system is continually being shaped, and new initiatives have been announced since the Royal Commission began its work.

The result of these frequent changes, combined with the frequency of reviews and inquiries into the system, is a complex, confusing, bureaucratic maze. Despite all the rhetoric about ‘choice’ and ‘consumer-directed care’, the person needing aged care is far from being the central focus of the system. The Royal Commission will have more to say about the design and structure of the system in our Final Report.

The Royal Commission acknowledges the many dedicated people currently providing aged care services, and the important contributions of family, friends, neighbours, volunteers and communities.

The Secretary of the Australian Department of Health told the Royal Commission that ‘based on the evidence and information available to the Department...serious instances of substandard care do not appear to be widespread or frequent’.¹⁰⁸ We beg to differ.

The personal experiences of older people and their friends and families, which have been provided to the Royal Commission through submissions and hearings and at community forums, suggest that the quality of care provided within Australia’s aged care system is variable. The quality of aged care can fall well short of expectations and, at worst, allow substandard care to occur.

The Australian aged care system should be a system which has services that are compassionate, fit for purpose, customised to individual needs and of the highest standards in terms of quality and safety. We must recognise the uniquely individual circumstances for each person receiving aged care.

The Royal Commission will continue to monitor the system very closely before making recommendations in our Final Report that start with the principle that older people deserve high quality care that is respectful and which upholds their wellbeing and dignity.

108 Exhibit 1-23, Adelaide Hearing 1, Statement of Glenys Beauchamp, 4 February 2019, WIT.0022.0001.0001 at 0037 [163].

2. The Well-travelled Path

I am left with a sense that the 10 recommendations have all been accepted in principle but the devil is in the detail and I can't help suspecting that some of them are not actually being progressed and, given what we're talking about here, given what this whole Royal Commission is about and given what we were reviewing, I think one needs to go back to the rationale for the recommendations. I believe there is still force to them but, of course, that is a matter that will now be revisited by this Royal Commission.¹

Introduction

The aged care system has been reviewed repeatedly, with more than 35 major public reviews over the past 40 years. Many more internal reviews, studies and consultancies into aspects of the aged care system have also been commissioned by the Australian Department of Health. Despite these frequent examinations, instances of substandard care recur at distressingly frequent intervals.

In October 2019, the Royal Commission released *Background Paper 8: A history of aged care reviews*, which provides an in-depth overview of the reviews into the aged care system and a record of the Government action that has followed from the most recent of them. In this chapter, we consider the reviews and inquiries over the past four decades, placing more emphasis on the most recent of them.

This chapter should be read in conjunction with Chapter 1, which, in part, provides a history of major changes in the aged care sector. Together, these chapters show that many of the issues identified in previous reviews and inquiries persist, despite the actions of successive governments.

Successive reviews and inquiries

The Aged Care Royal Commission is not operating in a vacuum. There is a long and rich history of previous reviews and inquiries into various aspects of the aged care system at both an Australian Government and State and Territory level. Our Terms of Reference direct us to have regard to the findings and recommendations of previous relevant reports and inquiries. Our examination of these inquiries and reports has provided us with an

¹ Transcript, Ron Paterson, Brisbane Hearing, 7 August 2019 at T4603.8-15.

insight into the often ad hoc changes that have been made to the aged care system over time.² This examination has also shown the problems, particularly with respect to quality and safety, which continue to plague the system. These problems include:

- the difficulty people have in understanding and navigating the aged care system
- the need for improved advocacy services for older people
- the lack of coordination in care and services provided to older people, whether this involves different levels of government or different types of services
- 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 are still living at home
- poor quality of care right across the aged care system, but most marked in the care provided to people with dementia and other cognitive disabilities
- the excessive use of chemical (that is, sedatives, psychotropic medication and other drugs) and physical restraints by residential aged care providers
- serious current and projected shortages of nursing and personal care workers
- ineffective regulatory oversight of aged care providers, and a lack of focus on the quality of care
- the absence of any rating or assessment system for providers that can give older people and their families accurate, or any, information about the services they are seeking to access
- complaints mechanisms that are difficult to access, a lack of responsiveness by the Commonwealth complaints authority and situations where people fear to make a complaint because of the risk of retaliation by the service provider
- inadequate access to, and integration with, the broader health care system, impacting on the health outcomes of older people
- failings in the quality of the care provided for people who are close to death.

As the Royal Commission has investigated specific themes, including clinical and personal care, quality of life, palliative care, dementia care, and regulation, we have considered the relevant views and recommendations of previous reviews and inquiries. These have informed the direction of our investigations. Where appropriate, witnesses have been, and will continue to be, called in relation to previous reviews and inquiries. For example, on 7 August 2019, at the Brisbane Hearing, the Royal Commission heard from Professor Ron Paterson, who, with Ms Kate Carnell AO, authored the 2017 *Review of National Aged Care Quality Regulatory Processes* (the Carnell-Paterson review) to explore his insights into the regulation of aged care. The Royal Commission will continue to take appropriate account of these previous reviews and inquiries in the context of its investigations, deliberations and recommendations in the next twelve months.

2 Productivity Commission, *Caring for Older Australians*, Inquiry Report, 2011, Vol 1, p 13.

Many of the previous reviews and inquiries relevant to the Royal Commission's Terms of Reference have been conducted by Parliamentary Committees. In line with the requirements set out in s16(1) of the *Parliamentary Privileges Act 1987* (Cth), the Royal Commission draws on the findings and recommendations of those reports as background information. Nothing in this chapter, or the Interim Report more generally, is intended to draw, or invite the drawing of, inferences or conclusions wholly or partly from those reports. This approach has been confirmed as appropriate by the presiding officers of Parliament.³

It should not be inferred that the Royal Commission agrees, or disagrees, with the recommendations of all of the reviews and inquiries discussed in this chapter. The Royal Commission's recommendations with respect to the topics relevant to our Terms of Reference will be determined in due course and will be informed by a detailed analysis of all of the evidence available. The larger point is that there appears to have been multiple recommendations about issues that continue to plague the aged care sector.

Structural reform

Public concern about nursing home scandals in the late 1970s and early 1980s led to a series of major reviews of the aged care system. Many of the media articles on nursing homes at the time raised serious allegations of ill-treatment or lack of care and painted a bleak and depressing picture of the quality of life in nursing homes.⁴ An Auditor-General's report in 1981 questioned whether the Australian Government's nursing home programs were delivering value for money.⁵ Parliamentary inquiries looked at accommodation and home care for the aged⁶ and the administration and operation of nursing homes.⁷ These reports criticised the quality of care in nursing homes and the adequacy of its regulation.⁸

In 1986, the Australian Government introduced major changes to the aged care system directed at moderating the growth of nursing homes and encouraging hostel and home care for the aged.⁹ Nursing homes were then firmly based on a health model and provided 24-hour nursing care, while hostels developed within a social services model

3 Correspondence between the Honourable Richard Tracey AM RFD QC and Ms Lynelle Briggs AO and the presiding officers of the Parliament: Senator the Hon. Scott Ryan, President of the Senate, and the Hon. Tony Smith MP, Speaker of the House of Representatives, 7 March 2019 and 16 May 2019.

4 Senate Standing Committee, *Private Nursing Homes in Australia: their conduct, administration and ownership*, Parliament of Australia, 1985.

5 Auditor-General, *Efficiency Audit: Commonwealth Administration of Nursing Home Programs*, Parliamentary Paper No 12, 1981.

6 House of Representatives Standing Committee on Expenditure, *In a Home or At Home: Accommodation and Home Care for the Aged*, Parliamentary Paper No 292, 1984.

7 Senate Select Committee on Private Hospitals and Nursing Homes, *Private Nursing Homes in Australia: Their Conduct, Administration and Ownership*, the Parliament of the Commonwealth of Australia, 1985.

8 J Braithwaite, T Makkai and V Braithwaite, *Regulating Aged Care: Ritualism and the New Pyramid*, 2007, pp 3536.

9 R Le Guen, *Residential Care for the Aged: An overview of Government policy from 1962 to 1993*, *Parliamentary Research Service: Background Paper No 32*, 1993, p 1.

and provided living support but not nursing care. The changes in 1986 included the provision of more Commonwealth funding for home and community care as an attempt to reduce inappropriate admissions to residential aged care,¹⁰ and also served to reduce some of the funding burden on the States and Territories.

A system in crisis

The policy focus in the late 1980s and early 1990s shifted to addressing concerns about the sustainability of growth of the nursing home industry and about a trend toward institutionalisation of the elderly.¹¹ This was underpinned by an increased awareness of an ageing population and concerns that the existing aged care system could not adequately service the future needs of older Australians. As the aged care system was primarily Commonwealth funded, the expected growth in demand for aged care in the coming years had serious implications for the Federal Budget.¹²

Another series of reviews and inquiries in the 1990s identified continuing problems with the aged care system, including the dominance of institutional care, a lack of choice in care, an inadequate supply of home and community-based services, a lack of coordination, inefficiencies in the system, and the unequal distribution of services by geographical area.¹³

Prominent among these reviews was the 1993 Gregory Review of the funding structure for nursing homes, which found that the existing administrative and funding arrangements were incapable of responding effectively to the changing needs of older Australians and the aged care sector.¹⁴ This review discussed options for addressing rigidities and administrative costs in the aged care system but cautioned that market-based proposals (such as removing acquittal requirements for providers)¹⁵ could jeopardise the ability of the funding system to ensure proper levels of quality care.¹⁶ Two years later, the National Commission of Audit made the case for increased efficiencies in the system and expanding consumer choice.¹⁷ The objectives of expanding the market and increasing consumer choice identified in these reviews were reflected in the subsequent 1997 changes to the system.¹⁸

10 R Le Guen, 'Residential Care for the Aged: An overview of Government policy from 1962 to 1993', *Parliamentary Research Service: Background Paper No 32*, 1993, p 1.

11 J Clare, A De Bellis and D Jarrett, 'Planning aged care in Australia: a review and critique of the reforms 1975–96', *Collegian: The Australian Journal of Nursing Practice, Scholarship and Research*, 1997, Vol 42 Ed 1, pp 22–29.

12 DJ Cullen, *Historical Perspectives: – the evolution of the Australian Government's involvement in supporting the needs of older people*, Australian Government Department of Health and Ageing, 2003, p.72.

13 D Gibson, 'Reforming Aged Care in Australia: Change and Consequence', *Journal of Social Policy, Cambridge University Press*, 1996, Vol 25, Ed 2, pp 157–79.

14 R Gregory, *Review of the Structure of Nursing Home Funding Arrangements: Stage 1*, Department of Human Services and Health, 1993.

15 Acquittal requirements oblige providers to account for how government money has been spent.

16 R Gregory, *Review of the Structure of Nursing Home Funding Arrangement: Stage 1*, Department of Human Services and Health, 1993, pp. 21, 32, 79.

17 National Commission of Audit, 'Health and Health Related Services', *Commonwealth of Australia*, June 1996, <https://www.finance.gov.au/archive/archive-of-publications/ncoa/appc.htm>, viewed 28 August 2019.

18 *Aged Care Act 1997* (Cth).

New challenges

The Australian Government implemented a package of reforms in 1997 that introduced fundamental structural changes to the aged care system through the *Aged Care Act 1997* (Cth). The funding system was simplified and it became easier for more providers, including for-profit providers, to enter the residential aged care market. These changes included:

- the unification of nursing home and hostel funding
- reduction of the reliance by providers on Government capital funding, to encourage private investment
- greater reliance on resident contributions
- a single resident classification scale which determined the level of subsidy for each resident
- income testing of residential care benefits
- a relaxation of the previous requirements for nursing homes to acquit expenditure on nursing and personal care.

These changes were accompanied by a relaxation of previous regulatory requirements and their replacement by a 'lighter-touch' accreditation approach.¹⁹

Concerns about the sustainability of the system and the cost to the Federal Budget of an ageing population continued to dominate policy thinking in the following years. These concerns were elucidated in a series of reviews into the level of nursing home subsidies and the pricing of residential aged care services.²⁰ In 2005, a House of Representatives Committee inquiry explored long-term strategies to address demands associated with the ageing of the population.²¹ The focus of the Committee was on the actions that communities might take to improve the quality of life for older people, support healthy ageing and provide opportunities for older people to be productive while they remained active in the community. Formal aged care was a relatively small part of the inquiry, although the Committee noted that much of the evidence it received related to 'concerns about current aged care and health service[s]'.²² With respect to aged care, the Committee concluded that the workforce needed to be more attuned to, and skilled for,

19 J Braithwaite, T Makkai and V Braithwaite, *Regulating Aged Care: Ritualism and the New Pyramid*, 2007, p 182.

20 Productivity Commission, *Inquiry into Nursing Homes Subsidies*, Inquiry Report, 1999; WP Hogan, *Review of Pricing Arrangements in Residential Aged Care, Final Report*, Commonwealth of Australia, 2004.

21 House of Representatives Standing Committee on Health and Ageing, 'Future Ageing, Inquiry into long-term strategies to address the ageing of the Australian population over the next 40 years', Report on a draft report of the 40th Parliament, 2005.

22 House of Representatives Standing Committee on Health and Ageing, *Future Ageing, Inquiry into long-term strategies to address the ageing of the Australian population over the next 40 Years*, Report on a draft report of the 40th Parliament, 2005, p 115.

the needs of older people; there needed to be more research into the care of older people and better integration of services at all levels to achieve person-centred care.²³

Subsequent reviews of the health and aged care systems argued for significant further reforms to the aged care system and its interactions with the broader health system. In 2009, the National Health and Hospitals Reform Commission, tasked with developing a long-term health reform plan for Australia, made a number of broad recommendations about the governance and stewardship of the aged care and health care systems. These included the Australian Government assuming full responsibility for the public funding of aged care.²⁴ This recommendation was agreed through the Council of Australian Governments in 2011 and was fully implemented in 2018 when Western Australia joined the national framework.²⁵ These changes meant that, for the first time, the Commonwealth controlled all of the policy, administration, funding and planning for all aged care services.²⁶

The 2011 *Caring for Older Australians* inquiry by the Productivity Commission commented that ‘deficiencies in Australia’s aged care system are well known and the need for significant reform to meet future challenges has been highlighted in a number of recent reports’.²⁷ The Productivity Commission proposed further changes to funding, regulatory and policy settings. In particular, its recommendations included:

- a simplified, regionally based gateway to care
- increasing consumer choice in the community and residential care settings
- providing consumers with direct access to low intensity community support services
- providing care services based on individual need, with a focus on reablement
- increasing consumer contributions to care and accommodation costs, with protections for the family home and a safety net system for those with limited financial means
- removing limits on the number of residential places and care packages
- removing distinctions in types of care provided
- the establishment of an Australian Aged Care Commission responsible for quality and accreditation.²⁸

23 House of Representatives Standing Committee on Health and Ageing, *Future Ageing, Inquiry into long-term strategies to address the ageing of the Australian population over the next 40 Years*, Report on a draft report of the 40th Parliament, 2005, p 119.

24 National Health and Hospitals Reform Commission, *A Healthier Future for all Australians*, Final Report, 2009, p 23.

25 Australian Government, Department of Health, ‘History’, Ageing and Aged Care updated: 22 February 2019, <https://agedcare.health.gov.au/programs-services/commonwealth-home-support-programme/consultation-process>, viewed 20 September 2019.

26 Council of Australian Governments, *National Health Reform Agreement*, 2011 pp 4–7.

27 Productivity Commission, *Caring for Older Australians*, Inquiry Report 2011, Vol 1, p 3.

28 Productivity Commission, *Caring for Older Australians*, Inquiry Report No. 53, 2011, Vol 1, p xxii.

These reports generated a series of further changes that were, according to the Australian Department of Health, intended to create a ‘more consumer-driven, market-based and less regulated’ aged care system.²⁹ However, the increased focus on a market approach did not resolve persistent concerns held by advocacy groups and the broader community about the quality and safety of aged care.

Quality and safety

The 1997 reforms were followed by the collapse of some newly-accredited aged care facilities and well-publicised failures of care.³⁰ Questions about the quality and safety of care were more prominent in reviews in the years following these scandals. A 2005 Senate Community Affairs Committee inquiry into quality and equity in the aged care system raised issues that have recurred in subsequent reports and inquiries.³¹ The Senate report commented on the accreditation process and the performance of the regulator. It drew attention to shortages of appropriately trained health care workers willing to work in the aged care sector, expressed concerns about the effectiveness of complaints mechanisms, and pointed to failings of the health and aged care systems in providing appropriate services for younger people with disability and for people who were ageing with disability.³²

In 2004 the Australian Department of Health and Ageing commissioned the Campbell Review to assess the quality of aged care since the introduction of the accreditation system in 1997.³³ In 2007, this review found that the quality of care and the quality of life for residents in aged care homes was of a high standard and had improved over the previous 10 years. Despite arriving at this finding, the review noted the absence of nationally consistent measures of quality—quality of care and quality of life—and suggested there was a ‘need to provide a more rigorous mechanism for the monitoring of quality and for the identification of areas for improvement’. In particular, the review called for the ongoing review of the Standards to ensure best practice was incorporated into the accreditation framework and for system-wide quality measures.³⁴ Ten years later, in 2017, the Carnell-Paterson review made similar recommendations.³⁵ Despite this, a regular

29 Australian Government Department of Health, Client Information and Support’, *Ageing and Aged Care*, updated: February 2017, <https://agedcare.health.gov.au/programs/my-aged-care/client-information-and-support>, viewed 10 January 2019.

30 F Reynolds, ‘Parliament hears kerosene bath led to death’, *ABC PM Archive*, 8 March 2000, <http://www.abc.net.au/pm/stories/s108761.htm>, viewed 10 July 2019; J; Braithwaite, ‘The challenge of regulating care for older people in Australia’ *British Medical Journal*, 2001, No 323, pp :443–446; M Wynne, Saitta Pty Ltd and Neviskia Pty Ltd: Kenilworth and Belvedere Park Nursing Homes’, updated: September 2008, https://www.bmartin.cc/dissent/documents/health/nh_sialto_neviskia.html, viewed 10 July 2019.

31 Senate Community Affairs References Committee, *Quality and equity in aged care*, Commonwealth of Australia, 2005.

32 Senate Community Affairs Reference Committee, *Quality and equity in aged care*, Commonwealth of Australia, 2005, pp 28, 37–38, 46, 64, 125–126.

33 Campbell Research & Consulting, *Evaluation of the impact of accreditation on the delivery of quality of care and quality of life to residents in Australian Government subsidised residential aged care homes*, Final Report, October 2007, Commonwealth of Australia, 2007.

34 Campbell Research & Consulting, *Evaluation of the impact of accreditation on the delivery of quality of care and quality of life to residents in Australian Government subsidised residential aged care homes*, Final Report, Commonwealth of Australia, 2007, p x, xiv.

35 K Carnell and R Paterson, *Review of National Aged Care Quality Regulatory Processes*, 2017, pp 101, 147.

review process of the Standards has not been implemented. It was only in July 2019 that it became mandatory for providers to collect and report on a mere three quality indicators.³⁶ The Government has indicated it proposes to add two more indicators, but not until 2021.³⁷

In 2011, the Productivity Commission identified the variability in the quality of care as a key weakness of the aged care system.³⁸ While the Productivity Commission favoured deregulation and market-based measures in many areas, it recommended that quality and safety standards and oversight remain in Government control, and that these activities be expanded.³⁹ Further, the Productivity Commission argued that its proposed reforms would promote quality care by:

- increasing consumer choice
- improving funding and working conditions
- strengthening regulation and regulatory oversight
- making standardised performance information publicly available
- improving recognition of the needs of diverse population groups
- increasing access to consumer advocates.⁴⁰

The Senate Community Affairs Committee raised questions about the care and management of people living with dementia and the adequacy of existing residential care arrangements available for younger people with disabilities.⁴¹ In 2014, the committee found that aged care in Australia was not always well suited to the needs of people with dementia, especially those with behavioural and psychiatric symptoms of dementia and younger people with younger onset of dementia.⁴² It identified a lack of skills and training of aged care personnel, noted claims of the use of physical restraints, and found a significant overuse of ‘psychotic’ medication in aged care, which it said ‘must not be allowed to continue’.⁴³ Overall, the Committee called for personalised care from well-trained staff, noting there is not one ‘correct model of care for those with dementia’.⁴⁴

36 My Aged Care, ‘Quality indicators’, Australian Government, 2019, <https://www.myagedcare.gov.au/quality/quality-indicators>, viewed 28 August 2019.

37 Submissions of the Commonwealth in response to submissions of Counsel Assisting, 4 September 2019, RCD.0012.0028.0011 at 0014 [9].

38 Productivity Commission, *Caring for Older Australians*, Inquiry Report No. 53 2011, Vol 1, p xxiii.

39 D Tune. *Legislated Review of Aged Care*, Australian Government Department of Health, 2017, p 18.

40 Productivity Commission, *Caring for Older Australians*, Inquiry Report No. 53, 2011, Vol 1, p xlviii.

41 Senate Community Affairs References Committee, *Care and Management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)*, Commonwealth of Australia, 2014; Senate Community Affairs References Committee, *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*, Commonwealth of Australia, 2015.

42 Senate Community Affairs References Committee, *Care and Management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)*, Commonwealth of Australia, 2014, pp 56, 97.

43 Senate Community Affairs References Committee, *Care and Management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)*, Commonwealth of Australia, 2014, pp 68, 80, 85.

44 Senate Community Affairs References Committee, *Care and Management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)*, Commonwealth of Australia, 2014, p 99.

In 2015, the Committee again raised questions about the adequacy of existing residential care arrangements available for young people with disabilities.⁴⁵ It concluded that residential aged care was inappropriate for young people, repeating findings in previous inquiries.⁴⁶

The focus in official inquiries on the quality and safety of aged care was intensified following the Oakden scandal in South Australia in 2017, which involved catastrophic failures of care for elderly dementia patients, the closure of a State-owned mental health facility for the aged, and several subsequent scathing State and national inquiries.⁴⁷ These revelations have been followed by more public disclosures of substandard care across the aged care system.⁴⁸ In May 2017, the Australian Law Reform Commission pointed to 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.⁴⁹ The Australian Law Reform Commission considered ensuring quality of care for older people was the best safeguard against abuse and neglect, noting that mistreatment is more likely to be a cultural issue than a ‘bad apple’ problem.⁵⁰

In October 2017, the Carnell-Paterson review explored why the Australian Government’s regulatory processes failed to detect the systemic and longstanding failures at the Oakden facility and found that ‘current regulatory mechanisms do not consistently provide the assurance of quality that the community needs and expects’.⁵¹ The review made recommendations that it believed would improve the regulatory system. In particular, the review called for:

- better coordination of regulatory functions through the establishment of a single agency that regulates safety and quality in aged care—the Aged Care Quality and Safety Commission
- expanded intelligence-gathering capacity, including capturing resident, family and staff views, contemporising risk / quality indicators, increasing reporting of risk indicators and serious incidents and restraint practices by service providers, and developing risk profiling capability

45 Senate Community Affairs References Committee, *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*, Commonwealth of Australia, 2015.

46 Senate Community Affairs References Committee, *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*, Commonwealth of Australia, 2015, pp 15–31, 34, 77; Senate Community Affairs References Committee, *Quality and equity in aged care*, Commonwealth of Australia, 2005, pp 125–6; Senate Community Affairs References Committee, *Care and Management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)*, Commonwealth of Australia, 2014, p 97.

47 See for example, The Hon. Bruce Lander QC, *Oakden: ‘A Shameful Chapter in South Australia’s History’*, Independent Commissioner Against Corruption, 28 February 2018.

48 See, for example, Four Corners, ‘Who Cares?’, posted Mon 17 Sep 2018, updated 20 September 2018, <https://www.abc.net.au/4corners/who-cares/10258290>, viewed 2 August 2019.

49 Australian Law Reform Commission, *Elder Abuse - A National Legal Response*, Final Report, 2017, pp 112–113, 144–147.

50 Australian Law Reform Commission, *Elder Abuse - A National Legal Response*, Final Report, 2017, p 103 - quoting Professor Simon Biggs.

51 K Carnell AO and R Paterson ONZM, *Review of National Aged Care Quality Regulatory Processes*, 2017, pp , 115.

- a better system for sharing information on provider performance with the public and aged care service providers to promote service improvement, including developing performance benchmarking and a star-rated system for providers
- changes to accreditation, compliance monitoring and complaints-handling processes to make them more responsive to emerging issues with care quality, including unannounced accreditation visits and increased powers of the Complaints Commissioner.⁵²

The Australian Government has not publicly released an action-by-action response to the Carnell-Paterson review.⁵³ Measures included in the 2018–19 Budget reflect some, but not all, of the recommendations of the Carnell-Paterson review.⁵⁴ Many of these changes remain in progress.⁵⁵

In 2018, the House of Representatives Standing Committee on Health, Aged Care and Sport reported on the quality of care in residential aged care facilities. It noted the inquiry was established in response to well publicised instances of mistreatment of people in aged care, particularly in South Australia, Queensland and New South Wales, and ‘highlighting potential gaps in the existing system and the urgent need for reform’.⁵⁶ The Committee focused on the effectiveness and adequacy of regulatory protections for the quality and safety of residents in aged care facilities and made recommendations it believed would improve the aged care system, including:

- increasing protections and choice for consumers by improving the program that supports volunteers visiting residential aged care facilities; developing a consumer rating system for aged care facilities; improving consumer information provided to aged care residents; and providing consumers with greater transparency about complaints lodged against individual aged care centres
- reviewing the Aged Care Funding Instrument to ensure it is providing for adequate levels of care
- ensuring all aged care facilities have at least one registered nurse on site at all times and monitoring staffing mixes and their impacts on reducing complaints and abuse
- developing mandatory and more effective quality indicators
- restricting the use of restrictive practices.⁵⁷

At the time of finalising this chapter, the Australian Government had not responded to this inquiry.

52 K Carnell AO and R Paterson ONZM, *Review of National Aged Care Quality Regulatory Processes*, 2017, pp v—x.

53 Transcript, Amy Laffan, Brisbane Hearing, 8 August 2019 at T4638.15–43.

54 Transcript, Amy Laffan, Brisbane Hearing, 8 August 2019 at T4638.15–43.

55 Exhibit 8-29, Brisbane hearing, *Precis of evidence prepared by Professor Ron Paterson*, RCD.9999.0143.0001 at .0003-0004 [23]–[32].

56 House of Representatives Standing Committee on Health, Aged Care and Sport, *Report on the Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia*, Parliament of the Commonwealth of Australia, 2018, p 1.

57 House of Representatives Standing Committee on Health, Aged Care and Sport, *Report on the Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia*, Parliament of the Commonwealth of Australia, 2018, p v.

In April 2019, the Senate Community Affairs References Committee reported on the effectiveness of the aged care quality assessment and accreditation framework.⁵⁸ In light of this Royal Commission being announced and the focus of the Carnell-Paterson review, the Committee elected to focus on the regulation of clinical, medical and allied health care in the aged care context.⁵⁹ In its interim report, the Committee observed:

Perhaps the most compelling argument pointing to a regulatory system that is failing to provide adequate oversight of the aged care sector is the number of recent reviews and inquiries into various aspects of aged care service delivery.⁶⁰

This view was endorsed by the Committee's final report.⁶¹ The Committee reflected on a number of issues facing aged care:

- The overall approach to compliance to minimum standards by individual providers does not support sector-wide capacity building or encourage improvements beyond the minimum benchmarks.
- There is not an accreditation process specific to aged care services with specialist elements of mental health or behavioural and psychological symptoms of dementia...services.
- There is a clear schism in how the aged care sector defines different levels of aged care services as personal care as opposed to clinical or medical care, and therefore the level of clinical governance required for that care.
- Accreditation auditors do not necessarily have a background in clinical care, and may not be best placed to audit clinical care standards.
- Clinical governance within the aged care sector is significantly less developed than in the health care sector.
- Rates of physical and chemical restraint are too high and these practices are largely unregulated in the aged care sector.
- Workforce pressures impact on care standards, including both a lack of a suitably trained workforce as well as staffing levels within individual [residential aged care facilities].

58 Senate Community Affairs References Committee, *Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised*, Final Report, 2019.

59 Senate Community Affairs References Committee, *Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised*, Final Report, 2019, p 8.

60 Senate Community Affairs Committee, *Effectiveness of the Aged Care Quality Assessment and Accreditation Framework. Interim Report*, 2018, p 64.

61 Senate Community Affairs References Committee, *Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised*, Final Report, 2019, p4-6.

- A lack of data on quality of care is a significant barrier to ensuring an appropriate quality framework for aged care services.
- Complaints handling, by individual residential aged care facility providers and by the Commonwealth aged care regulatory regime, is done poorly and the adversarial nature does not support open disclosure and industry-wide collaboration and improvement of care standards.⁶²

Overall, the Committee considered ‘the lack of appropriate regulation of clinical care standards’ within residential aged care facilities as the overarching regulatory failure underpinning these issues.⁶³ Its recommendations included:

- an explicit recognition of a duty of care for people in residential aged care, held by both the residential aged care facility and the Aged Care Quality and Safety Commission
- a continuous improvement approach to aged care, driven by the Aged Care Quality and Safety Commission
- the development of a clear service framework, including a model of care, with a clinical governance framework and clearly defined scope of personal and clinical care
- the reduction and elimination of restrictive practices
- increased regulation of the use of antipsychotic medications and medication use more generally.⁶⁴

At the time of finalising this chapter, the Australian Government had not responded to the final report of this inquiry.

Many of the reviews that have addressed the quality and safety of care in the aged care system over the past 20 years have identified the same problems. Reviewers and inquirers, whether parliamentary or independent consultants, have continued to point to system-wide failings in the Australian Government’s stewardship of aged care, and breakdowns, inconsistencies and rigidities in the way that the aged care, disability and health systems interact with each other. Underlying all of these failings is the fundamental reality of loss of autonomy, dignity and wellbeing that too many older people suffer when they enter the aged care system.

62 Senate Community Affairs References Committee, *Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised*, Final Report, 2019, pp 2–3.

63 Senate Community Affairs References Committee, *Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised*, Final Report, 2019, p 3.

64 Senate Community Affairs References Committee, *Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised*, Final Report, 2019, pp xiii–xv.

A history of piecemeal reform

As can be seen from this survey of multiple reviews, successive Governments have continued to commission reviews of the aged care system, or aspects of it, when serious issues arise. They have been slower to deal with the underlying issues that generated the need for the review in the first place. Many of the recommendations of reviews have been restated in subsequent inquiries. When reforms have been promised, implementation has often been painfully slow. When changes are made, the problems have often persisted.

Given the manifold failings in the delivery, administration and regulation of services to older Australians, it is difficult not to be critical of successive governments' failures to fix the aged care system. Funding has been a challenge, although Governments have injected considerable sums of money into the aged care system across the years.⁶⁵ The fragmentation of the system and its dependence on other sectors, such as health and vocational education and training, both of which have identified problems,⁶⁶ has added to the difficulty of implementing reform, but such factors cannot and should not excuse years of systemic neglect.

Some commentators have suggested that providers have too much influence over aged care policy and even that, at times, regulation of aged care may advance the interests of aged care providers at the expense of quality care.⁶⁷ This element of regulatory capture, they argue, has prevented policy makers and regulators from rigorously implementing necessary changes to the system. Whether or not that argument holds true, there can be no doubt that older Australians are not guaranteed the quality care that they deserve.

Some reflections

While many reviews of the aged care system since 1997 have criticised it in whole or part, it is also fair to say that movement of the system toward what the Australian Law Reform Commission has described as the 'marketisation and individualisation' of aged care has generally been accepted.⁶⁸ This shift in approach towards the provision of services has been occurring since the 1980s. In particular, Governments have placed their focus on 'consumer-driven' care, the provision of care in people's homes, increasing competition within the aged care market, and reducing 'unnecessary' regulation.

65 Australian Institute of Health and Welfare, 'Government Spending on Aged', Factsheet 2017-18', https://www.genagedcaredata.gov.au/www.aihwgen/media/2018-factsheets/spending_factsheet.pdf, viewed 24 July 2019.

66 See for example: J Quiggin, 'Vocational education policy is failing, and it's not hard to see why', *Inside Story*, updated: 22 February 2018, <https://insidestory.org.au/vocational-education-policy-is-failing-and-its-not-hard-to-see-why/>, viewed 14 August 2019; JMacMillan, 'NSW hospitals under pressure as emergency visits increase by almost 20,000, doctors warn', *ABC News*, updated: 15 March 2017, <https://www.abc.net.au/news/2017-03-15/nsw-hospitals-under-pressure-after-spike-in-emergency-visits/8354382>, viewed 14 August 2019.

67 J Braithwaite, T Makkai and V Braithwaite, 'Regulating Aged Care: Ritualism and the New Pyramid', 2007, pp .176, 189, 194, 214; L; Trigg, 'Improving the quality of residential care for older people: a study of government approaches in England and Australia', *Doctoral dissertation, London School of Economics and Political Science (United Kingdom)*, 2018, p 116.

68 Australian Law Reform Commission, *Elder Abuse - A National Legal Response*, Final Report, 2017, pp 106–107.

In 2011, the Productivity Commission argued that Government involvement in aged care is required to address failures in the less-than-perfect aged care market. It noted multiple ways in which the aged care sector lacked features of an ideal market, including:

- informed consumer choice is hindered through lack of consumer knowledge, particularly with respect to clinical quality; decisions about aged care are often made ‘at short notice during times of emotional or acute medical crisis’; aged care is a need, not a want, and many Australians cannot afford such care without government assistance; some older people are frail and vulnerable to exploitation
- demand for services is variable, particularly in rural and remote areas or for groups with special needs, which means that without government assistance these groups may not be adequately serviced
- some government policies restrict the market, such as constraints on the number of available residential places.⁶⁹

While the Productivity Commission considered a need to adjust for the failings of the market, in May 2017 the Australian Law Reform Commission raised questions about the applicability of the market to aged care.⁷⁰ Despite this questioning, the Australian Law Reform Commission ultimately concluded that the review into the 2011 legislative changes to the Aged Care Act and associated legislation (the ‘Tune review’ conducted by Mr David Tune AO PSM) was the ‘appropriate place to consider the broader policy settings for aged care, including in relation to marketisation and individualisation’.⁷¹ In July 2017, the Tune Review concurred with the Productivity Commission’s view that quality and safety standards and oversight should be retained to temper deregulation and market-based measures.⁷²

In October 2017, the Carnell-Paterson review concluded that ‘the rationale for regulation of residential aged care quality is that the market is an inadequate mechanism to ensure the safety and wellbeing of highly vulnerable residents’.⁷³

Despite these discussions within recent reviews, in the main reviews conducted since 1997 have not questioned the evolution of the aged care system into one more reliant on ‘market forces’ or re-examined the institutional structures through which aged care is provided. In the months ahead, the Royal Commission will further explore the need for measures to manage a fragmented market for the delivery of aged care, along with consideration of alternatives.

69 Productivity Commission, *Caring for Older Australians*, Inquiry Report 2011, Vol 1, pp .75–76.

70 Australian Law Reform Commission, *Elder Abuse - A National Legal Response*, Final Report, 2017, pp 106–107.

71 Australian Law Reform Commission, *Elder Abuse - A National Legal Response*, Final Report, 2017, p 107.

72 D Tune, *Legislated Review of Aged Care*, Australian Government Department of Health, 2017, pp 18–19.

73 K Carnell AO and R Paterson ONZM, *Review of National Aged Care Quality Regulatory Processes*, 2017, p v.

Inquiries by the Productivity Commission and the Senate Community Affairs Committee have highlighted the increasing responsibility of the aged care system for people with high care needs or who are reaching the end of their lives.⁷⁴ These reviews have identified tensions between the existing model of service provision and the needs of many of the recipients of aged care services, noting trends of increasing complexity of needs for people both in home and residential settings.

In 2018, the Senate Community Affairs Committee suggested that many dementia-related and other mental health services being delivered by aged care services should be classified as health services and therefore be regulated by the appropriate health quality standards and accreditation authorities and processes.⁷⁵ Such a suggestion raises complex issues about the design of the aged care system, the business models under which aged care is provided and how care for older people is funded, regulated and managed.

Conclusion

It is impossible to escape the melancholy conclusion that aged care services and the people who receive them have simply not been seen as a priority by successive Australian Governments. Advocacy group COTA argues that Australian society does not attach enough value to older people to bring pressure to bear on governments to ensure that older Australians are able to live the last years of life with dignity and respect.⁷⁶ The Royal Commission has heard and read a great deal that confirms this opinion. The sheer volume of reviews into the aged care sector is itself indicative of deep and entrenched systemic flaws. After so many reviews, the problems still exist.

74 Productivity Commission, 'Caring for Older Australians', Inquiry Report No. 53, 2011, Vol 1, p xxii; Senate Community Affairs References Committee, *Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised*, Final Report, 2019, p 35.

75 Senate Community Affairs Committee, *Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised*, Interim Report, 2018, p 68.

76 Council on the Ageing, *State of the (Older) Nation*, 2018, pp 21–22.

3. Demographic, Social and Economic Pressures

[W]hat we've noticed over time is there is a changing nature in the residential aged care population. When I first started working in aged care it would be true to say that people who came into residential aged care were very much more independent... That is not the case now. People come in at an older age. They often come in now with much more complex health care and...dementia. We think that with some of...those changes...that the funding hasn't kept pace and doesn't reflect the changed nature of residential aged care and one area that clearly has been discussed quite significantly of late is the access with and interface with primary health care.¹

Introduction

Australians are living longer than ever before.² However, the later years of life are not necessarily free of illness or other limitations. The prevalence of dementia, mental illnesses such as anxiety and depression, as well as physical diseases like diabetes and arthritis, mean that many older people face significant challenges in their daily lives. There is also the inescapable fact that with advanced age comes greater frailty: bones become brittle, balance becomes less certain, posture less straight.

All these factors mean that while our increased life expectancy is rightly regarded as a measure of the improved health and welfare of Australians, it brings with it particular tests for the aged care system. In 2016, there were over 3.6 million Australians aged 65 years or older, accounting for 15.7% of the Australian population. The percentage of older people is projected to increase to 18% by 2027, according to the Australian Bureau of Statistics.

While older Australians are generally healthier and more independent than prior generations, they still need support to assist them at different times and for differing periods. This may include financial, medical and daily living support such as cooking, budgeting and maintaining medical appointments. The aged care sector provides services to around 1.3 million people. Most of the funding for aged care is provided

1 Transcript, Patricia Sparrow, Adelaide Hearing 1, 19 February 2019 at T420.9-19.

2 Except where otherwise indicated, population statistics in this chapter are drawn from the publications of the Australian Bureau of Statistics (ABS) www.abs.gov.au: ABS, 3105.0.65.001 - *Australian Historical Population Statistics, 2014*, updated: 18 September 2014; ABS, 3302.0.55.001 - *Life Tables, States, Territories and Australia, 2015-2017*, updated: 30 October 2018; ABS, 3222.0 - *Population Projections, Australia, 2017 (base) - 2066*, updated: 22 November 2018, verified 1 October 2019. Analyses are based on the 'Series B' projections, which assume no changes in the fertility rate and the migration rate, and a moderate increase in life expectancy over the next 50 years.

by the Australian Government (\$18.1 billion in 2017–18).³ This chapter outlines demographic, social and economic trends that will affect the future design, funding and delivery of aged care.

Changing demographics will impact on the future demand for aged care in several ways. Changing preferences, differing tastes and the prevalence of dementia will affect both the duration of residence in residential aged care and the care that will be required.⁴ Demographic changes and an increase in the care needs of an ageing population will impact on demand for aged care services. There will be a need for more variety of care choices and attention to healthy ageing to meet the needs of individuals.

The nature and composition of aged care funding will also need to adapt as more of the population ages. The economics of aged care funding will be significantly influenced by factors such as the ratio of working Australians to those no longer working, the number of women in the workforce, the search for carers and staff, and the growing preference to age at home. The cost of supplying informal care from family and friends may well be an important factor. As the need for care rises, the time spent by family and friends looking after their older loved ones will come at the cost of paid employment. This loss of working hours translates into a loss of taxable income and government revenue. Overall, less revenue for the Australian Government reduces its ability to subsidise aged care.

Maintaining services and a high quality of care under this dynamic landscape are among Australia's leading challenges for the future. However, it is well within our nation's capability to meet and manage this challenge. Some of the important ways to ensure a high standard for future aged care are:

- continuing to invest in innovative models of care
- pursuing excellent care
- striving to find people committed to delivering high quality care to work in the system.

3 Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, July 2019, https://agedcare.health.gov.au/sites/default/files/documents/08_2019/acfa-seventh-report-2019-acc.pdf, viewed 25 September 2019. Note that this total figure of 1.3 million people incorporates all types of Australian Government funded aged care. The main three programs (home support, home care and residential care) account for around 1.2 million people.

4 DJ Cullen, *Estimating Key Parameters for Long Term Care Insurance in Australia*, National Centre for Social and Economic Modelling Seminar Series, 2017, <https://www.governanceinstitute.edu.au/magma/media/upload/ckeditor/files/NATSEM%20Seminar%2020170509.pptx>, viewed 25 September 2019.

Changing demographics

Australia's changing demographics will have significant effects on its economy. Key changes will occur in the age of the population, its public health status, the composition of its communities, and in the expectations and preferences of individuals.

Ageing population

In 1980–82, the life expectancy of Australians aged 65 years was 13.8 years for men and 18 for women.⁵ By 2000–02, it had increased to 17.4 years for men and 20.8 years for women, and by 2015–17 it had further increased to 19.7 years for men, with the figure for women unchanged. The number of people likely to be concentrated in older age brackets reflects this increase.

In the last 40 years, the share of the Australian population aged 85 years and over has increased from 0.6% (1978) to 2% (2018). Based on current projections, the proportion of Australians aged 85 years and over will continue to increase to 3.7% by 2058. It is important to note that while the absolute percentage of Australians aged 85 years and above is increasing, the rate at which it has been increasing has been declining. That is, the share of Australians aged 85 years or older is expected to increase by 83% in the next 40 years compared with 216% in the last 40 years. These trends suggest that while there will need to be significant adjustments to the aged care system in the next 40 years, the size of these adjustments is unlikely to be greater than those that have occurred in the previous 40 years.

Population health

Current disability surveys break down the remaining life expectancy for men and women. While the surveys reveal that people are adding more years to their life, they do not yet provide clear evidence of an increase in disability-free years to their life. On the one hand, the increased incidence of dementia in older ages will increase the need for disability support. On the other hand, better health and fitness levels, revealed in longitudinal studies, indicate the number of people living with disability may reduce. In an ageing population, it is likely increased numbers of older Australians will be living with more than one health condition (co-morbidity). The impact of these trends, and of increasing conditions such as obesity, depression and others, on aged care is still unknown.⁶ New types of health care, or strategies for caring for older people, will be needed as the aged care system adapts to the changing health status of older Australians.

5 'Life expectancy' measures how many years, on average, a person of a given age can expect to live if current age-specific death rates do not change.

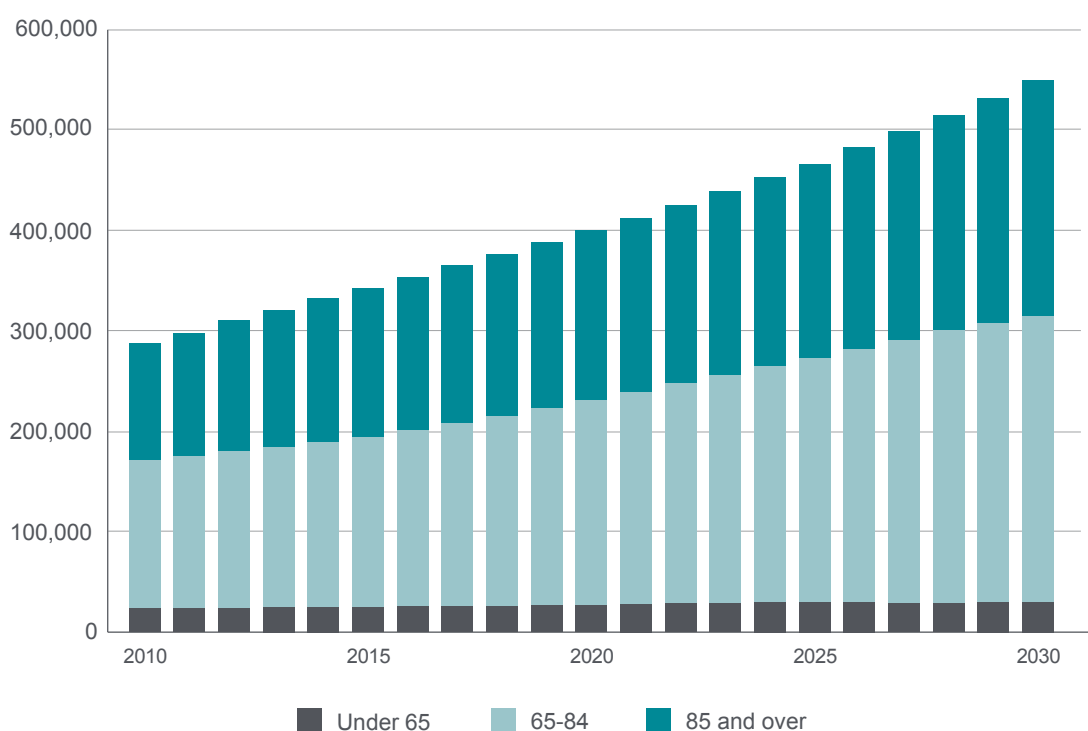
6 MJ Prince, F Wu, Y Guo, L M Gutierrez Robledo, M O'Donnell, R Sullivan and S Yusuf, 'The burden of disease in older people and implications for health policy and practice', *The Lancet*, 2015, Vol 385, 9967, pp 549–562; M Cutler, S Chatterji, J Byles, T Seeman and E Verdes, 'Health, Functioning, and Disability in Older Adults-Present Status and Future Implications', *The Lancet*, 2015, Vol 385, 9967, pp 563–575; S Banerjee, 'Multimorbidity—older adults need health care that can count past one', *The Lancet*, 2015, Vol 385, 9968, pp 587–589.

The Australian Institute of Health and Welfare integrated data from over 5 million people to analyse how people used aged care services between July 1997 and June 2014. They discovered that people took over 1000 different pathways into aged care, but 76% had first accessed home and community care. The three most common aged care pathways, for 54% of the 2013-14 cohort were:

- 26% used home support services, then went into residential care
- 18% used home support services, then respite care, then went into residential care
- 10% went straight into residential care.

The study showed a clear pattern of ‘moving up’ through aged care programs, beginning with entry level programs to progressively higher levels of support and residential aged care. The study did also observe people moving back and forth between programs as their need for care and support changed.⁷

Figure 3.1: Estimated number of Australians with dementia by age group, 2000 to 2030



Source: Australian Institute of Health and Welfare, *Australia's health 2018*, 2018, p 138.

⁷ Australian Institute of Health and Welfare, *Pathways to permanent residential aged care in Australia: a pathways in aged care (PIAC) analysis of people's aged care program use before first entry to permanent residential aged care in 2013-14*, 2017, <https://www.aihw.gov.au/reports/aged-care/permanent-residential-aged-care-2013-14/contents/table-of-contents>, viewed 26 September 2019.

Neurological conditions will contribute to the increase in dependency of older Australians. Dementia is one of the most prevalent diseases among older people, particularly those of advanced ages. In 2018, the Australian Institute of Health and Welfare reported that 376,000 Australians are living with dementia.⁸ Figure 3.1 illustrates this prevalence and shows that approximately 550,000 Australians are expected to be diagnosed with dementia by the year 2030, with 42.8% of those aged 85 years or older. This is largely due to the dramatic increase in the incidence of dementia after the age of 70, where it roughly doubles every five years. This projection is reinforced by an Institute of Health Metrics and Evaluation study which found that approximately 0.1% of the population under 65 years of age has dementia, compared with 5.2% between the ages of 65 and 70, and 28.8% aged 85 years or older.⁹ However, according to some recent research, rates of dementia by age group appear to be diminishing. This means that the numbers affected will not be as high as they would have been if the rates had remained constant or even increased.¹⁰

Diverse communities

Australia is home to a multicultural and linguistically diverse population, and Australians identify with more than 270 ancestries. Aboriginal and Torres Strait Islander people in Australia are the world's oldest continuous culture. The 2016 Census reported that 37% of Australians aged 65 years or over were born overseas. Of the Australians aged over 65 years who were born overseas, 6% either spoke English poorly or did not speak English at all. In terms of aged care services, 25.7% of all recipients of home care services in 2018–19 were from culturally diverse backgrounds. In general, older people from culturally and linguistically diverse backgrounds have a relatively lower socio-economic status and may face language barriers in accessing the care services they need.¹¹

One of the challenges of ensuring the provision of culturally appropriate care is the changing makeup of the migration population. People over 65 who were born overseas were more likely to have been born in Europe (67%) than in Asia (16%) and other continents. In comparison, those aged under 65 years who were born overseas were more likely to have been born in Asia (46%) than Europe (25%).¹² This is partly a reflection of Australia's migration history, with earlier post-war migration from Europe and then more recent increases in migration from Asia. However, those aged 50 to 60 years are unlikely to experience the same difficulties with language as their parents who migrated to Australia. This cohort will also be the next generation of people seeking to access aged care.

8 Australian Institute of Health and Welfare, *Australia's health 2018*, 2018, p 138.

9 Institute of Health Metrics and Evaluation (IHME), 'Epi Visualisation', 2019, <http://ihmeuw.org/4q1k>, viewed 25 September 2019.

10 See I Skoog, J Najar and H Wetterberg, 'The Importance of Birth Year for the Incidence of Dementia', *Journal of the American Geriatrics Society*, 2019, Vol 67, No 7, pp 1330–1332; S Gao, HN Burney, CM Callahan, CE Purnell and HC Hendrie, 'Incidence of dementia and Alzheimer disease over time: a meta-analysis', *Journal of the American Geriatrics Society*, 2019, Vol 67, No 7, pp 1361–1369.

11 Federation of Ethnic Communities' Councils of Australia, *Review of Australian research on older people from culturally and linguistically diverse backgrounds*, 2015, <http://fecca.org.au/wp-content/uploads/2015/06/Review-of-Australian-Research-on-Older-People-from-Culturally-and-Linguistically-Diverse-Backgrounds-March-20151.pdf>, viewed 25 September 2019.

12 Exhibit 1–6, Adelaide Hearing 1, Statement of Justine Louise Boland, 31 January 2019, WIT.0001.0001.0001; Exhibit 1–6, Adelaide Hearing 1, Region of birth of older Australians, 2016, CTH.0001.7000.0018.

The needs of Aboriginal and Torres Strait Islander people also need to be recognised by the aged care system. Aboriginal and Torres Strait Islander people currently represent 3.3% of the Australian population. Aboriginal and Torres Strait Islander people, who have lower life expectancy, tend to require aged care services at a younger age. In the 2016 Census, 27% of Aboriginal and Torres Strait Islander people aged 65 years and over reported a need for assistance with core activities—self-care, mobility or communication tasks—compared with 19% of non-Aboriginal and Torres Strait Islander people.

According to the 2014–2015 National Aboriginal and Torres Strait Islander Social Survey, Aboriginal and Torres Strait Islander people were half as likely as non-Aboriginal and Torres Strait Islander people to assess their health as ‘excellent’ or ‘very good’. Long-term health conditions affect almost nine in 10 Aboriginal or Torres Strait Islander people over the age of 55, with higher risks of certain conditions, including diabetes, cardiovascular disease and respiratory disease.¹³ Aboriginal and Torres Strait Islander people also have a proportionally higher representation in home care services and a proportionally lower representation in residential care services relative to the total aged care population.¹⁴ In 2018–19, about 3.7% of all recipients of home care services were Aboriginal and Torres Strait Islander people, compared with 1.0% for residential aged care.¹⁵

Older Australians’ aged care preferences

Changing demographics will also cause the preferences towards aged care to shift. Surveys reveal that people reaching the pension age in 2019 are wealthier than prior generations. In 2015–16, the average superannuation balance of people aged 65–74 years was \$376,800, which is 56% higher than people aged 75 years and over.¹⁶ Given that aged care needs normally arise 20 to 30 years after retirement, many older people have already spent much of their accumulated wealth by then and many will rely on government financial support to meet their care needs. There is also evidence that fewer older Australians own their own home than previous generations.¹⁷ Not owning a home results in older people having fewer assets to rely on when they retire and compromises their financial security.

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- 13 Australian Bureau of Statistics, *4714.0—National Aboriginal and Torres Strait Islander Social Survey, 2014–15*, updated: 28 April 2016, <https://www.abs.gov.au/ausstats/abs@.nsf/mf/4714.0>, viewed 25 September 2019.
 - 14 Australian Department of Health, *2017–18 Report on the Operation of the Aged Care Act 1997*, 2018, p 63, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%e2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%e2%80%931997.pdf, viewed 25 September 2019.
 - 15 Steering Committee for the Review of Government Service Provision, *Report on Government Services 2019*, Table 14A.18, <https://www.pc.gov.au/research/ongoing/report-on-government-services/2019/community-services/aged-care-services/rogs-2019-partf-chapter14-attachment.xlsx>, viewed 25 September 2019.
 - 16 Australian Bureau of Statistics, *6523.0—Household Income and Wealth, Australia: Summary of Results, 2015–16*, updated: 13 September 2017, Table 15.3, https://www.abs.gov.au/ausstats/Subscriber.nsf/log?openagent&65230do015_201718.xlsx&6523.0&Data%20Cubes&1B10737E3059E640CA2584340018A0CD&0&2017-18&12.07.2019&Latest, viewed 25 September 2019.
 - 17 R Ong, G Wood, M Cigdem and S Salazar, *Mortgage stress and precarious home ownership: implications for older Australians*, Australian Housing and Urban Research Institute, Final Report No 319, 2019, p 84, <https://www.ahuri.edu.au/research/final-reports/319>, viewed 25 September 2019.

Figure 3.2: Population of Australia 2018, age and sex

Source: Australian Bureau of Statistics, 3101.0 – *Australian Demographic Statistics*, June 2018, updated: 20 December 2018, Table 3101059.

Figure 3.2 shows Australia's current age distribution and indicates how much larger the baby boomer cohort (those in 50–64 age groups) is than those born before 1950, especially those in the 65–75 age group. The size of this cohort is then eclipsed by the size of the cohort aged in their 30s and 40s, as shown in the figure. These different sized cohorts, combined with the differing levels of superannuation and home ownership, will result in diverse groups of older Australians, all with contrasting levels of wealth, different expectations, and differing levels of dependency.

There will be significant differences in expectations of aged care because of different levels of wealth. Older people will expect greater access to independent information and a more refined set of responsibilities for service providers. Access to this information will be necessary to ensure that people who are receiving care know what they are entitled to, and that they are receiving it. Expectations will also be focused on a continuing need to maintain and monitor quality standards to ensure that older people receive high quality care and value for their money.

Current arrangements

Changes to Australia's demographics will have important impacts on the demand for aged care. The biggest of these will be in the overall demand for services. Pressure on the quantity and availability of services will increase as more people live to an age where they need assistance. The type of services demanded will also change. With the increasing prevalence of dementia and the growing desire of people to age in their own home, the type and duration of aged care services are likely to experience significant changes that are important to understand.

In 2017–18, the aged care sector provided services to 1.3 million people and generated \$22.6 billion in revenue.¹⁸ A majority of these services were classified as ‘low intensity’ and were provided to people in their own homes. The section below outlines the current aged care service arrangements in the context of the future pressures aged care is likely to face and the innovations required to deliver high quality care.

The most ‘in-demand’ aged care service is the lowest level of support and is delivered to people in their homes. A total of 847,534 people received basic home support at some time across Australia in 2017–18 through the Commonwealth Home Support Programme and the Western Australian HACC program.¹⁹ The average cost of the Commonwealth Home Support Programme was \$2762 per recipient.²⁰ More intensive packages of home-based care range in cost between about \$8000 and \$50,000 and the average Home Care Package in 2017–18 cost the Australian Government \$24,892 per person.²¹ A total of 116,843 people received these types of packages at some time in 2017–18. People who are unable to live independently at home are eligible to receive subsidised permanent residential aged care. A total of 241,723 people received permanent residential aged care in 2017–18 and the average cost to the Australian Government was \$65,588 per person.²²

An increased number of older people will undoubtedly put pressure on this system, mostly from increasing demand. In 2014, only 4% of men and 5.6% of women aged 80 years were receiving permanent residential care. Even at age 90 years, only 17.9% of men and 29.9% of women were receiving permanent residential aged care at any one time. Using a ‘lifetime risk of entry’ measure—the likelihood of a person not in residential aged care entering into permanent residential aged care at some time in the future—admission to permanent residential care was estimated to be 38.3% for men and 55.4% for women.²³ In other words, more than a third of all men and more than half of all women will enter

18 Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, Annual Report, 2019, pp 6, 11, https://agedcare.health.gov.au/sites/default/files/documents/08_2019/acfa-seventh-report-2019-acc.pdf, viewed 25 September 2019.

19 Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, Annual Report, 2019, pp 11, 39 https://agedcare.health.gov.au/sites/default/files/documents/08_2019/acfa-seventh-report-2019-acc.pdf, viewed 25 September 2019. The total number of people incorporates 783,043 older people receiving services from the Commonwealth Home Support Program plus 64,491 people receiving HACC services in Western Australia (these services transitioned into home support from 1 July 2018).

20 Australian Institute of Health and Welfare, *Fact Sheet: Commonwealth Home Support Program (CHSP) aged care services*, 2018, p 2, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/Factsheet-PDFs-and-thumbnail/CHSP-Fact-Sheet-2017-18.pdf?ext=.pdf, viewed 25 September 2019.

21 Calculated using data from: Australian Institute of Health and Welfare, *Aged Care Data Snapshot 2018 – 6th release*, Australian Department of Health, 2018, [https://www.gen-agedcaredata.gov.au/www_ahwgen/media/Data-Snapshot/Aged-Care-Data-Snapshot-2018-6th-release-\(final\).xlsx](https://www.gen-agedcaredata.gov.au/www_ahwgen/media/Data-Snapshot/Aged-Care-Data-Snapshot-2018-6th-release-(final).xlsx), viewed 25 September 2019 (2017–18 total expenditure, and people with a package at 30 June); Australian Institute of Health and Welfare, *Aged Care Data Snapshot—2017*, Australian Department of Health, 2018, <https://www.gen-agedcaredata.gov.au/Resources/Access-data/2018/January/Aged-care-data-snapshot%E2%80%94942017>, viewed 25 September 2019 (people with a package at 30 June).

22 Australian Institute of Health and Welfare, *Aged Care Data Snapshot 2018 – 6th release*, Australian Department of Health, 2018, [https://www.gen-agedcaredata.gov.au/www_ahwgen/media/Data-Snapshot/Aged-Care-Data-Snapshot-2018-6th-release-\(final\).xlsx](https://www.gen-agedcaredata.gov.au/www_ahwgen/media/Data-Snapshot/Aged-Care-Data-Snapshot-2018-6th-release-(final).xlsx), viewed 25 September 2019. Average amount per person is computed by dividing data on funding claims by the total numbers of days people are in care, multiplied by 365.

23 DJ Cullen, *Estimating Key Parameters for Long Term Care Insurance in Australia*, National Centre for Social and Economic Modelling Seminar Series, 2017, <https://www.governanceinstitute.edu.au/magma/media/upload/ckeditor/files/NATSEM%20Seminar%2020170509.pptx>, viewed 25 September 2019; DJ Cullen, *Technical Paper on the changing dynamics of residential aged care*, Productivity Commission, 2011, <https://www.pc.gov.au/inquiries/completed/aged-care/residential-care-dynamics/residential-care-dynamics.pdf>, viewed 25 September 2019.

residential aged care at some time in their lives if population trends remain as they were in 2014. The reason that the lifetime risk of admission is increasing is the increase in life expectancy. With more people living to the age when chronic conditions are more common, there will be an increase in the number of people entering permanent residential aged care.

Increasing life expectancies and the prevalence of diseases like dementia are likely to lead to people requiring care for longer periods. However, in 2016–17, the most common service received immediately before admission into permanent residential aged care was for respite care—temporary accommodation in a residential care facility aimed at supporting the carer—which accounted for 39% of services. In all likelihood, this reflects an increase in care needs prior to admission into permanent residential care.²⁴

Older people living in their homes at times require additional assistance, including residential care, for short periods—for example, to allow carers to receive medical treatment, take holidays or otherwise temporarily reduce their caring responsibilities. Providing more services such as respite care will allow older people to stay in, or return to, their home after a period of more intense care.

The combination of the increasing incidence of diseases like dementia and the preference of older people to age in their own homes suggests that the duration of residential aged care demanded will, to an extent, shift into longer- and shorter-term services. That is, the ageing population will shift more people into more intense care as a result of the higher prevalence of dementia, while other people move out of lower level residential care and into care at home while also seeking shorter-term residential respite care services.

Table 3.1 shows the length of permanent ‘residential care stays’—days spent in residential care—between 2000 and 2006. The average total completed length of stay was 890 days, or about two years and five months.²⁵ However, 50% of people admitted remained for less than 598 days, 25% for less than 175 days and 10% for less than 43 days. On the other hand, 25% of final discharges occurred after 1311 days and 10% of final discharges occurred after 2167 days.²⁶ The distribution of duration in residential care, which already has large groups at short and long stays, may become even more divided into long- and short-term care services with greater intensity.

24 Australian Institute of Health and Welfare, *Pathways to permanent residential aged care in Australia: a Pathways in Aged Care (PIAC) analysis of people’s aged care program use before first entry to permanent residential aged care in 2013–14*, 2017, p 14, <https://www.aihw.gov.au/getmedia/71d37559-36f7-4274-9417-83977cb6e4f6/21233.pdf.aspx?inline=true>, viewed 25 September 2019.

25 DJ Cullen, ‘The financial impact of entering aged care’, *Australasian Journal on Ageing*, 2007, Vol 26, No 3, pp 145–147.

26 The most common reason for leaving permanent care was death (82%).

Table 3.1: Distribution days spent in residential care

2000–2006			
Percentage of residents	Less than (days)	Years	Change in days
10%	43	0.12	43
25%	175	0.48	132
50%	598	1.6	423
75%	1311	3.6	713
90%	2167	5.9	856
Average	890	2.4	-

Source: DJ Cullen, 'The financial impact of entering aged care', *Australasian Journal on Ageing*, 2007, Vol 26, 3, pp 145–147.

Responding to significant demographic trends

Several key changes are required to tackle these issues. We believe that they are not outside the reach of Australia's current care system if there is a proper focus on providing quality care tailored to the needs of individuals.

One of the most important things that people can do at little or no cost to themselves is to take ownership of their good health and make every effort to maintain it. Governments, community organisations and health professions play an important role in encouraging and supporting people to make sensible food and exercise choices and to be as healthy as possible. This is important in reducing the dependency on care services. Governments have successfully invested significant sums in anti-smoking campaigns and support for people who are quitting tobacco. The rate of smoking almost halved between 1991 and 2016.²⁷

However, obesity rates have continued to rise. In June 2019, the Australian Institute of Health and Welfare advised that two-thirds of Australian adults were overweight or obese.²⁸ Obesity and being overweight increases the risk of high blood pressure and diabetes, which contribute to cardiac and kidney disease. Older people who are overweight or obese can find their mobility decreased and suffer difficulties in performing routine tasks as they age, which can reduce their ability to live independently.

27 Australian Institute of Health and Welfare, 'Alcohol, tobacco & other drugs in Australia', *Australian Government*, updated: 23 September 2019, <https://www.aihw.gov.au/reports/alcohol/alcohol-tobacco-other-drugs-australia/data>, viewed 24 August 2019.

28 Australian Institute of Health and Welfare, 'Australia's health 2018', *Australian Government*, 2018, p 188, <https://www.aihw.gov.au/getmedia/7c42913d-295f-4bc9-9c24-4e44eff4a04a/aihw-aus-221.pdf.aspx?inline=true>, viewed 25 September 2019.

Growth in assistive technologies—hearing aids, bed handles and chair lifts—which are already impacting broadly and positively on aged care in Australia, is also important in reducing the dependency on care services.²⁹

Finally, the aged care system has to be able to offer a wide variety of care alternatives and to combine different forms of care. This flexibility is necessary to help cater for increasing reliance on both shorter- and longer-term care. Flexibility and innovation will also play a role in meeting the challenge of the increasing prevalence of dementia in Australia. As with other conditions, choice will be vital for people with dementia, so a variety of programs will need to be accessible and promoted. This includes dementia intervention programs that provide strategies for older people and their carers, plus special care services such as memory clinics and dementia day care centres.³⁰

Funding arrangements

With the demand for aged care services poised to grow significantly in the coming years, there is also a need to understand how this growth will be funded by the Australian Government. This is necessary in order to construct manageable and sustainable reforms. The areas that will experience significant changes which will have implications for aged care funding are:

- the anticipated increase in the number of aged care users in comparison with the number of aged care funders (working Australians)
- the changing preferences of older Australians to age in their own homes
- the changing supply of care workers and staff.

Dependency of funding

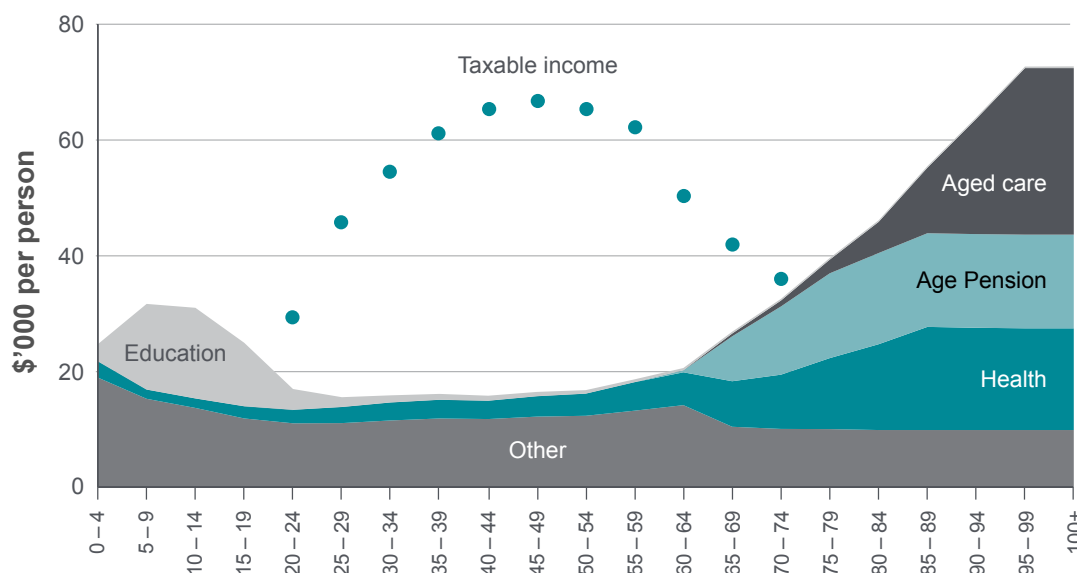
Figure 3.3 shows that public spending per person, by age, is largest above the age of 65 years, while the largest contributors of age-attributable tax are aged 20 to 60 years. About half (49.9%) of the Australian Government's revenue comes from personal income tax and can be attributed to the age of the taxpayer.³¹ The other half is more properly attributed to all taxpayers, on a pro rata basis. This half can be considered to be a flat line of revenue located between 20 and 60 years of age in Figure 3.3, on which the effect of age attributable income tax revenue is shown by the dotted line.

29 JJ Cerqueira, DAS Compston, R Gerales, MM Rosa, K Schmierer, A Thompson, M Tinelli and J Palace, 'Time matters in multiple sclerosis: can early treatment and long-term follow-up ensure everyone benefits from the latest advances in multiple sclerosis?', *Journal of Neurological Psychiatry*, 2018, Vol 89, No 8, pp 844–850.

30 K Laver, S Dyer, C Whitehead, L Clemson and M Crotty, 'Interventions to delay functional decline in people with dementia: a systematic review of systematic reviews', *British Medical Journal Open*, 2016, Vol 6, No 4, <https://bmjopen.bmj.com/content/6/4/e010767>, viewed 7 August 2019.

31 Australian Government, *Table 3: Australian Government general government sector (cash) receipts*, Final Budget Outcome 2018-19, 2019, p 5, https://archive.budget.gov.au/2018-19/fbo/FBO_2018-19_web.pdf, viewed 25 September 2019.

Figure 3.3: Total Australian, State and Territory Government spending and taxable income by age (2011–12)



Source: Productivity Commission, *Migrant Intake into Australia*, Inquiry Report No 77, 2016, p 303.

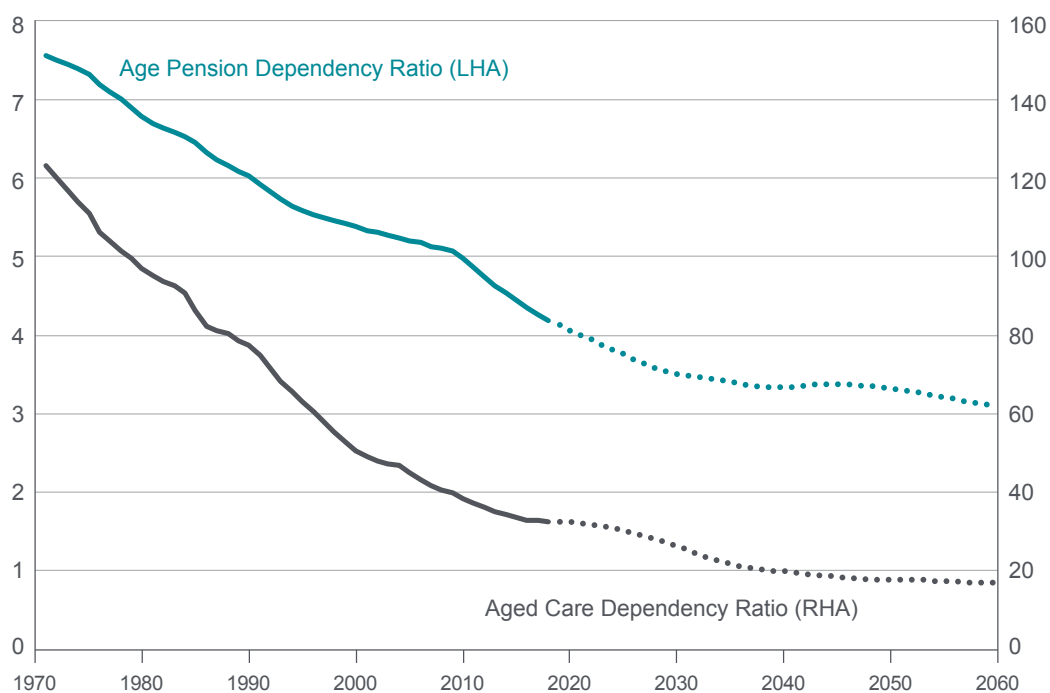
An ageing population will cause the number of people in the above 65 years bracket—people who consume aged care—to increase, while the number of people in the 20–60 years age bracket—people who fund aged care in the form of tax revenue—remains relatively constant (or perhaps even increases slightly in absolute terms). As Figure 3.2 illustrates, the size of the age groups currently in their 30s and 40s is even larger than the baby boomer cohort. As a consequence, there will be no decline in the numbers of people in these working ages over the near future. Moreover, the current small size of the cohorts aged between 15 and their late 20s will probably not carry forward into older cohorts because of net overseas migration.

Figure 3.4 shows the calculated age pension dependency ratio on the left axis, and the projected aged care dependency ratio from 1970 to 2050 on the right axis. The age pension dependency ratio, which measures the number of people of traditional working age (15–64 years) for every person aged 65 years or older, provides some understanding of the issues governments will face in financing the age pension and services for older people in the coming decades. Currently, there are 4.2 Australians of working age for every Australian aged 65 years and over. By 2058, this will have decreased to 3.1. Although this is a significant change, we are conscious that it is smaller than the decrease that occurred over the last four decades, given that the ratio was 7.0 in 1978.

The aged care dependency ratio similarly measures the number of people of traditional working age (15–64 years) for every person aged 85 years and older. The latter is chosen because it corresponds broadly with the average age of entry to permanent residential

aged care for women.³² Here, too, there has been a significant decline over the last four decades—from 101.4 people of traditional working age (15–64 years) for every person aged 85 years or older in 1978 to 32.5 in 2018. The decline over the next four decades will be much more significant than the change in the age pension dependency ratio. By 2058, there will only be 14.6 people of traditional working age (15–64 years) for every person aged 85 years or older. This rapid decline has implications for the financing of aged care and the aged care workforce, which will have relatively fewer workers to draw on to meet the growing demand for aged care services.

Figure 3.4: Australia's dependency ratios, 1970 to 2060



Source: Background paper No. 2, p 5.

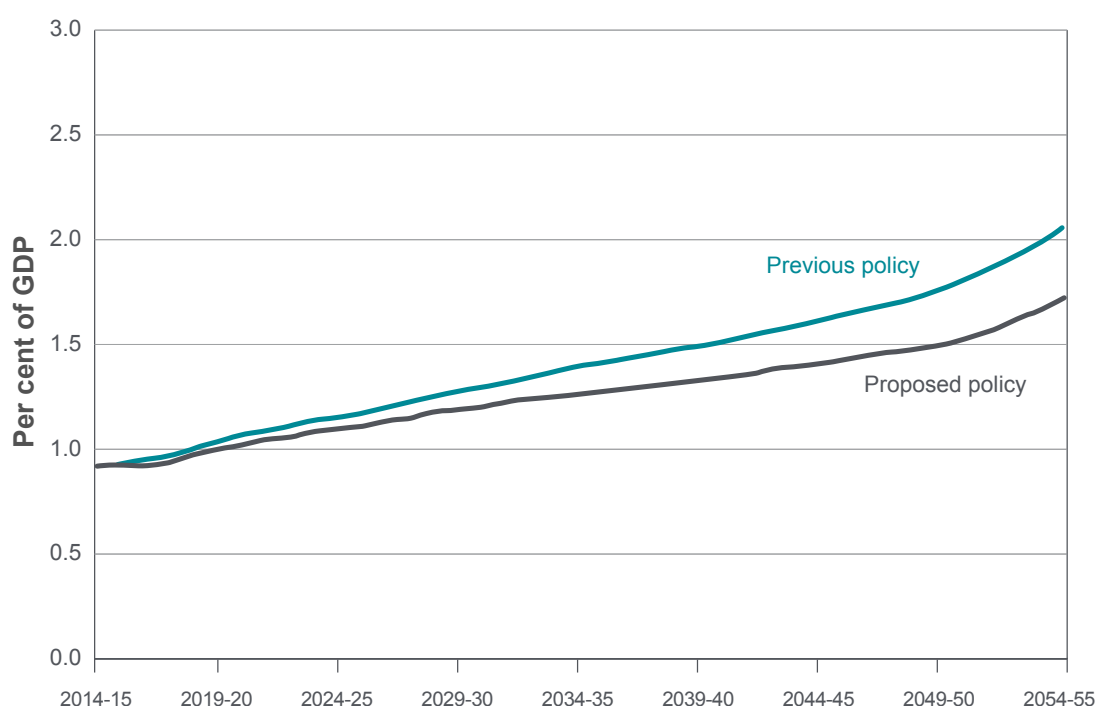
Ageing in home

It is important to note that the growing demand for care may not necessarily dictate an increased cost of care. The preference of older people to age in their own home and the implementation of government programs designed to help them to do this—for example, the home care programs introduced under the ‘Living Longer Living Better’ package in 2013, have provided the scope to substitute or deter the entry into expensive residential aged care with relatively more cost effective Home Care Packages and home support services.

32 DJ Cullen, *Estimating Key Parameters for Long Term Care Insurance in Australia*, National Centre for Social and Economic Modelling Seminar Series, 2017, <https://www.governanceinstitute.edu.au/magma/media/upload/ckeditor/files/NATSEM%20Seminar%2020170509.pptx>, viewed 25 September 2019.

Figure 3.5 shows that in 2014–15, the Australian Government’s expenditure on aged care accounted for around 0.9 per cent of Gross Domestic Product. This includes funding for residential aged care and a range of community care services, including care in the home. The dominant influences on aged care spending projections, displayed in Figure 5, are the number of people over the age of 70 years and the Government’s commitment to provide 125 aged care places per thousand people aged over 70 years. The number of people aged 70 years and over is expected to almost triple over the next 40 years, reaching around seven million by 2055.³³

Figure 3.5: Australian Government aged care spending, 2014–2055



Source: Treasury projections. Projections assume trend economic growth from 2021–22 to 2054–55.

In light of the ageing population and changing demographics, the Government has adopted several measures aimed at reducing the budgetary pressures associated with growing public expenditure on aged care services. For example, in the 2014–15 Federal Budget, the Australian Government lowered the real annual growth rate in funding for home support services from 6% to 3.5%, starting in 2018–19.³⁴

33 Australian Government, *2015 Intergenerational Report: Australia in 2055*, 2015, p 71, https://treasury.gov.au/sites/default/files/2019-03/2015_IGR.pdf, viewed 25 September 2019.

34 L Belardi, 'Government changes tack on CHSP fees policy', *Australian Ageing Agenda*, updated: 17 June 2015, <https://www.australianageingagenda.com.au/2015/06/17/government-changes-tack-on-chsp-fees-policy/>, viewed 20 February 2019.

Consistent with the changing nature of people's preferences, namely the desire to age in home, a great emphasis has been put on home support and home care; expenditure on home support and home care increased at an average annual rate of 12.2% over the four years from 2013–14 to 2017–18, compared with 5.7% for residential care.³⁵

Since these budget measures have been implemented, long-term projections of Australian Government aged care expenditure became smaller. Figure 3.5 shows that under the 'proposed policy' scenario of more home care, Government aged care expenditure is projected to rise from 0.9% of Gross Domestic Product in 2014–15 to 1.7% in 2054–55. Under the 'previous policy' scenario, projections show that spending would have increased to 2.1% of Gross Domestic Product by 2054–55.

Expenditure on aged care is expected to grow, regardless of this. A total of \$93.4 billion has been allocated to aged care over the four year projected estimate period of 2019–20 to 2022–23. This represents a 5.5% annual increase on the estimated expenditure in 2018–19 of \$20.4 billion.³⁶

While changing dependency ratios may cause funding to become scarcer in the future, care services funded by the Australian Government are also expected to become more cost-effective as a result of more funds being allocated towards more home-based care initiatives. On average, these are currently cheaper to provide than residential care.³⁷

Informal care and the aged care workforce

Care is not only provided by the Government. There is also a substantial contribution made by informal carers in unpaid care. While the value of this work is not fully captured in surveys and statistics, informal care imposes substantial costs on the Australian economy. In 2015, one in eight people were providing some form of informal care, with 91.5% of primary carers providing assistance to a partner, child, or parent. The forgone alternative of this informal care is paid employment. The cost of forgone employment is estimated to be 0.6% of Gross Domestic Product, which is approximately 9.9% of the tax contribution to subsidised health care. In other words, if all informal care hours were replaced by formal care work, the replacement value would be 3.8% of Gross Domestic Product—equivalent to approximately 60% of Gross Domestic Product contributions to health care.³⁸

35 Royal Commission calculations based on: Steering Committee for the Review of Government Service Provision, *Report on Government Services 2019*, 2019, Tables 2A.50 and 14A.5, <https://www.pc.gov.au/research/ongoing/report-on-government-services/2019/community-services/aged-care-services/rogs-2019-partf-chapter14-attachment.xlsx>, viewed 25 September 2019.

36 Australian Government, 'Statement 5: Expenses and Net Capital Investment', *Budget Paper 1: Budget Strategy and Outlook 2019-20*, 2019, p. 5-23, https://budget.gov.au/2019-20/content/bp1/download/bp1_bs5.doc, verified 2 October 2019.

37 Australian Institute of Health and Welfare, *Aged Care Data Snapshot 2018 – 6th release*, Australian Department of Health, 2018, [https://www.gen-agedcaredata.gov.au/www_aihwwgen/media/Data-Snapshot/Aged-Care-Data-Snapshot-2018-6th-release-\(final\).xlsx](https://www.gen-agedcaredata.gov.au/www_aihwwgen/media/Data-Snapshot/Aged-Care-Data-Snapshot-2018-6th-release-(final).xlsx), viewed 25 September 2019.

38 Deloitte Access Economics and Carers Australia, *The economic value of informal care in 2015*, 2015, <https://www.carersaustralia.com.au/storage/access-economics-report3.pdf>, viewed 24 September 2019.

Changing family structures and living arrangements will also affect the amount of aged care available to older people. Where previously women were living longer than men, recent studies reveal the life expectancy gap between women and men is narrowing, which, in principle, is an increase to the supply of informal care. The smaller gap translates into fewer years of widowhood, and more time at home, since the loss of a partner often precipitates the need for residential care.³⁹ This effect is then partially offset by the increase of participation of women in the workforce. The majority of carers of older people are women and more than half of all primary carers are in the workforce. Changing working patterns will also have implications for the future availability of family carers.⁴⁰

Pay remains the most important factor to the workforce, with evidence of an aged care skills shortage being driven by relatively lower wages.⁴¹ There is also continuing evidence that this low pay continues in part because of the devaluation of aged care work as ‘women’s work’.⁴²

To address the issues associated with the supply of aged care in Australia, there must be strong linkages between aged care service providers and more specialised services to assist older people who need additional services, such as specialist mental health services. Innovations in building design, landscaping, the increased use of technology and, above all, a flexible and adaptive mindset within both government and the aged care sector will be essential to design and provide appropriate services.

The nature and composition of aged care funding will need to adapt. Funding dependency and informal care costs will play a more prominent role as the population ages. Investing in innovative models of care, pursuing excellent care, and striving to find people committed to delivering the best care they can, are the keys to quality. Above all, the search for aged care workers and providers cannot come at the expense of high quality care. The aged care system must always be kept accountable for the quality of service it delivers.

39 DN Lakdawalla and T Philipson, ‘The Rise in Old-Age Longevity and the Market for Long-Term Care’, *American Economic Review*, 2002, Vol 92, No 1, pp 295–306; DN Lakdawalla and R Schoeni, ‘Is nursing home demand affected by the decline in age difference between spouses?’ *Demographic Research*, 2003, Vol 8, No 10, pp 279–304; MB Thomeer, S Mudrazija, and JL Angel, ‘Relationship Status and Long-Term Care Facility Use in Later Life’, *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 2016, Vol 71, No 4, pp 711–723.

40 LH Ryan, J Smith, TC Antonucci, and JS Jackson, ‘Cohort Differences in the Availability of Informal Caregivers: Are the Boomers at Risk?’ *The Gerontologist*, 2012, Vol 52, No 2, pp 177–188.

41 K K Mavromaras, P Sloane, and Z Wei, *Skill Shortages in the Australian Aged Care Sector: The Role of Low Wages*, International Conference on Public Policy (ICPP-2017), National University of Singapore, 2017.

42 E Palmer and J Eveline, ‘Sustaining Low Pay in Aged Care Work’, *Gender, Work & Organization*, 2012, Vol 19, No 3, pp 254–275.

Conclusion

Changing demographics will impact upon the future of aged care in Australia in several ways. The most notable will be an increase in demand for services. There will also be an increase in numbers of people developing neurological conditions such as dementia, and other diseases. These will require greater focus and agility than are embedded in the current system. Another significant change will be growth in contrasting expectations of and ‘tastes’ associated with aged care services, driven by variations in financial means. Finally, the durations of stay in residential care will shift into both longer and shorter periods, and the proportion of older people receiving care in their own homes will continue to increase.

Maintaining a healthy, active lifestyle remains the strongest contributor towards healthy ageing. Although this is a choice made by individuals, governments, community organisations and health professionals also play a crucial role in encouraging people to be as healthy as possible. This will be important in reducing the time people spend dependent on aged care services. Some other changes that will help reduce the dependency on aged care services include the growth in assistive technologies such as hearing aids, bed handles, and chair lifts. The provision of flexible care alternatives to meet the diverse needs of the elderly, and research and innovation to tackle dementia in Australia will also help.

The Royal Commission’s next phase of work will examine in more detail the systemic barriers to innovation and flexibility which currently impede positive change.

Part 2

**‘An overwhelming
sense of loss’**

4. ‘An overwhelming sense of loss’

There’s a shock when you move into aged care. There is the shock of loss because what happens is it is so quick. There’s not the recognition of loss because loss is not just death. Loss is loss of your way of life...There’s the feeling of suddenly I’m in an institution. I have to follow what the institution wants, the time to get up, the time to have meals and there’s no—there’s no choice. So you lose your choice totally when you come into aged care. And that’s one of the things that needs to change.¹

Introduction

No one wants to get old. While growing older may bring with it many benefits—retirement from full-time work or all work, more time for leisure activities, hobbies, volunteering, travel—it also has many downsides. Bodies begin to show the signs of wear and tear: old injuries can become arthritic, formerly flexible limbs move less easily, immunity to colds and flu seems weaker. Some people need joint replacements, and some develop diabetes—and a greater risk of heart disease—because they start to avoid physical activity in favour of more passive pursuits.

Although the media and advertising are full of images of happy older people going on cruises or adventure holidays, taking up new interests and generally staying active, these images are an idealised depiction, not a faithful representation, of the full reality of ageing for everyone. This chapter tells the story of people’s experiences with the aged care sector in their own words.

As people get into their late seventies and eighties, they become more frail and less agile. Some—because of genetics, chronic illness or injury, a life time of hard manual work or a combination of these—will be less physically capable than at a younger age.

Decline in cognition can also occur. People can develop one of the forms of dementia, or experience some memory loss. Older people who live alone or who lack family support can become withdrawn to the point of disengagement from friends and neighbours.

Similarly, although getting older can have its benefits such as freedom from other people’s timetables, more time with family and friends, deeper understanding, wisdom, perspective and tolerance, it can also be laden with feelings of fear and loss: fear of becoming partially or wholly dependent on others; fear about finances and housing; fear of illness or disease; and fear of losing mental faculties.

1 Transcript, Merle Mitchell, Sydney Hearing, 6 May 2019 at T1148.26-35.

With fear can come loss: loss of the sense of identity that is conferred by having a job, a workplace and colleagues; loss of social networks because of the need to curtail volunteering and other pursuits; and, above all, loss of individuality, of choice, of control.

Arguably, people's fear of losing control over the details of their own lives—of losing their self-determination and autonomy—underlies an avoidance to make decisions about entering the aged care system, whether care at home or residential aged care. To face squarely the reality of ageing requires a person to acknowledge that other people, unknown people, may decide the details of daily life. For some older people, this admission brings with it an overwhelming sense of loss.

Avoidance

While many people prepare for a healthy old age, it seems they do not prepare for aged care or how they want to be cared for at the end of their life. No one wants to lose their physical and social independence, tied so closely to self-worth and autonomy:

With the progression of [her] symptoms, she lost her driving licence. This was traumatic for her as she had always been a good and accomplished driver and she valued the license as a recognition of her competence and worth.²

We are all willing to plan ahead for stages in life, such as retirement, or events such as a long-anticipated overseas trip, that we look forward to eagerly. We are much less likely to plan for events that we wish to avoid. Aged care is a notable example of this. It seems that many people fear entering aged care as the beginning of the end, and they will avoid making decisions for as long as possible:

I have family members who have been counselled over the years to prepare for the inevitable deterioration that will occur with the conditions that they have and yet they have resisted the calls from children, siblings and friends to do such planning until this past week when both family members entered the residential aged care and hospital systems at the same time...³

Most older people want to stay in their own home for as long as possible. When a person needs more support with the activities of daily life, they often identify this with the loss of dignity and their sense of self. People who need help can struggle to find it. If circumstances dictate that they need assistance, who can they turn to?

2 Submission AWF.600.00256.

3 Submission AWF.001.00572.

While some people have the support of family, friends or neighbours, other people do not have these informal supports. Informal carers—often partners, spouses or daughters, but also sons, other relatives, friends or neighbours—face great highs and lows in their caring roles. Carers may find themselves struggling to support an older person with all of their personal care needs:

I would say that caring for people is not easy. It exposes our weaknesses, our prejudices and our failures. It consumes our time and our energy. It draws on our financial resources.⁴

Caring for a parent is emotionally very hard with little relief. I have experienced the dilemma and guilt when a break is needed...I was not happy relinquishing the care of my mother to strangers.⁵

Jill has taken on much of the caring role since my diagnosis. Jill would say she has enough support but I would say she needs more. Jill is a real Trojan when it comes to that sort of stuff. She is always helping but she needs more support. She needs days off.⁶

Whether or not a person has a network of supportive family and friends, they will probably need to access aged care services to help them stay at home. The perceived loss of independence can be daunting:

I want to stay in my home. I don't know how I would handle it if I ever had to have someone constantly caring for me because I have just always been very independent and I want to remain that way for as long as possible. Because I've always been so independent I feel bad asking family to help me with things I used to be able to do by myself. I'm even more reluctant to ask friends and other people outside of my family for assistance.⁷

After speaking to some of our Stolen Generation Elders I would like to share some of their responses when asked ‘what worries you about going into aged care’. They responded by saying that they would prefer to remain with family and spend their last days in their home. They prefer to be around places that are familiar to them, one of our Stolen Generation Elders stated that he would lose his mind if he were taken away from his home and would basically give up hope.⁸

4 Exhibit 1-63, Adelaide Hearing 1, Statement of Barrie Anderson, 15 February 2019, WIT.0030.0001.0001 at 0004 [38].

5 Exhibit 7-3, Mildura Hearing, Statement of Dorothy Frances Holt, 23 July 2019, WIT.0336.0001.0001 at 0003 [21].

6 Exhibit 3-82, Sydney Hearing, Statement of Trevor Douglas Crosby, 8 May 2019, WIT.0142.0001.0001 at 0004 [35].

7 Exhibit 2-80, Adelaide Hearing 2, Statement of Rita May Kersonvske, 13 March 2019, WIT.0088.0001.0001 at 0005 [49].

8 Broome Community Forum, 19 June 2019.

When people come to accept that they need support to stay at home, they must find the ‘front door’ of the aged care system: My Aged Care. We have heard that people’s experience of seeking help from My Aged Care is generally not positive:

My aged care had made a complicated mess of allocation and assessment of need. The jargon is hard to understand, it is difficult to navigate and it is incongruous. One person will directly contradict another, confusing the person trying to navigate the system. There are too many steps in the process with different organisations to be involved.⁹

At a time of deep trauma this is the last thing that is needed. My mother cannot use a computer and was so upset that she was unable to manage much of what was required.¹⁰

I do not have sufficient time to articulate the entire debacle that has been my experience with My Aged Care.¹¹

Typically, people have limited knowledge of the aged care system. People who may be in a state of crisis genuinely struggle. The system itself is extremely complex. It is riddled with jargon and acronyms. The processes and paperwork are confusing:

I was offered ACAT assessments and HACC packages and other phrases that I didn’t understand. I struggled to make sense of what Mum could access and what she was eligible for. Every person I spoke to assumed I had a detailed knowledge of a system that was laden with acronyms. No one seemed to be speaking to me from the perspective of what Mum needed, or an ‘older person’-centric approach. I felt enormous pressure to make the right decision. It was overwhelming and confusing and sad.¹²

People want to know where support is located, how good it is, and how much it will cost. They also want to know about other people’s experience of a provider: are they helpful, kind and trustworthy? They want to know if the provider has enough staff and if the staff are well-trained.

Unfortunately, My Aged Care cannot answer most of these questions:

The worst thing with the aged care system is that you’re constantly reaching out for support or guidance without anyone asking if you need a hand. It wears you down.¹³

9 Submission AWF.001.01771.

10 Submission AWF.001.02010.

11 Brisbane Community Forum, 19 August 2019.

12 AWF.001.01660.

13 Exhibit 7-2, Mildura Hearing, Statement of Elaine Maree Gregory, 25 July 2019, WIT.0315.0001.0001 at 0003 [23].

...you have to go by word of mouth as to whether a place is good or not. And also the hospital told us that he had to leave within a relatively short space of time. They did allow us time to find a facility but we really just felt like we were doing this quite blindly.¹⁴

The situation is even harder for people living with dementia, people for whom English is difficult, people with difficulty hearing or those with visual impairments:

Expecting an 88 year old with dementia and mental health issues to be computer literate and to deal with letters about her financial affairs is just one form of institutionalised cruelty.¹⁵

In the system: home care

A person’s eligibility for aged care services depends on how much support they need to do everyday activities. An initial assessment is done over the phone by staff in the My Aged Care call centre. This assessment must be confirmed by a face-to-face assessment at the person’s home. There are two kinds of face-to-face assessment:

- If call centre staff decide the person needs a low level of support to maintain their independence in their own home, they will refer the person for a home support assessment. This can lead to provision of basic level supports at home.
- If staff decide that the person needs more support than the basic level, they will refer the person for a comprehensive assessment. This can lead to provision of more coordinated packages of care at home. Depending on the assessed level of need, it may also result in residential respite care or permanent residential care.

The Royal Commission has heard frequently that the assessment process is confusing. People are unaware or unsure of which path they are on and what it means. Sometimes, during the face-to-face assessment, a person can receive an immediate referral to providers for care. At other times, they need to wait for a letter telling them when care can start. The outcome depends on the person’s needs: the higher the need, the more likely they will need to wait for a letter. In these early stages, people have to give the same information about themselves more than once:

Each time, they began by conducting a memory assessment—even though Mum had already been diagnosed with mixed dementia (vascular dementia and Alzheimer’s disease). Mum found the constant stream of questions really distressing...The tasks were relentless and degrading. She could never remember her full name, the year, the month, the season. They never seemed to have the notes from the previous person and always insisted we couldn’t continue until the

14 Transcript, Shannon Maree Ruddock, Perth Hearing, 27 June 2019, T2630.41–44.

15 Submission AWF.001.01152.

assessment was complete. I pleaded with workers not to make her do the tests again but they insisted it was part of the process. Until one day she broke down like a small child and sobbed, 'no more please'.¹⁶

People can find the assessment itself confronting, and the paperwork that follows intimidating. They can be overwhelmed as they move from initial assessment, to finding out what services are available, to negotiating with a provider and finally entering into a contract. We have heard that people want support; they do not want to jump more and more hurdles. They might need equipment to help them get around their home more easily. They might need regular personal care, such as someone to help them have a shower. The whole process can resemble an obstacle race:

Getting and maintaining Home Care services is a nightmare. One has to deal with [My Aged Care], [the Aged Care Assessment Team], [equipment providers] and [care providers]. Navigating through these Agencies is close to impossible. On many occasions I have been run in circles by referring me from one Agency to another and back again. For example, being told by [My Aged Care] that a service has been authorized and to arrange it with my Provider. Only to be told by the provider that they have not received authorisation.¹⁷

Negotiating the network of government and provider red tape is more stressful than my husband's dementia.¹⁸

In their first experiences with aged care, people may only receive one to two hours of help each week—most often some receive light housekeeping or laundry, organised social activities, exercises or going to a community activity centre:

I am, at present, in reasonably good health and I don't need any care or assistance at home. Except for a cleaner who comes once a fortnight, I look after myself.¹⁹

People seek help in their home because the way they once lived their life is breaking down. At the same time that they must get used to receiving help, they must also adjust to the physical and emotional effects of these changes:

Mum and Dad always looked after each other but when Dad died, Mum was lost. There wasn't anyone to help her. I have siblings but they were running the family farm, lived away or weren't involved.²⁰

16 Submission AWF.001.01660.

17 Submission AWF.001.02179.

18 Wollongong Community Forum, 13 March 2019.

19 Exhibit 5-17, Perth Hearing, Statement of Kevin Charles Chester, 3 June 2019, WIT.1137.0001.0001 at 0001 [5].

20 Exhibit 7-2, Mildura Hearing, Statement of Elaine Maree Gregory, 25 July 2019, WIT.0315.0001.0001 at 0002 [11].

Some organisations and individuals who provide home care have described to us the impact they have on older people's lives, and how fortunate they feel to bear witness to a person's final years. Home care workers have also described situations where older people are alone at home for long periods of time with nothing but the television for company:

There is one woman who we provide at home cleaning services to, who previously had no contact from anyone and no visits to her home. Whenever our staff attend her home, she begs them to stay for longer and talk to her.²¹

The impacts and symptoms of ageing can be difficult for both the individual and their families to acknowledge and accept. In some medical conditions where cognition is affected, such as dementia, it can take time for people to adjust to and understand what this means for their lives. In the early stages, dementia may be imperceptible to all but those people who know the person well. The person will often be aware that their recall is slower, and may face pressure from family to visit a doctor because something is not right:

...Jill and a good family friend of ours, who happened to be my GP, started to sense something was not quite right. They noticed that I wasn't engaging socially like I had been previously. Throughout my life I had always been the leader of the pack. They noticed that I had started dropping off to be at the back of the pack, for want of an expression.²²

Marie and all her family were musical but now she can't remember how to play a single note. We tried to get to her play the piano at her nephew's house but she sat at the piano and sort of froze. I said 'go on, play', but you could see she was lost when she hit two keys and said 'I can't do it.'²³

As people get older, it is likely that their need for help around the home will increase beyond such things as getting to appointments, doing the grocery shopping, and some housekeeping. They may also start to need more help with the care of their own bodies: with showering or with caring for wounds. They may have problems with toileting or with taking medications correctly. While having someone in your home to clean and tidy can be a big change, having a stranger shower or dress your wounds, or help you use the toilet, can be confronting:

I had countless different people appear at my door. I did not know who to expect...The trouble with having different people come to my house is that I need to explain where everything is like the power points and laundry items.²⁴

21 Exhibit 4-2, Broome Hearing, Statement of Faye Philomena Dean, 5 June 2019, WIT.1142.0001.0001 at 0004 [30].

22 Transcript, Trevor Crosby, Sydney Hearing, 17 May 2019 at T1919.28-32.

23 Exhibit 5-17, Perth Hearing, Statement of Kevin Charles Chester, 3 June 2019, WIT.1137.0001.0001 at 0002 [13].

24 Exhibit 2-15, Adelaide Hearing 2, Statement of Josef Rack, 4 March 2019, WIT.0068.0001.0001 at 0002 [10].

Grace and I were both happy with the home care services she received. I remember that one of the home carers we saw regularly used to sing to Grace in the shower. She would have Grace singing along with her.²⁵

A deterioration in a person's ability to continue to stay at home may lead them or their carers back to My Aged Care. These enquiries almost inevitably lead to another face-to-face assessment for care—this time at a higher level, which means that the Government will provide more funding. People who want to stay at home seek to receive a Home Care Package. The Package represents a more coordinated set of aged care services at home. However, there is a long waiting list for a Package.

The Royal Commission has heard and read a great deal of evidence about the heavy toll of stress and anxiety that the long waiting times for Home Care Packages place on older people:

I have been in contact with My Aged Care a number of times to see if we can access extra help for my mother. I am told each time that the waiting list is 12–24 months for a package to help my mother. As well as the waiting list, each time we approach My Aged Care, we are told that she needs to be assessed once again. This is so frustrating as it is a further cost to the community – at 93 years of age, she is deteriorating so I am asking that these cases should not require assessment each time.²⁶

People don't know where they are up to in the queue for [Home Care Packages]. The information about when a package is assigned is not helpful or accurate. I feel that the information is used to pacify us and keep us quiet. We are kept in the dark and given false hope. There are many unanswered questions about how the system works. Is the government hoping it all gets too hard and that we drop out of the 'queue'?²⁷

For carers, too, the wait for care at home can cause considerable stress. The carer worries that the older person is at home alone, or they struggle to balance their caring responsibilities with their own jobs and families. While they worry about leaving the older person, carers need support in their caring role and may use overnight or longer-stay respite care options to take a break. People can have up to nine weeks of respite each year in a residential aged care facility, subsidised by the Government. Respite can be difficult to organise for short periods or without advance notice:

It would seem that these magical respite beds don't really exist. Well, they do on the My Aged Care Website but that's just fantasy stuff...For those of you who haven't done it, caring for a person living with dementia is a 24 hour seven day a week job. There are no weekends here. You are often left stressed, depressed, anxious and socially isolated. And respite is our only hope of a break from this.²⁸

25 Exhibit 1-63, Adelaide Hearing 1, Statement of Barrie Anderson, 15 February 2019, WIT.0030.0001.0001 at 0002 [18].

26 Submission AWF.001.01918.

27 Exhibit 1-61, Adelaide Hearing 1, Statement of Kaye Frances Warrenner, 18 February 2018, WIT.0031.0001.0001 at 0005 [43–45].

28 Submission AWF.001.00046.

Despite the best intentions of carers, or the supports in place (Government funded or otherwise), for some people there will come a time when they can no longer be cared for at home. This may be preceded by one or several events: a fall, an accident, too long a wait for a Home Care Package, a stay in hospital, a medical diagnosis, a pre-existing condition that worsens, or a new condition. Or their circumstances may change: a carer moves further away, transport services are no longer available or suitable, the person’s housing situation changes, or their spouse dies. In any of these cases, permanent residential care can become the only option:

Due to me not being able to lift her we had problems, I remember sitting on the bathroom floor with her for hours waiting for an ambulance to come, I have never felt so helpless.²⁹

My mother is suffering with dementia, she requires 24 hour care and is very fearful of being left on her own for even 5 minutes. She will wander, scream, cry and become overwhelmed easily and suffers from delusions and severe anxiety.³⁰

Just before Clive entered full-time care, he started to fall out of bed, meaning that I had to be even more attentive and aware of his movements during the night. As a result, my sleeping patterns became more and more disturbed, meaning that my own health suffered as I was not getting adequate sleep.³¹

In the system: residential aged care

Commonly, older people are unwell when they move into permanent residential aged care. The move is often a last resort, and can be one of the most daunting of life experiences:

When I moved into aged care, I experienced an overwhelming sense of loss. The sense of loss that comes from moving to aged care is really underestimated. There is the loss of your privacy, the loss of your independence and for me, it was the fear of the loss of my community as well.³²

Making the decision to go into residential aged care is just the first step. The challenge of finding a suitable room in an aged care facility can be considerable. The Royal Commission has heard from many people who struggled to get useful information about suitable services, and who found the processes of establishing how much care would

29 Submission AWF.001.02076.

30 Submission AWF.001.00130.

31 Exhibit 7-16, Mildura Hearing, Statement of Kay Gray, 26 July 2019, WIT.0310.0001.0001 at 0002 [13].

32 Exhibit 3-1, Sydney Hearing, Statement of Merle Valma Mitchell AM, 27 April 2019, WIT.0107.0001.0001 at 0002 [17].

cost, who would pay and exactly what care would be provided, frustrating and difficult. These difficulties are exacerbated if the move to residential aged care must be undertaken quickly:

My brother and I researched, searched and visited aged care facilities in the Geelong area—something that these facilities must understand is bloody horrible—scary and upsetting for the family. We were new to this process and OMG—this is a horrific process, difficult, confusing and frightening—even intimidating.³³

In some instances, older people can end up in an unsuitable location or non-preferred facility because there are no places available elsewhere at the time. Decisions are often made in haste due to the urgency of their health and care needs, or because people find they do not have the finances to move to their desired location. Stress and confusion about the financial options and consequences is common:

A lot of the elderly that come and want to enter are very concerned about the cost, and there's still definite confusion out there as to how much it's going to cost them. Do they need to sell their home? What can they do? They're very, very fearful.³⁴

Once a facility has been selected, the older person will transition from hospital, another facility or their home, into residential care. This involves moving clothes, a few personal treasures such as pictures of family and furniture items such as a favourite chair. For some people, it is their first move in many years, and we have heard that it comes with great personal cost. The experience can be distressing, as staff show the person around their new residence and explain the new routines, including meal times, medications and visiting hours:

Her room was no more than 3.5m x 4m (my guesstimate) grey walls, curtain for a door and Mum was one of the lucky ones having a window that looked out into the hallway.³⁵

So people come in and they're told this is your home now. Well, it's not. It's an institution, and it's where you live. But it's not a home, and no matter how many times they tell you, it's still not your home. So my answer always to anyone who tells me that is, 'This is where I live but it's not a home.'³⁶

While the initial transition to the facility is quick and sharp, it takes much longer for people to settle in. Knowing how to get help when it is needed, meeting many new people, becoming familiar with other residents, and connecting with staff and management, are all hurdles that people face. In many instances, the adjustment includes a cultural shock, as the person joins a community of strangers.

33 Submission AWF.001.00231.

34 Transcript, Gaye Whitford, Perth Hearing, 26 June 2019 at T2537.38–41.

35 Speaker at Rockhampton Community Forum, 20 August 2019.

36 Transcript, Merle Mitchell, Sydney Hearing, 6 May 2019 at T1149.3–6

Aboriginal and Torres Strait Islander people are particularly at risk when providers or staff do not recognise or respect the important role of culture and connection to Country:

The cultural aspects need to be looked at...especially anywhere that is predominantly cultural.³⁷

Sometimes some of the...white staff...they don't know the culture...sometimes I say...they have to learn more about our culture...to know the differences because about when someone dies they have no idea...we talk to them about what happens when an Aboriginal person dies [in care], we talk about the smoking ceremony...you have to talk to the right people to understand what can be done and what can't be done...the room's got to be smoked...and no one can go in there for 12 months.³⁸

The Royal Commission has heard about the particular experiences of Aboriginal and Torres Strait Islander people and the issues that are vital to their receiving good care. At the heart of their concerns is the important concept that older people are intrinsically valuable holders of cultural knowledge:

Our elderly people, they are our living treasures—they've earned the right to be treated with respect and dignity.³⁹

Don't treat them like children...remember they are adults...remember they have got probably more cultural knowledge than we've ever had. They are important people in our community.⁴⁰

Aboriginal and Torres Strait Islander people have a strong preference to remain with their family in their communities. However, in remote communities, with few aged care services, and a lack of respite, this can be challenging. One Aboriginal woman spoke about how the 'one size fits all' approach from the cities did not work in a remote setting where there were little or no alternative care options.⁴¹ It is clear that culturally appropriate care, including suitable food, is important in the care of Aboriginal and Torres Strait Islander people:

The aged care residential services are not culturally well informed. Many aspects of culture are discouraged or not permitted. It is hard to communicate how upsetting this is.⁴²

37 Submission AWF.600.01100.

38 Submission AWF.600.01099.

39 Broome Community Forum, 19 June 2019.

40 Submission AWF.600.01100.

41 Broome Community Forum, 19 June 2019.

42 Broome Community Forum, 19 June 2019.

Those old people, they're not there to be on a diet. They have to have a good feed and enjoy the rest of their life. Don't be feeding them...sandwiches. Give them proper cooked meals...Kangaroo meat...its soft...it's what they like...even stingray.⁴³

We were also clearly told that culturally appropriate servicing 'includes employment of Aboriginal people'.⁴⁴ There is a need for better awareness about when and how to use interpreters to communicate with Aboriginal and Torres Strait Islander people.

People from culturally and linguistically diverse communities may also experience difficulties feeling seen, heard and understood. Language and cultural barriers are common and misunderstandings between staff and residents complicate the transition into residential aged care further:

I noticed he would be speaking in English but conceptually in Egyptian and it sort of didn't make sense and...when he spoke English it felt like he was struggling but when he spoke Egyptian he was quite coherent. He was, you know, people had said that they didn't think he had dementia when he spoke in Egyptian because he was—it was just like he was a different person in the two different languages.⁴⁵

Mum dearly loved Australia, but her ethnicity is Dutch. So, I think she wanted to go into a home where she felt that Dutch community would care for her, and that's why she wanted to go there, yes.⁴⁶

The Royal Commission has heard and read that the losses people experience in moving into residential aged care are permanent, damaging and demeaning. People who are physically active feel imprisoned by strict rules about who can enter and leave a facility. People who are mentally active feel the lack of stimulation, company, conversation and intellectual activity. The response from the staff in the facility to a person's needs has a major impact on the person's health and wellbeing, and on that of their families:

Dad has declined dramatically, and it breaks my heart to see this once fit, active, kind gentleman left in his bed or princess chair, confused, lonely and fading fast. I want to see my Dad cared for and looked after...the way he should be.⁴⁷

The definition of care on those 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 summoning of the carer or floating carers by

43 Submission AWF600.01100.

44 Paraphrased from statement of Philip Matsumoto at Broome Community Forum, 19 June 2019.

45 Transcript, George Akl, Sydney Hearing, 6 May 2019, T1156.33–38.

46 Transcript, Johanna Aalberts Henderson, Cairns Hearing, 15 July 2019, T3457.40–43.

47 Exhibit 6-31, Darwin Hearing, Statement of Jo-Ann Lovegrove, 3 July 2019, WIT.0209.0001.0001 at .0008 [45]

the resident pressing a button. And once the resident immediately is satisfied, it's off to the next most urgent task or call, leaving the parties neither satisfied nor fulfilled.⁴⁸

Even if an older person needs full-time care, institutionalisation and the powerless that comes with it can worsen their condition:

Patients are BROKEN! They are stripped of their identity—their history, their contribution to society, they become simply work which has to be done. They are shown no respect. They have no VALUE. And their deterioration in these circumstances is to be expected.⁴⁹

Residential aged care can result in marked physical or behavioural changes in older people. People may become more fragile, less mobile and less active. People with mobility issues can often require more attention and more care. Behavioural changes may be prompted by new challenges and a loss of control over daily life. People may become defiant and insist on certain ways of living, despite the facility's processes and rules. These new behaviours can prompt serious and often exaggerated responses from the facility's staff. On the grounds that they must avoid the risk that the older person could hurt themselves or others, staff may restrain some people, by physical restraints or by administering medication for the purpose of sedation:

Mum's level of agitation can spike during any given day. If tired, hungry, scared or confused she can become overwrought and is capable of lashing out. This behaviour is not uncommon to dementia patients and she receives medication aimed at both reducing anxiety and managing her distress. During these times she requires a great deal of patience, kindness and competency.⁵⁰

We have heard that the ways people are cared for in residential facilities varies widely. In some instances, older people receive respectful and excellent care: their needs are met and they feel valued and nurtured. In contrast, we have heard many other reports of abuse, including intrusive and indecent actions, and neglect in residential care. The standard of care in a particular facility can be driven by operators or management, the carers, or, in some instances, the residents. Some people are healthier in residential aged care compared with home because their personal and medical needs are now being met, while others flounder if they do not receive proper care, including nutrition and hydration. One of the major issues we have heard, however, is that the food is not appealing:

Very bland. They don't use any salt or pepper. But they do have salt and pepper shakers on the table but some food you don't—you need to have it put in the cooking, and they don't use any spices...I've never had curry since I've been there. So you're just straight out plain food. If you get vegetables, there's no butter in the vegetables.

48 Submission AWF.600.00812.

49 Submission AWF.001.00330.

50 Exhibit 6-20, Darwin and Cairns Hearing, Statement of Lisa Backhouse, 3 July 2019, WIT.0221.0001.0001 at 0004 [26].

Potato, mashed potato, no butter in the mashed potato. It's so sticky and dry.⁵¹

...there were signs on resident's doors saying this or similar, 'please give mum an extra dessert, she is losing weight'. I spoke to family who said they actually bring in their own food and feed their family member but what happens to those without family?⁵²

...unless they are getting fed within 15 minutes of the food leaving the kitchen, they are being fed a cold meal.⁵³

Dementia care

The need for dementia care is one of the primary reasons people enter residential care. As the older person struggles to deal with the fact of moving into residential care, they also struggle to cope with memory loss and difficulties with thinking, problem-solving or language, and grapple with their sense of self:

She has since been moved to the dementia ward and since being there has lost numerous items of clothing, glasses, slippers, jumpers etc. Which I am not happy about. I worry about whether she is getting the care she really needs.⁵⁴

Personal experiences of dementia are largely under-explored. As a person's cognitive capacity declines, it may be difficult for them to make themselves understood. Other people may not always take the time to listen and to understand them. There is no doubt that residents with dementia experience fear and confusion.

For some people, dementia develops quickly. When it progresses more slowly, people can develop strategies to hide the condition. Because of the complexities of behaviour and emotions, people who are not cared for respectfully can experience outbursts of frustration and rage. This impacts on personal care and nursing staff, including heightening the possibility of injury. In turn, this leads to further distress for the family:

My father was like a caged animal and we asked how long he was restrained at any one time. The policy is 2 hours and then they are unrestrained but with one to one care for a bit for him to be toileted before being restrained again. It's appalling to see this.⁵⁵

51 Transcript, Darryl Melchhart, Sydney Hearing, 6 May 2019 at T1144.4-9.

52 Exhibit 6-44, Darwin and Cairns Hearing, Statement of Timothy Deverell, 19 June 2019, WIT.0216.0001 at 0002 [10]

53 Exhibit 6-43, Darwin and Cairns Hearing, Statement of Nicholas Micael Zane Hall, 4 July 2019, Wit.0215.0001 at 0005 [41].

54 Submission AWF.001.00121.

55 Submission AWF.001.00081.

Dad was off his face, drugged up to the eyeballs, incoherent and lying in a pool of urine. I have video of this, it was very, very distressing.⁵⁶

As the illness progresses, families and friends 'lose' the person and feel powerless to provide support or care:

The nursing home...had illegally stopped me from taking [him] out... Many of his friends do not know he is there. He has no free access to a phone and no access to his contacts.⁵⁷

Not only was it clear just looking at her that she was very unwell, but she had a letter from her doctor. This is very substandard care. I feel she was treated as though she had no rights because she was elderly.⁵⁸

The end of life

People suffering from a terminal illness, or nearing the end of their life's span, may need palliative care while they are in residential care. For some people, their whole experience of residential aged care is in palliation, or in dying. This may last a few months. For others, the time in palliation and end-stage care is at the end of a number of years in the residential facility. We have heard that the availability and standard of palliative care provided in residential aged care is widely variable:

...we started to have discussions with the [hospital] staff about him needing to move back to the facility, and I was begging them, I said they can't look after him at Alkira Gardens; they've demonstrated that twice, I'm very worried about him moving back there. I was very worried about him being hoisted out of bed because...it was very distressing and painful for him.⁵⁹

When I arrived, I could hear Mum's breathing from about 20 metres down the corridor, it was so loud. When I got into the room I could see that her breathing was very laboured and she looked uncomfortable. There was no one around to help my mum. I ran around the facility doing laps of the corridors trying to find a nurse or just someone to assist...This went on for at least 30 minutes before we could find someone to help us. Even when we were able to find people, we felt they did not know how to handle the situation.⁶⁰

Residential aged care is a place where people will and do die, and that experience should be as free from pain and fear as possible for the person.

56 Submission AWF.001.00271.

57 Submission AWF.001.00680.

58 Submission AWF.001.03515.

59 Transcript, Shannon Ruddock, Perth Hearing, 27 June 2019 at T2660.1-6.

60 Exhibit 3-36, Sydney Hearing, Statement of DJ, 12 May 2019, WIT0190.0001.0001 at [20]-[21].

Conclusion

In describing what it can be like to seek access to, and live within, the current aged care system, the Royal Commission has drawn on the evidence and research presented to us in the first phase of our work. Our Final Report will have more to say on these topics.

The story this chapter tells us about the aged care system is a distressing story. Every person's experience of aged care is different and, happily, some of the stories we have heard are positive. Unfortunately, the positive stories are the exception.

Over the next 12 months, the Royal Commission will also examine whether there are societal barriers to the enthusiastic acceptance of reforms to aged care. As the Age Discrimination Commissioner, the Honourable Dr Kay Patterson AO, said when Counsel Assisting asked her during the Perth Hearing if Australians value older people:

I don't think you can generalise in that way. I think that a large number of people value older Australians and respect them, but, sadly, they're not represented well in the press. Sadly, they're not represented well in various walks of life, and there is a lot of ageism in terms of people believing that older people are had it, dependent, a burden. I think sometimes, some of our policy affects it... we use negative language, and we actually, in fact, not only influence the community in having negative effects, but older people themselves begin to feel that they're worthless and useless. We may appreciate what they do as carers, for grandchildren and for their partners and for children with a disability. We—we value what they do as—as volunteers, but we underestimate and devalue their other contributions to the community.⁶¹

The next stage of our work and our Final Report will make recommendations on whole-of-system reform and redesign. No system that is supposed to support and care for older people, which they have helped to pay for through their taxes, should be instead a signifier for loss, abandonment and fear. The present generation of older Australians, and those who will follow them, deserve far more than this.

⁶¹ Transcript, Kay Patterson, Perth Hearing, 26 June 2019 at T2543.7-24.

Part 3

Inconvenient Truths

5. Finding the Door

Well, I really had only the telephone to make inquiries on. And it was very difficult, actually, but I did get in eventually...it was all online and very tiny, and I can't—I have never been online. I can't access online services due to my poor vision. I wish I could, of course I used computers as a librarian. But it's just not possible now. And that made it very, very hard. I did read, after a fashion, some of the material that was sent out by My Aged Care, and I took care to get everything I could. I went out of my way and—however, a lot of it was pretty vague and it was quite hard, a difficult process.¹

Introduction

The first contact most people have with the aged care system is when they are searching for information. The need to find out about aged care services can be prompted by a variety of events. An older person may experience a decline in their health or mobility, or receive a diagnosis, including of dementia, which means their ability to keep living independently, even with their spouse, is in decline. A husband or wife may die, leaving the older person alone. Many people come out of hospital after a surgical procedure much frailer than they were when they went in. A person may experience a sudden decrease in cognitive function, start to have episodes of dizziness or falls at home, or worsening incontinence. For these and other reasons, a person finds that they, and often their family, are facing the need to obtain support in the home, or to find a place in an aged care residence.

This chapter explores the gateway or 'front door' of the system for older people who need formal care and support, covering four broad areas:

- the limitations of online portals in providing information and support for the current generation of older people
- the lack of localised and face-to-face services to navigate the system and connect people to services
- the inadequacies of the My Aged Care website in meeting expectations to operate at a standard similar to other online services that provide detailed information and how it compares to aged care information services offered by some other countries
- the extent to which the long waiting lists and waiting times for people to access Home Care Packages, and the lack of communication about the list, is compounding frustration with the My Aged Care portal.

1 Transcript, Marie Dowling, Adelaide Hearing 2, 20 March 2019 at T903.3–14.

Most people put off the decision to seek help from, or accommodation within, the aged care system for as long as possible. To make this decision means acknowledging, even if tacitly, their own increasing frailty and inevitable mortality. People see entering aged care as a surrender of independence and a loss of control.

Ideally, information about aged care services would be easily available to everyone. It would be presented in clear language and would set out exactly what services are available in the person's home town or region, who provides these services, how much they cost, how much Government subsidy is available and how good the services are. The information would help people understand the assessment arrangements, how to get services organised, and what financial information they need to provide and to whom.

The Royal Commission has learnt that the reality is very different. A public submission described the administrative difficulties and emotional turmoil involved in beginning the search for aged care:

My brother and I researched, searched and visited aged care facilities in the Geelong area: something that these facilities must understand is...[this is] horrible, scary and upsetting for the family. We were new to this process and...this is a horrific process, difficult, confusing and frightening, even intimidating.²

Through public and expert submissions, at hearings and in community forums, the Royal Commission has heard again and again how difficult it is for older people and their families to navigate the aged care system, which they find complex and confusing. We have been told that people do not know where to turn for help and must make emotionally, financially and practically difficult decisions without the benefit of the right information and support, and often under time pressure:

The challenge is you don't know what to ask for because you don't know what's on offer, and so it goes around and around...I was dealing with both the death of my father, my mother—who was in a steady mental health decline—and a system that was cold and bureaucratic...It was soul destroying.³

The feedback from older people and their families does not seem to have changed much since the complexities of navigating the aged care system were comprehensively documented by the Productivity Commission in the report of its 2011 *Caring for older Australians* inquiry.⁴ This is despite the establishment of My Aged Care as the main entry point, or gateway, for the Australian aged care system in partial response to the Productivity Commission's recommendation.⁵

2 Submission AWF.001.00231_0001.

3 Submission AWF.001.01660_0001.

4 Productivity Commission, *Caring for Older Australians (Report No. 53, Final inquiry report)*—Overview, 2011.

5 Submissions of the Commonwealth – Hearing 2, 29 March 2019, RCD.0012.0003.0012 at 0016-17.

Many questions have been raised about how truly helpful My Aged Care is in educating older Australians about aged care services and helping them to make choices and decisions. We have heard that people continue to struggle to find out what to do when they need to access aged care services and support.

National Seniors Australia surveyed members on their readiness to navigate the aged care system in 2018. Findings indicated many Australians over 50 years of age were unprepared for the complexity of the aged care system. Many people's knowledge of the aged care system was limited and most had not used the My Aged Care website or call centre. This is despite more than 40% of people surveyed expecting to deal with aged care issues within five years. One surveyed member said:

The main problem with age services, you don't know what you don't know. When a problem comes up, one is not too sure of where or how to obtain the right information.⁶

The Royal Commission has heard that finding one's way into and through the aged care system is anything but easy.⁷ Mr Barrie Anderson, giving evidence in Adelaide, explained how he and his wife Grace struggled to understand their aged care options after Grace was diagnosed with dementia:

For us, navigating the system meant setting up a network of people who could help us. This was not an easy task.⁸

A gateway to the aged care system

Support to navigate a complex system

Reviews and inquiries into the aged care system have pointed out that the system is complex and fragmented and attempts at reform have often added complications.⁹ Chief Executive Officer of the Older Persons Advocacy Network, Mr Craig Gear, told us that on a person's aged care journey, the 'potholes' are in getting information about what services might be available, registering, waiting for assessment and then accessing timely

6 Exhibit 1-4, Adelaide Hearing 1, Statement of John McCallum, 31 January 2019, WIT.0004.0001.0001; K Rees, J Maccora and J McCallum, *You don't know what you don't know: the current state of Australian aged care service literacy*, 2018, NSA.999.0003.0001 at 0005.

7 Transcript, Craig Gear, Adelaide Hearing 1, 12 February 2019, T0140; Transcript, Maree McCabe, Adelaide Hearing 1, 19 February 2019, T0404 and T0408; Transcript, Kaye Warrenner, Adelaide Hearing 1, 21 February 2019, T0596.

8 Exhibit 1-63, Adelaide Hearing 1, Statement of Barrie Anderson, 20 February 2019, WIT.0030.0001.0001 at 0002 [14].

9 Refer to Chapter 2. See also Productivity Commission, *Caring for Older Australians (Report No. 53, Final inquiry report)*—Vol 1, 2011, D Tune, *Legislated Review of Aged Care*, 2017.

care.¹⁰ The Secretary of the Australian Department of Health told the Royal Commission that the Australian Government understands that the system is tough to navigate:

Part of our challenge is the aged care system has evolved over many years—there are many different programs and supports available (reflecting some historical arrangements), and many different providers. We know that finding the right services in the right place at the right time can be hard, and...may not be always possible.¹¹

The Australian Government established My Aged Care as the gateway into and through the aged care system in 2013.¹² It was supposed to be a visible and user-friendly entry point for people's early searches and make aged care more accessible, and is the main vehicle for providing people with advice about aged care in Australia.¹³ My Aged Care's call centre received over 1.4 million calls, 400,000 pieces of correspondence and over 3.5 million visits to the website in 2017–18.¹⁴

As described in Chapter 1, and in *Background Paper 1—Navigating the maze: an overview of Australia's current aged care system*, My Aged Care screens an older person before recommending that an assessment be undertaken to determine if they are eligible for support. There are two pathways for assessment. Both can be conducted in the home. One leads to the Regional Assessment Service and the possibility of care under the Commonwealth Home Support Programme. The other leads to an Aged Care Assessment Team and possible eligibility for Home Care Packages, permanent residential aged care, residential respite care, or a combination of those services. The Aged Care Assessment Teams make a comprehensive assessment of a person's needs to determine eligibility for care. Once a person enters residential aged care they are assessed a further time by the provider, under the Aged Care Funding Instrument, to allocate funding for their care needs. People may also be assessed by the Australian Department of Human Services (now called Services Australia), or by the Australian Department of Veterans' Affairs, for their financial capacity to contribute to their aged care either before or immediately after they start receiving care.

There are some positive reviews and evaluations of My Aged Care, particularly in evidence given on behalf of the Australian Department of Health by Ms Fiona Buffinton, the then First Assistant Secretary of In Home Aged Care Division. At the second Adelaide Hearing, we heard from Ms Buffinton that there is generally a high level of satisfaction with My Aged Care.¹⁵ At the Mildura Hearing, Ms Buffinton stated that while My Aged Care is not working as well as it could, the system is not broken. The Department claims that much effort has

10 Transcript, Craig Gear, Adelaide Hearing 1, 12 February 2019 at T0140.7–12.

11 Exhibit 1-23, Adelaide Hearing 1, Statement of Glenys Beauchamp, 4 February 2019, WIT.0022.0001.0001 at 0037 [164]–[166].

12 Australian Department of Health, *Australian Government Response to the Productivity Commission's Caring for Older Australians Report*, 2012, p 15, rec 9.1.

13 Exhibit 1-23, Adelaide Hearing 1, Statement of Glenys Beauchamp, 4 February 2019, WIT.0022.0001.0001 at 0037 [164]–[166].

14 Transcript, Fiona Buffinton, Adelaide Hearing 2, 22 March 2019 at T1061-30.

15 Transcript, Fiona Buffinton, Adelaide Hearing 2, 22 March 2019 at T10610-25.

been invested into designing the website, in consultation with the people who use it, and that improvements are made continually in response to feedback received.¹⁶

Various surveys conducted by or on behalf of the Department have produced positive findings. In 2017–18, it was estimated that 92.7% of people using the My Aged Care call centre were satisfied with the service provided,¹⁷ just falling shy of the Department's target of 95% satisfaction.¹⁸ At the beginning of 2019, the waiting time to speak to a person in the call centre was reported to be just 30 seconds.¹⁹ In evidence for the first Adelaide Hearing, the Secretary of the Department of Health, Glenys Beauchamp, pointed to the increasing satisfaction of users of My Aged Care, captured in surveys between 2015 and 2017.²⁰ Surveys between October 2016 and early 2017 reported that about 79% of participants were satisfied with the quality of information received from the call centre—although this was just 40% for carers.²¹ While government reporting indicates that people are generally happy with the My Aged Care call centre, the Royal Commission has heard the opposite. For example, Mrs Dowling, who is now receiving a Home Care Package, said:

I ended up absolutely at the end of my tether. I am a very persistent person. I am trained as a librarian and I always thought that if it's out there, I will find it, but My Aged Care defeated me.²²

The Department's performance indicator in 2017–18 for the My Aged Care website was that at least 65% of people using it found it useful or that it met their needs. However, even that low target was not met.²³ In 2017–18, it was estimated that barely half (55%) of surveyed users were happy with the service provided by the My Aged Care website.²⁴

Older people and their families, friends and carers have told the Royal Commission that My Aged Care is 'pretty useless', 'horrible', delivers 'standard lines'²⁵ and goes 'round in circles'.²⁶ We have heard that the website is hard to use and not user-friendly.²⁷ The Royal Commission has heard stories about people receiving incorrect information from the My Aged Care call centre and website. Call centre staff members can often provide different answers to the same question and the website is not always up to date.²⁸ Chief Executive Officer of Dementia Australia, Ms Maree McCabe, said that the information people received

16 Transcript, Fiona Buffinton, Mildura Hearing, 31 July 2019 at T4139.19-26.

17 Australian Department of Health, *Portfolio Budget Statements 2018-19: Budget Related Paper No. 1.9*, 2018, p 136.

18 Australian Department of Health, *Corporate Plan 2017-18*, 2018, CTH.1000.0001.1352 at 1386.

19 Transcript, Fiona Buffinton, Adelaide Hearing 2, 22 March 2019 at T1061.20.

20 Exhibit 1-23, Adelaide Hearing 1, Statement of Glenys Beauchamp, 4 February 2019, WIT.0022.0001.0001 at 0038 [167].

21 Healthdirect Australia, *My Aged Care Evaluation: Stage Two Wave 2 (Summary of Findings—Final)*, 2017, p 10.

22 Exhibit 2-34, Adelaide Hearing 2, Statement of Marie Dowling, 15 March 2019, WIT.0077.0001.0001 at 0023 [58].

23 Transcript, Fiona Buffinton, Adelaide Hearing 2, 22 March 2019 at T1060.13-16.

24 Australian Department of Health, *Portfolio Budget Statements 2018-19: Budget Related Paper No. 1.9*, 2018, p 136.

25 Exhibit 2-76, Adelaide Hearing 2, Statement of Ruth Harris, 12 March 2019, WIT.0074.0001.0001 at 0003 [22].

26 Exhibit 2-80, Adelaide Hearing 2, Statement of Rita Kersnovske, 13 March 2019, WIT.0088.0001.0001 at 0002 [13].

27 Transcript, Paul Sadler, Adelaide Hearing 2, 18 March 2019, T737.42-47.

28 Transcript, Maree McCabe, Adelaide Hearing 1, 19 February 2019 at T0406.6-8; Transcript, Raelene Ellis, Adelaide Hearing 2, 18 March 2019 at T0696.1-9.

from My Aged Care was inconsistent, and that the quality of information depended on the particular staff member at the call centre.²⁹ Carers report complicated approval processes to interact with the contact centre on behalf of a family member, as they repeatedly need to establish their authority with different agencies.³⁰ Similarly, a public submission noted that:

Phones are always answered quickly by an English-speaking staff member, though it depends who you speak to [in terms of] what information you receive. You can phone three times in the same day and get three different pieces of information.³¹

At the second Adelaide Hearing, the Australian Department of Health accepted that there are people who find accessing My Aged Care difficult.³² However, the Department did not accept that the current My Aged Care website and call centre are failing the community.³³

A 2017 review of aged care assessed the effectiveness of arrangements for accessing aged care services, including My Aged Care. The review was mandated by the *Aged Care (Living Longer Living Better) Act 2013* (Cth). The reviewer, Mr David Tune AO PSM, a former Secretary of the Australian Department of Finance and the current Chair of the Aged Care Sector Committee, said that the introduction of My Aged Care was a significant reform which faced ‘substantial implementation challenges’.³⁴ While concerns continued about accessibility of the system, Mr Tune concluded that My Aged Care was an important step forward for service delivery.³⁵

Mr Tune noted there were low levels of community awareness about aged care and of My Aged Care and that regular information campaigns were required to build awareness of its function.³⁶ Research funded by the Australian Department of Health in March 2018 found that 34% of those surveyed were not even aware that the Government subsidised aged care in the home and only 54% of people surveyed had ever used the My Aged Care website.³⁷

In 2014, there was a Government-funded information campaign, ‘Let’s talk about aged care’, followed in 2017 by a second wave of advertising and distribution of information, the ‘Find the help you need with My Aged Care’ campaign. Research into the impact of the 2017 campaign found that while people rationally saw relevance in knowing more about aged care, they were likely to delay interacting with the aged care system for as long as possible. Because of the emotional impact of even approaching the aged care decision, people were in effect limiting their own access to knowledge about the system.

29 Transcript, Maree McCabe, Adelaide Hearing 1, 19 February 2019 at T0406.6-8.

30 Transcript, Fiona Buffinton, Adelaide Hearing 2, 22 March 2019 at T1064.46—T1065.1; Transcript Maree McCabe, Adelaide Hearing 1, 19 February 2019, T0410.24-28.

31 Submission AWF390.00049.

32 Transcript, Fiona Buffinton, Adelaide Hearing 2, 22 March 2019 at T1065.11-12.

33 Transcript, Fiona Buffinton, Adelaide Hearing 2, 22 March 2019 at T1067.7-12.

34 D Tune, *Aged Care Legislated Review*, 2017, p 10.

35 D Tune, *Legislated Review of Aged Care*, 2017, p 10.

36 D Tune, *Legislated Review of Aged Care*, 2017, p 11.

37 Bastion Latitude, *Healthy Ageing Developmental Research Report*, Report for the Australian Department of Health, 2018, p 5.

This makes the design and targeting of public information campaigns very difficult. The Australian Department of Health's research clearly showed that when people did accept the necessity to interact with the system, they wanted practical help to find information.³⁸

There is evidence from the 2017 campaign evaluation that it increased access to My Aged Care after targeting advertising of the gateway towards baby boomers (those born between 1946 and 1964) and people older than this, rather than those of traditional working age.³⁹ While older people might have been more likely to know of My Aged Care, it was not a well-known government service for the general population.

The idea for a streamlined entry point

The Productivity Commission's *Caring for older Australians* inquiry investigated the array of government-funded portals and services that were then providing information on aged care and healthy ageing. This includes Commonwealth Carelink and Respite Centres, a web-based information service, a call centre, Home and Community Care program information services, and Aged Care Assessment Teams. This report concluded that these needed to be consolidated and streamlined. It recommended that the Government establish an Australian Seniors Gateway Agency to provide information and to assess people's needs and their financial capacity to pay fees, refer people to providers, and support them to coordinate their aged care. The gateway was to include a single platform and operate via a network of regional centres, and would also provide case management when necessary. This recommendation built on a concept proposed by COTA (formerly Council on the Ageing) to the Productivity Commission. The Royal Commission heard that COTA considered that such a gateway would overcome the challenges people faced in making separate phone calls, visits and repetitively providing the same information to gain entry to aged care.⁴⁰ However, COTA explained that their original concept included integrated face-to-face services.⁴¹

The Government supported part of the Productivity Commission's recommendation about setting up a gateway. It allocated funding to set up My Aged Care in stages, as follows:

- 1 July 2013—My Aged Care was introduced. It consisted of a website and call centre to provide 'clear and reliable information to older Australians, their families and carers'.⁴² At this stage, the role of My Aged Care was to provide information only. Providers managed referrals, waiting lists and assessments for the former Home and Community Care program.

38 Kantar Public, *Aged Care Changes Campaign Quantitative Benchmarking and Evaluation*, Final Report for the Australian Department of Health, 2017, p 9.

39 Kantar Public, *Aged Care Changes Campaign Quantitative Benchmarking and Evaluation*, Final Report for the Australian Department of Health, 2017, p 9.

40 Exhibit 1-3, Adelaide Hearing 1, Statement of Ian Yates, 31 January 2019, WIT.0006.0001.0001 at 0010 [38].

41 Transcript, Ian Yates AM, Adelaide Hearing 1, 11 February 2019 at T0077.7-16.

42 Australian Department of Health, *Australian Government Response to the Productivity Commission's Caring for Older Australians Report*, 2012, p 14.

- January 2015–September 2016—additional capabilities were introduced to My Aged Care, including a registration process for people calling to enquire about aged care (so that they would not need to repeat information), initial screening to determine people’s care needs, a referral service to let people know over the phone which providers might suit them, and online portals on the website through which both individuals and providers could access information on their My Aged Care records.
- July 2015—when the Home and Community Care program was combined with other programs to become the new Commonwealth Home Support Programme, assessments for eligibility were moved from providers to Regional Assessment Services which were in turn connected to My Aged Care.
- early 2016—assessments of eligibility for care, undertaken by Aged Care Assessment Teams, were linked into the My Aged Care gateway.⁴³

Since its establishment, further changes have been made to the My Aged Care website. The Department of Health received over \$273 million to operate the My Aged Care gateway in 2018–19, covering the call centre, website and assessments delivered by the Aged Care Assessment Teams and Regional Assessment Services around the country.⁴⁴ Given the size of this investment by the Government, it is surprising that My Aged Care is still unable to deliver relevant local and individually tailored information to the people who call upon its services or visit its website. Chief Executive Officer of COTA, Ian Yates AM, told us that some of the problems with My Aged Care involve its suitability for people from diverse backgrounds:

While we critique the implementation of My Aged Care as it was adopted by the then Government, it has been largely successful at providing a single place and process for entry into aged care. However, because it was never fully implemented as COTA envisaged, by the then or subsequent governments, it continues to present a barrier to entry for some population groups. This is particularly true for some Culturally and Linguistically Diverse populations and for most Aboriginal and Torres Strait Islander populations who are often not as confident engaging with government entities, or have capacity to do so.⁴⁵

In its response to the Productivity Commission report, the Government agreed that the My Aged Care gateway needed to be responsive to local needs but argued that it was ‘premature’ to invest in new regional infrastructure given the potential of the new website and call centre. It also argued that any investment in future infrastructure would need to build on premises and services of the former Department of Human Services (now Services Australia, and incorporating Centrelink and Medicare offices).⁴⁶ Seven years after the then Government made these statements, there is no local infrastructure for My Aged Care. Centrelink remains the only local government shopfront ‘on the ground’,

43 Australian Department of Health, ACAT Transition to My Aged Care, 2016, <https://agedcare.health.gov.au/programs-services/my-aged-care/acat-transition-to-my-aged-care>, viewed 9 October 2019.

44 Australian Department of Health, *Portfolio Budget Statements 2018–19: Budget Related Paper No. 1.9*, Australian Government, 2018, p 133–134.

45 Exhibit 1-3, Adelaide Hearing 1, Statement of Ian Yates, 31 January 2019, WIT.0006.0001.0001 at 0010 [39].

46 Australian Department of Health, *Australian Government Response to the Productivity Commission’s Caring for Older Australians Report*, 2012, pp 15–16.

but its role does not extend to linking people with aged care services and support, and the Royal Commission has heard accounts of a distinct lack of aged care knowledge amongst Centrelink staff.⁴⁷ The Government also announced that it would implement a linking service to assessments for the allocation of residential aged care funding per person as part of the gateway, but this has not been done.⁴⁸

From what the Royal Commission has heard, it is apparent that My Aged Care is not yet successfully working as the front door to the aged care system. Despite the move to a single platform, older people and their families continue to find navigation of aged care bewildering and frustrating, and say that information is still inconsistent. There is still a 'labyrinth' to negotiate after someone has gone through the gateway. A recent national study showed that carers need to access information from four or more sources to navigate the system successfully.⁴⁹

Research conducted for National Seniors Australia noted that one way of changing the public image of aged care could be to make entry to aged care much easier.⁵⁰ It is clear from the research done by National Seniors Australia that there is a need to increase the aged care knowledge of those who will have contact with the system in the next five to ten years.

Improving people's knowledge about aged care services and demystifying the processes of entry and access, requires a fundamental rethink of My Aged Care, a redesign of its website and crucially, education and ongoing training for call centre staff so that they deliver accurate, consistent information in a helpful and timely manner.⁵¹

Older people, their families and carers, need relevant, current and accurate information to make informed choices about aged care. The cost and quality of these services is an essential part of this information. In relation to cost, older people have a number of steps to go through. They must have their means assessed by the Department of Human Services (now Services Australia) or the Department of Veterans' Affairs, and try and understand a range of complicated information about the fees and charges they face. For people entering residential aged care, the financial decisions that must be made, such as whether to make an upfront or daily contribution for their accommodation, are significant and are often being made at times of great stress. Making judgements on the factors to consider about the quality of the respective providers and services, especially in the absence of service level information, is also difficult.

47 Exhibit 1-3, Adelaide Hearing 1, Statement of Ian Yates, 31 January 2019, WIT.0006.0001.0001 at 0010[39].

48 Australian Department of Health, *Australian Government Response to the Productivity Commission's Caring for Older Australians Report*, 2012, p 14.

49 Transcript, Lyn Phillipson, Mildura Hearing, 30 July 2019 at T4025.31–39 and T4027.19–23.

50 K Rees, J Maccora and J McCallum, *You don't know what you don't know: the current state of Australian aged care service literacy*, 2018, NSA.999.0003.0001 at 0006.

51 Exhibit 1-64, Adelaide Hearing 1, Response of Professor John Pollaers, 20 February 2019, ACW.9999.0001.0001.

While the Government could reasonably argue that My Aged Care has achieved its aim of consolidating many different paths into aged care into one place, My Aged Care is still no substitute for local knowledge and face-to-face interactions. There is a strong argument that no online portal should seek to be such a substitute. In an area that is so vitally important to peoples' lives, there should always be the ability to talk to someone who has the relevant information and can help identify the best local options for services and care.

Seven years after its introduction, My Aged Care is not delivering the vision the Productivity Commission outlined of seamlessly allowing people to navigate the aged care system. The Royal Commission will give further detailed consideration to the future of My Aged Care, including the need for appropriate local infrastructure and comprehensive information, in the next phase of its work.

Searching for safe and high quality services

While the most difficult choice facing older people and their families is about moving into residential aged care, older people increasingly want to receive care in their home. They will need support and information about all their care options. The 2017 Carnell-Paterson review of aged care quality regulation reported that the absence of reliable, comparable information about quality in residential care is a striking feature of the current system. The review recommended the publication of 'clear, readily intelligible information that includes some form of star rating against core standards'.⁵² This follows a number of other reviews which suggested that star ratings or another easily comparable rating system should be implemented.⁵³ The Carnell-Paterson review also said that greater emphasis should be given to measures of the quality of life (for example, time spent by staff with residents, types of care and support offered) and to evidence that the residence provides a home-like environment.⁵⁴ In the Sydney Hearing, the Chairman of Alzheimer's Disease International, Mr Glenn Rees, stated that basic information about the quality of residential services to enable people to make comparisons is lacking:

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 [and] have palliative care skills or other things. I think for the consumer it is very, very difficult to know where to go.⁵⁵

52 K Carnell and R Paterson, *Review of National Aged Care Quality Regulatory Processes*, 2017, p vii.

53 See: WP Hogan, *Review of Pricing Arrangements in Residential Aged Care*, Final Report, 2004, pp 244–45; The Senate Community Affairs References Committee, *Quality and equity in aged care*, 2005, p 42; Campbell Research & Consulting, *Evaluation of the impact of accreditation on the delivery of quality of care and quality of life to residents in Australian Government subsidised residential aged care homes*, 2007, p 96–101; Productivity Commission, *Caring for Older Australians (Report No. 53, Volume 2)*, 2011, p 218; K Carnell and R Paterson, *Review of National Aged Care Quality Regulatory Processes*, 2017, p 104.

54 K Carnell and R Paterson, *Review of National Aged Care Quality Regulatory Processes*, 2017, p 142–147.

55 Transcript, Glenn Rees, Sydney Hearing, 13 May 2019, T1546–T1547.

While My Aged Care is intended as a resource to assist people seeking care, the functionality of the site that allows the user to search for services that may meet their needs is poor. For example:

- No more than three services can be compared at any one time.
- While searches can be refined by the culture, religion and language capabilities of different providers, there are no limits or checks on what providers claim to offer. For example, a provider may state that it offers services for lesbian, gay, bisexual, transgender and intersex people but it is not required to have a Rainbow Tick, the standard accreditation for service providers. Similarly, a service may state that it has staff who speak a range of languages, but there is no way of ascertaining whether this is true and in some cases it appears that it may be accurate for the entire provider organisation but not for the particular local services.
- Services may be listed as available (with a tick) when the provider is not currently offering those services or does not have the capacity to take on new clients. This is particularly true for Home Care Packages and respite care.
- Information about the prices for Home Care Packages is only available by downloading each individual provider's price list, and not all providers show their prices.
- It is not possible to compare the performance of providers against even the most routine satisfaction measures.⁵⁶

The most obvious gap in the information available to compare services is the lack of detail about their performance against the Aged Care Quality Standards. Anyone seeking details on performance against the Standards is redirected from a provider search to the 'Compliance Information' section of the My Aged Care website and must then search again for the service that they were interested in. If a person wants to understand more about particular issues with that service, they must then go to the Aged Care Quality and Safety Commission website and search for the audit reports on the service. This is a time-consuming and difficult process, and still does not necessarily yield information that allows a person to differentiate between barely adequate and high quality services. While auditors and assessors from the Aged Care Quality and Safety Commission may be able to differentiate between services that far exceed the standards and those that 'just fall over the line', they only report outcomes on a met or not met basis.

The Aged Care Quality and Safety Commission collects data on the services and providers involved in contacts, complaints, and formal referrals for regulatory action. However, in the case of entities that own or operate multiple services, this information is not published about each service or even about each provider. The Australian Department of Health also collects information on 'reportable assaults'⁵⁷ (certain unlawful sexual contacts with residents of aged care facilities and the unreasonable use of force on residents),

56 Based on searches of the website conducted by Royal Commission staff in May, June and July 2019 (noting that the website was updated on 24 June 2019).

57 *Aged Care Act 1997* (Cth) s 63-1AA(2).

as well as ‘unexplained absences’ of residents but again does not report these at a service or provider level.⁵⁸ There is no public transparency of these data.

The Australian Department of Health collects financial information from approved residential care providers annually and this information is then used in reports by the Aged Care Financing Authority (a committee established to provide independent advice to Government on funding and financing issues, and currently chaired by Mr Mike Callaghan AM PSM).⁵⁹ However, the information that is published by the Aged Care Financing Authority is aggregated to market segment level, that is:

- for-profit
- not-for-profit
- size of provider
- location: metropolitan / regional.

There is *no* public information on the way providers use taxpayers’ funds and individuals’ contributions to deliver aged care services.

In both the United Kingdom and the United States of America, public websites offer considerably more information than does My Aged Care on the performance of individual aged care services. One of the reviewers on the 2017 review of the Aged Care Quality Framework, Professor Ron Paterson ONZM, has closely examined the information published in those two countries, and told us:

In my view, Australia does not publish good quality comparative information for consumers about aged care services, particularly when compared to the information available in the United States and the United Kingdom. Australia, like New Zealand, is lagging behind international trends in transparency of comparative healthcare quality information and failing to take advantage of an important driver for quality improvement among providers.⁶⁰

The American Medicare.gov ‘Nursing Home Compare’ site provides star ratings for staffing levels, quality and health inspections, as well as details of recent inspections for thousands of government subsidised nursing homes. The site also sets out the number of hours spent per day per person in the home by registered nurses, assistant nurses and physical therapists. People searching for information in the United States can also find—on the same site—the number of hospitalisations, emergency department visits, falls, uses of antipsychotic medication, urinary tract infections, catheters and other health measures for residents of each home.⁶¹

58 *Aged Care Act 1997* (Cth) s 63-1(1)(m); *Accountability Principles 2014* (Cth) s 25.

59 Australian Department of Health, ‘Aged Care Financing Authority’. *Ageing and Aged Care*, updated: 4 July 2019, <https://agedcare.health.gov.au/aged-care-reform/aged-care-financing-authority>, viewed 19 September 2019.

60 Exhibit 8-29, Brisbane Hearing, Precip of evidence prepared by Ron Paterson ONZM, RCD.9999.0143.0001 at 0003 [28].

61 See US Government, ‘Nursing Home Compare’. *Medicare*, <https://www.medicare.gov/nursinghomecompare/search.html?>, viewed 24 July 2019.

Dr Lisa Trigg, an academic and civil servant in the Welsh social services, has made a detailed comparison of the aged care systems of Australia and the United Kingdom. In the Perth Hearing, she noted how increasing the information available on sites like Nursing Home Compare can assist people to make informed choices about providers, and it is more likely to incentivise providers to improve their care. Dr Trigg observed, however, that some studies suggest that people still do not use the information on care and performance in Nursing Home Compare to differentiate between providers.⁶²

Dr Trigg also described how being able to understand and express the lived experience of residential aged care is critical to helping people make informed decisions about residential aged care.⁶³ In England, the Care Quality Commission provides easy to read reports on its residential facilities on its website. These reports have quotes taken directly from residents of the facility and an easy to follow star rating system so that people know if the facility is ‘outstanding’, ‘good’, ‘requires improvement’ or ‘performing badly’.⁶⁴ The Care Quality Commission also promotes the idea of lived experience in its ‘Mum test’, asking its inspectors to consider whether they would be prepared to have a loved one live in the residential aged care facility that they are examining.⁶⁵

The Royal Commission has heard from a range of witnesses and has been informed by a number of previous reviews that the amount and type of information about quality and safety in residential and home care needs to be significantly expanded. Over coming months, the Royal Commission will give further consideration to the recommendations to be made in this important area.

Successive governments have been at pains to stress that changes to aged care programs, and new programs, are aimed at providing greater choice for older Australians. Most recently, the 2018–19 Federal Budget announced 42 separate measures under the umbrella title of ‘More Choice for a Longer Life’. These measures were characterised as ‘support[ing] Australians to be better prepared—to live a healthy, independent, connected and safe life’.⁶⁶ Despite the rhetoric, the My Aged Care website falls far short of being able to support choice by providing meaningful information or to connect people with services. There is still very little information available to older people or their families to assist them in making choices between services. The information that is available is not clearly set out. A researcher and Dementia Fellow at the University of Wollongong, Dr Lyn Phillipson, told us that people require very high literacy skills to be able to understand and use information from My Aged Care—such as a three-year undergraduate degree from a university. There are also few training opportunities for people wanting to learn to use My Aged Care.⁶⁷

62 Exhibit 5-40, Perth Hearing, Statement of Dr Lisa Trigg, 4 June 2019, IT.0156.0001.0001 at 0015 [84]–[85].

63 Exhibit 5-40, Perth Hearing, Statement of Dr Lisa Trigg, 4 June 2019, IT.0156.0001.0001 at 0017 [101].

64 See Care Quality Commission, ‘Care Quality Commission: The independent regulator of health and social care in England’, <https://www.cqc.org.uk/>, viewed 13 August 2019.

65 Exhibit Perth Hearing, 5-40, Statement of Dr Lisa Trigg, 4 June 2019, IT.0156.0001.0001 at 0021–22 [124].

66 The Hon K Wyatt AM MP, *Guaranteeing essential services – record investment in Health*, Media Release, 8 May 2018, retrieved from: <http://pandora.nla.gov.au/pan/159736/20180601-0019/www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediareel-yr2018-wyatt059.html>, viewed 25 September 2019.

67 Transcript Lyn Phillipson, Mildura Hearing, 30 July 2019, T4025.31–39.

On 24 June 2019, the Australian Government launched an updated My Aged Care website. An amount of \$61.7 million is being invested in the website across 2018–19 and 2019–20 to improve its accessibility and function.⁶⁸ In the second Adelaide Hearing, witnesses from the Australian Department of Health described the planned improvements to My Aged Care as:

- In mid-2019: a better home page, greater use of white space to support people with vision impairments, the rearrangement of information to flow more logically, and updating the service finder tool to make it easier to use and provide greater transparency about pricing.⁶⁹
- Later in 2019: the addition of a feature that will allow general practitioners and specialists to directly refer people to My Aged Care.⁷⁰
- In early 2020: improvements to the client portal, providing people and their carer with the ability to register the older person's interest in aged care online, as opposed to only through the call centre.⁷¹
- From July 2020: the publication of performance ratings of residential aged care service providers on the My Aged Care website.⁷²

The homepage has since been updated. It provides clearer and more consistent basic information. However, it is still difficult to find information on particular providers and there is still very limited information available on the safety and quality of services. There are hundreds of examples of web-based information systems—for example, hotel and travel bookings, car hire, insurance, personal care services and even medical services—designed to allow users to compare products or providers and choose one that meets their needs. Those sites operate in highly competitive environments. They are far easier to use and provide much more detailed information than My Aged Care. Users can search for services which meet their designated criteria, rather than having to trawl through the details of service providers three at a time in a manual search, as is the case with My Aged Care. Despite its myriad of shortfalls, My Aged Care's monopoly as a government owned and operated service ensures that people will continue to use it, despite the practical difficulties and, indeed, distress it can cause.

A website is only part of the answer

The Royal Commission acknowledges that, even in our digital age, a website and call centre can only do so much to address the complexities of the aged care system. The My Aged Care website has received particular focus in hearings, but it was only one aspect of what is needed to streamline a complex system that is easier for people

68 Australian Department of Health, *Portfolio Budget Statements 2018-19: Budget Related Paper No. 1.9*, Australian Government, 2018, p 135.

69 Transcript, Fiona Buffinton, 22 March 2019 at T1066.5-15.

70 Commonwealth Post-Hearing Submissions, 29 March 2019, RCD.0012.0003.0012 at .0013, [8].

71 Transcript, Fiona Buffinton, 22 March 2019 at T1072.35.

72 Australian Department of Health, *Portfolio Budget Statements 2018-19: Budget Related Paper No. 1.9*, Australian Government, 2018, p 26.

to access. One witness described how linking everything to a call centre and website is unsuitable for the current population of older people who have not grown up with technology and digital services.⁷³ Mr Gear, of the Older Persons Advocacy Network, expressed the view that My Aged Care has not resolved aged care access issues, and that it works only for people who have access to IT.⁷⁴ Relying to such a large extent on a website seems to ignore the state of digital literacy of people currently in their early 80s, which is the age at which they typically enter the aged care system. Challenges are compounded for those with cognitive impairment, blindness, literacy or other language issues, those who do not have family or friends to help them, or those outside the range of quality internet, data or mobile connections.

The reliance on technology for the aged care gateway is not the only concern with My Aged Care. Some older people, especially those in their later 70s and older, who have not had access to computers on the job or in the home, may be less skilled in using technology. Other people, especially the baby boomer generation (those born between 1946 and 1964) or even older, are very technologically savvy and use various websites and technologies in their daily lives. It is also not beyond the capacity of older people to learn to use technology: a recent study in Queensland pointed to the willingness and ability of older Australians to learn and develop their digital skills.⁷⁵

The contention that the problems people experience with My Aged Care are not primarily due to unfamiliarity with technology was reinforced in the Perth Hearing. Giving evidence to the Royal Commission, Dr Trigg noted that the decision-maker is often not the older person but rather a carer.⁷⁶ Carers may be children, grandchildren or other family members and are likely to be more familiar with technology. However, as Dr Trigg explained, to make good decisions, carers need access to ‘easily interpretable comparative quality information’ and to be able to identify their own preferences based on that information.⁷⁷ We have heard that carers also find the My Aged Care website unhelpful and difficult to access and that it does not provide quality information.⁷⁸ The entry point to the system, whether it’s the website or the contact centre, should be constructed so that it is easy to use for the very people it is seeking to help—the older people themselves. A model that relies on friends and family to assist, excludes those older people who do not have access to that assistance. For those who do have assistance, building a system that relies on that assistance is patronising and disempowering, and contributes to sidelining older people in decision-making about their own futures.

73 Transcript, Marie Dowling, Adelaide Hearing 2, 20 March 2019 at T0908.9–11.

74 Transcript, Craig Gear, Adelaide Hearing 1, 12 February 2019 at T0140.40–47.

75 A Antonio and D Tuffley, ‘Bridging the Age-based Digital Divide’, *International Journal of Digital Literacy and Digital Competence*, 2015, Vol 6, Issue 3, p 1.

76 Exhibit 5-50, Perth Hearing, Statement of Lisa Trigg, 4 June 2019, WIT.0156.0001.0001 at 0014 [82].

77 Exhibit 5-50, Perth Hearing, Statement of Lisa Trigg, 4 June 2019, WIT.0156.0001.0001 at 0014 [76].

78 Exhibit 7-9, Mildura Hearing, Statement of Donald Geoffrey Laity, 23 July 2019, WIT.0313.0001.0001 at 0008 [57]; Exhibit 7-14, Mildura Hearing, Statement of Dr Lyn Phillipson, 19 July 2019, WIT.0287.0001.0001 at 0006 [25]–[27]; Exhibit 7-16, Mildura Hearing, Statement of Kay Gray, 26 July 2019, WIT.0310.0001.0001 at 0004 [23].

The role of face-to-face assessment, linking and referral in aged care

A website and call centre, even one that is fully functional and allows meaningful comparisons and choice, cannot and should not replace localised, face-to-face assistance for people who are preparing to enter aged care.⁷⁹ National Seniors Australia reported to us that it is clear that older Australians have a consistent preference for high levels of human contact and communication, and that this needs to be addressed, whatever technological assistance is used at the gateway.⁸⁰ The Australian Department of Health argued that the face-to-face component of My Aged Care is in the assessment conducted by the Regional Assessment Services and Aged Care Assessment Teams.⁸¹ The main role of these teams is to assess people in one appointment for their eligibility to enter Government-subsidised aged care. While the teams are also meant to help people access aged care, it is unclear to what extent this occurs during their single appointment.⁸² It is apparent to the Royal Commission that whether or not this service occurs depends on the knowledge and experience of the staff member delivering the assessment. More often than not, elderly people and their families report that it is not a regular and normal part of the assessment process.

Since the Australian Government assumed responsibility for all aged care services and centralised their administration and regulation, other levels of government have moved out of aged care.⁸³ Because the Australian Department of Health has not replicated or replaced the local arrangements in each State and Territory, this has created gaps in services for older people.⁸⁴ The Royal Commission heard that previous assessment arrangements, especially in the former Home and Community Care Programme, offered a more localised approach to information, referral and coordination.⁸⁵ There is no existing replacement for these local mechanisms.

79 Transcript, Craig Gear, Adelaide Hearing 1, 12 February 2019, T0141.34–36.

80 National Seniors Australia, *Accentuating the Positive: Consumer experiences of aged care at home*, 2018, <https://nationalseniors.com.au/research/health-and-aged-care/accelerating-the-positive-consumer-experiences-of-aged-care-at-home>, viewed 26 September 2019.

81 Transcript, Glenys Beauchamp, Adelaide Hearing 1, 18 February 2019 at T0329.1–4.

82 Australian Department of Health, *My Aged Care Assessment Manual for Regional Assessment Services and Aged Care Assessment Teams*, 2018, p 9.

83 Exhibit 2-68, Adelaide Hearing 2, Statement of Hjalmar Swerissen, 7 November 2019, WIT.0085.0001.0001 at 0005 [25].

84 Exhibit 2-68, Adelaide Hearing 2, Statement of Hjalmar Swerissen, 7 November 2019, WIT.0085.0001.0001 at 0005 [26].

85 Exhibit 2-25, Adelaide Hearing 2, Statement of Clare Hargreaves, 14 March 2019, WIT.0071.0001.0001 at 0020 [91]–[94].

For a significant number of older Australians, the current assessment arrangements can involve duplication and inefficiency in the assessment of their individual needs.⁸⁶ The current arrangements mean that a person needing care may need to be assessed by both the Regional Assessment Service and Aged Care Assessment Team, and again by the service provider once they are in residential aged care.⁸⁷ The person's information does not always make its way from the assessment services to their My Aged Care client record, resulting in inconsistent screening or multiple unnecessary assessments.⁸⁸ Mr Tune reported on the issue in his 2017 review:

Consumers reported frustration at having to repeat their story and answer questions many times over, particularly when their client record should have included this information from previous assessments. Consumers said they found the distinct assessments confusing and that the unnecessary duplication was a disincentive to access services.⁸⁹

Mr Tune's Report raised concerns about the timeliness, quality and consistency of the assessment process under My Aged Care. He recommended a more rigorous and integrated assessment model, with the first step being the amalgamation of Regional Assessment Services with Aged Care Assessment Teams, and later incorporation of the residential care assessment function which sets personal funding levels, and is currently undertaken by providers.⁹⁰ The Government has announced that it will implement this recommendation and will integrate the two assessment workforces from 2020.⁹¹ The Royal Commission considers that this integration needs to be progressed urgently. We will, therefore, maintain a continued interest in these developments and will monitor their progress; we will make recommendations as necessary in the Final Report.

The Royal Commission has heard and read that the main barriers people face when trying to access aged care services are:

- the difficulty in finding useful information about what options are available where they live
- the difficulty in working out how to coordinate services which may be delivered by different providers
- the time-consuming, repetitive efforts that have to be made in order to access a home-based service or transition into residential care.⁹²

86 Transcript, Paul Sadler, Adelaide Hearing 2, 18 March 2019 at T738.13–29; Exhibit 2-80, Adelaide Hearing 2, Statement of Rita Kersnovske, 13 March 2019, WIT.0088.0001.0001 at 0002 [17]–[22]; Transcript, Ruth Harris, Adelaide Hearing 2, 21 March 2019 at T949.45–T949.34.

87 Exhibit 2-80, Adelaide Hearing 2, Statement of Rita Kersnovske, 13 March 2019, WIT.0088.0001.0001 at 0002 [17]–[22]; Transcript, Ruth Harris, Adelaide Hearing 2, 21 March 2019, T949.45–T949.34.

88 Exhibit 2-25, Adelaide Hearing 2, Statement of Clare Hargreaves, 14 March 2019, WIT.0071.0001.0001 at 0024 [115].

89 D Tune, *Legislated Review of Aged Care*, 2017, p 140.

90 D Tune, *Legislated Review of Aged Care*, 2017, p 140–141.

91 Australian Department of Health, *Australian Government Response to the Productivity Commission's Caring for Older Australians Report*, 2012, p 26.

92 Exhibit 1-4, Adelaide Hearing 1, Statement of John McCallum, 31 January 2019, WIT.004.0001.0001.

Some people have told us that after getting information from My Aged Care, they are left to fend for themselves.⁹³ We have heard that there is a pressing need for tools to enable people to coordinate, plan and manage the care that they or a family member receive. This is particularly true in home care and dementia care, where information and assistance can be very fragmented.⁹⁴ Ms Dietrich, the primary carer for her mother Beryl, reported that her mother did not realise that she needed help, and if asked her mother would have said that she did not need much.⁹⁵ Ms Dietrich noted that lots of people did not know how to navigate the system and, in accessing My Aged Care for her mother, that people need specific information and help to choose a suitable provider.⁹⁶

In my experience, picking a home care provider is more about trying to select who isn't the worst. It's not about the agency, it's about the workers. You could get a good worker in an agency that you think is dodgy.⁹⁷

When we asked Ms Raelene Ellis, the primary carer for her mother, about her interaction with My Aged Care, she said that the call centre gave information, but it was up to the person and their carer to follow up with providers:

All that they can do when you ring them is say hey, why don't you try ringing these people, or try that telephone number, or have a look on our website that will give you some availability and then ring the service providers. There was never a circumstance that I contacted My Aged Care where it was a one-stop-shop...My experience with My Aged Care is that it's really just an operator assist type facility. They can direct you to places but really nothing more than that.⁹⁸

As part of its response to the Productivity Commission's 2011 report, the Australian Government established the centralised system for access to aged care. This includes the national call centre, website, funding arrangements and management of waiting lists.⁹⁹ Mr Paul Sadler of Presbyterian Aged Care, who was involved in the design of My Aged Care through a National Aged Care Alliance working group, told us that these new arrangements were designed to create fairer and more consistent national arrangements, with greater choice and control and simpler access.¹⁰⁰

93 Transcript, Suzanne Hodgkin, Mildura Hearing, 30 July 2019, T4012.25–32. See also Submission AWF.001.00592_0002; Submission AWF.001.00231_0001; Submission AWF.001.01570; Submission AWF.001.00081_0001.

94 See, for example, Transcript, Glenn Rees, Sydney Hearing, 13 May 2019 at T1550.44–47.

95 Exhibit 7-10, Mildura Hearing, Statement of Bonney Dietrich, 25 July 2019, WIT.0314.0001.0001 at 0006 [34].

96 Transcript, Bonney Dietrich, Mildura Hearing, 30 July 2019, T3964.14–18.

97 Exhibit 7-10, Mildura Hearing, Statement of Bonney Dietrich, 25 July 2019, WIT.0314.0001.0001 at 0007 [47].

98 Transcript, Raelene Ellis, Adelaide Hearing 2, 18 March 2019 at T707.7–18.

99 Transcript, Hjalmar Swerissen, Adelaide Hearing 2, 21 March 2019 at T1038.15.

100 Exhibit 2-12, Adelaide Hearing 2, Statement of Paul Sadler, 11 March 2019, WIT0078.0001.0001 at 0003 [14].

The Royal Commission has heard a range of opinions about the impact of this centralisation, including:

- although providers, consumer advocates and other interested parties were consulted on the changes, the end result is still very much a bureaucratic, Canberra-based, centralised product with a distinct lack of flexibility, responsiveness and individual and regional focus¹⁰¹
- there is a lack of options in rural and particularly remote areas;¹⁰² and some ‘absentee providers’ operating without a local office or a real understanding of the local population¹⁰³
- there is an absence of alternative approaches with guaranteed funding, for remote service provision or for services delivered into Aboriginal and Torres Strait Islander communities.¹⁰⁴

In submissions to the Royal Commission, several people have pointed out that this centralised approach obscures local information and means that providers do not have enough information to enable them to develop comprehensive models of service provision in particular areas. As well as creating problems for providers, centralisation has left many individuals without support to access the entry pathway to aged care or to coordinate and manage services once they start receiving them. A number of suggestions have been made as to how best to bring local support to aged care, ranging from local government to Primary Health Networks.¹⁰⁵

The 2017 Tune review found evidence that people living in remote areas, hard-to-reach people, those with complex needs and those with limited access to technology, are struggling with access to the aged care system. He recommended the introduction of ‘system navigators’ and outreach services to assist those who find existing channels difficult to use.¹⁰⁶ Mr Sadler noted that ‘navigators’ may be especially helpful for Aboriginal and Torres Strait Islander communities and people from culturally and linguistically diverse backgrounds.¹⁰⁷ Chairperson of the Federation of Ethnic Communities’ Councils of Australia, Ms Mary Patetsos, observed that My Aged Care is not an adequate point of access for older people who do not have English as a first language.¹⁰⁸ Dementia advocacy witnesses Mr Rees and Ms McCabe said that My Aged Care, in its current state, is not suitable for use by people with mild cognitive impairment or for those living with dementia.¹⁰⁹

101 Exhibit 2-12, Adelaide Hearing 2, Statement of Paul Sadler, 11 March 2019, WIT0078.0001.0001 at 0003 [15].

102 Exhibit 2-12, Adelaide Hearing 2, Statement of Paul Sadler, 11 March 2019, WIT0078.0001.0001 at 0006 [28].

103 Transcript, Clare Hargreaves, Adelaide Hearing 2, 19 March 2019 at T0792.45.

104 Transcript, Paul Sadler, Adelaide Hearing 2, 18 March 2019 at T0744.40.

105 See, for example, Statement of Clare Hargreaves, WIT0071.0001.0001 at .0015, [64.7]; Transcript, Hjalmar Swerissen, Adelaide Hearing 2, 21 March 2019 at T1038.15

106 D Tune, *Legislated Review of Aged Care*, 2017, p 134.

107 Transcript, Paul Sadler, Adelaide Hearing 2, 18 March 2019 at T0739.34–35. See also Transcript, Leon Flicker, Broome Hearing, 17 June 2019 at T2035.23–30; Transcript, Kim McRae, Darwin Hearing, 8 July 2019 at T2859.28–34.

108 Transcript, Mary Patetsos, Adelaide Hearing 2, 20 March 2019, T0933.31–38.

109 Transcript, Glenn Rees, Sydney Hearing, 13 May 2019 at T1550.13–21; Transcript, Maree McCabe, Adelaide Hearing 1, 19 February 2019 at T0405.34–39.

In an attempt to inject face-to-face support into the My Aged Care gateway, the Australian Department of Health is now funding trials of ‘system navigators’.¹¹⁰ Conducted over 18 months, the trials comprise:

- 30 hubs to provide locally targeted information
- 20 community hubs where older people can support each other
- six full-time specialists placed in consumer-focused organisations to offer one-on-one support
- six full-time aged care financial information support officers located in Services Australia (formerly the Australian Department of Human Services).¹¹¹

Navigators will help people understand the complicated letters that are sent by My Aged Care¹¹² and help them connect to providers in their area. COTA’s Mr Yates, whose organisation is sponsoring the trials by supporting a range of navigator organisations across Australia, has argued that this is where the gateway should have been all along.¹¹³ Chief Executive Officer of Aged Care Services Australia, Ms Patricia Sparrow, said that the navigators should have been rolled out progressively throughout Australia and not merely as a trial.¹¹⁴ We will watch the progress and outcomes of the ‘navigator’ trials and planned integration of the assessment services with interest.

There are other advocacy and support models that could be used to assist people to access the right services. We have heard from advocacy groups of the role that could be played by independent third-party mediators or ‘key workers’ to help younger people with a disability navigate the complexity of the aged care and disability systems.¹¹⁵ The Royal Commission is also aware of the role of support coordinators within the National Disability Insurance Scheme who work to connect participants to services.¹¹⁶

We agree that more face-to-face support services are required at a regional level to support older people and link them to services in their local areas. We will consider advocacy models used in other sectors and internationally and make recommendations on this issue in the Final Report.

110 Transcript, Ian Yates AM, Adelaide Hearing, 11 February 2019 at T0077.18.

111 Submissions of the Commonwealth – Hearing 2, 29 March 2019, RCD.0012.0003.0012 at. [6].

112 Transcript, Patricia Sparrow, Adelaide Hearing 1, 19 February 2019 at T0425.25–35.

113 Transcript, Ian Yates AM, Adelaide Hearing 1, 11 February 2019 at T0077.29–30.

114 Transcript, Patricia Sparrow, Adelaide Hearing 1, 19 February 2019 at T0425.32–35.

115 Exhibit 9-19, Melbourne Hearing 1, Statement of Bronwyn Elizabeth Morkham, 30 August 2019, WIT.0372.0001.0001 at 0013 [50]–[51].

116 Transcript, Dr Nicholas Gerard Hartland, Melbourne Hearing 1, 9 September 2019, T4899.1; Transcript, Neale Marcum Radley, 10 September 2019, T2970.1.

Information about waiting lists

A recurring theme in direct evidence and submissions to the Royal Commission is frustration with the absence of information about the criteria used to place people in the queue for Home Care Packages. My Aged Care does not provide such information. People have told us that the My Aged Care website promises services that are not available in their area, or they get a response from My Aged Care that the system cannot tell them where they are on the list or when a Package will be available.¹¹⁷

The Royal Commission has heard that some of the problems identified with My Aged Care are in effect problems created by the long waiting times for Home Care Packages. The frustration these waiting times create is reflected in the number of complaints the Commonwealth Ombudsman received in 2017–18 about the My Aged Care program. The Ombudsman received 164 complaints about the Australian Department of Health, with 44% of these being about My Aged Care.¹¹⁸ The complaints focused on delays in the allocation of Home Care Packages and Packages being allocated and then withdrawn. People also suffer serious delays in receiving letters from the Department, and these letters are all too often unnecessarily complex and poorly written.¹¹⁹ After Home Care Packages are approved, there is a lack of follow-up from the Department.

A report issued earlier this year by provider peak body Leading Age Services Australia identified that wait times for Home Care Packages are often much longer than the waiting time advised by My Aged Care.¹²⁰ A number of witnesses have identified the inability to provide specific wait times or to resolve issues in accessing a Home Care Package as a significant source of dissatisfaction with My Aged Care. For example:

- Ms Ellis contacted My Aged Care for information on where her mother was on the National Priority List: ‘In fact, when I ring—when I rang My Aged Care to say, ‘Look, what’s happening? We really, really need this level 4 package’, they would say, ‘We simply can’t tell you where on the list. It’s being managed and we can’t give you any indication of where on the list you are’.¹²¹

117 Transcript, Kaye Warrener, Adelaide Hearing 1, 21 February 2019 at T0600.23–26; Transcript, Raelene Ellis, Adelaide Hearing 1, 18 March 2019 at T0706.1–5.

118 Commonwealth Ombudsman, *Annual Report 2017–18*, 2018, Canberra, p 29.

119 Exhibit 2-12, Adelaide Hearing 2, Statement of Paul Michael Sadler, 11 March 2019, WIT.0078.0001.0001 at 0005 [20]; Exhibit 1-61, Adelaide Hearing 1, Statement of Kaye Warrener, 18 February 2019, WIT.0031.0001.0001 at 0002.

120 Leading Age Services Australia, *Third Home Care Provider Survey Report*, 2019, p 4.

121 Transcript, Raelene Ellis, Adelaide Hearing 2, 18 March 2019 at T706.2–5.

- Although her mother had been waiting for a Home Care Package for over nine months, Ms Harris was given the same information that she had been given when her mother was first approved for a Package—it should be expected in three to six months.¹²² Ms Harris told us that she never received any feedback or information to say that she had done everything required and just had to wait.¹²³
- Mrs Dowling said that she did not receive any additional assistance from My Aged Care, despite the fact that she had a registered disability.¹²⁴ She nearly missed the deadline to accept the offer of a Package because she could not work out how to find a provider to deliver it.¹²⁵

Both the My Aged Care website and call centre use stock or scripted responses to answer questions on when a Package might become available. A person might ask on different occasions, separated by months, how long the expected wait is for a Package, only to be given the same answer.¹²⁶ It is rarely the case that a person receives a Home Care Package at their assessed level within the timeframe advised by My Aged Care.¹²⁷ The real length of the waiting list is often much longer than publicly stated.

When an Aged Care Assessment Team advises an older person of their eligibility for a Home Care Package, that person and often their spouse and family members have been over many hurdles. The pathway to being recognised as having a need for subsidised aged care can at times be long and the next steps become entirely opaque. The Royal Commission has heard that older people and their carers are left alone, and can develop problems with health and wellbeing, while they wait for the actual Package to come on stream.¹²⁸ Many submissions have expressed their frustration with the waiting lists. One person wrote:

Every politician, every My Aged Care office worker, should spend a week with a full-time carer who cannot access a Home Care Package and see the hell and misery we all endure and how hard we work.¹²⁹

122 Exhibit 2-76, Adelaide Hearing 2, Statement of Ruth Harris, 12 March 2019, WIT.0074.0001.0001 at .0003, [22]; See also, Transcript, Ruth Harris, Adelaide Hearing 2, 21 March 2019, T950.43.

123 Transcript, Ruth Harris, Adelaide Hearing 2, 21 March 2019 at T952.12–13.

124 Exhibit 2-34, Adelaide Hearing 2, Statement of Marie Dowling, 15 March 2019, WIT.0077.0001.0001 at 0013 [32].

125 Exhibit 2-34, Adelaide Hearing 2, Statement of Marie Dowling, 15 March 2019, WIT.0077.0001.0001 at 0013–0016 [32]–[33], [35]–[40]; Transcript, Adelaide Hearing 2, Marie Dowling, 20 March 2019 at T907.16–25.

126 Transcript, Ruth Harris, Adelaide Hearing 2, 12 March 2019 at T952.17–27; Exhibit 2-76, Adelaide Hearing 2, Statement of Ruth Harris, 12 March 2019, WIT.0074.0001.0001 at 0003 [22].

127 Exhibit 2-89, Adelaide Hearing 2, Statement of Fiona Kathryn Buffinton, 11 March 2019, WIT.0058.0001.0001 at 0021 [Tables 4 and 5].

128 Exhibit 1-4, Adelaide Hearing 1, Statement of John McCallum, 31 January 2019, WIT.004.0001.0001.

129 Public submission, 18 February 2019, AWF.001.01182.03_0002.

When a Home Care Package becomes available, My Aged Care writes to the recipient, giving them 56 days (eight weeks) to select a provider to deliver their Package. This deadline can be extended by a further 28 days (four weeks) if necessary.¹³⁰ These letters provide vital and anticipated advice on approval for a Package, or an interim Package at a lower level of care. The Royal Commission has heard that these letters do not always arrive in time, or at all. They go missing in the post, for example.¹³¹ My Aged Care does not follow up on correspondence that is not replied to, either shortly before or after the deadline. There is no system of reminder letters.¹³² The hopelessness, frustration and disappointment people experience when they call My Aged Care to find out when their or their family member's Package will be assigned, only to hear that they have missed a deadline they had no knowledge of because the notification was never received, is heartbreaking. People with higher care needs who miss out in this way often have no option but to go into residential aged care, against their express wishes.¹³³

The Australian Government should ensure that people waiting for a Home Care Package at their assessed level have access to up to date (or even real time) information on their place in the national prioritisation queue and when they are likely to be assigned a Package. This information should be available by phone and on the website (via the portal).

We have heard that the letters are written in a bureaucratic manner.¹³⁴ Letters should be revised into plain English, with the most important details highlighted for the older person and their carer. The Government should also ensure that My Aged Care has procedures in place to follow-up on the letters they send and assist people to find a provider for their Package within the 56 days. This increased transparency in communications could go a long way to improving the reputation of My Aged Care.

My Aged Care, of itself, is not responsible for the policy that underpins the provision of Home Care Packages, including waiting lists. However, it is the Government's mechanism for providing information and communicating with people applying and waiting for this support. As such, it is the only resource people have to turn to, and they too often find it unresponsive, uninformed and uninterested in them as individuals. There is much that can be done to improve the accuracy, consistency and timeliness of information and communication about the current aged care system provided by the call centre and the website, without waiting for larger changes to the system.

130 Aged & Community Services Australia, Public submission, AWF.600.00644, p. 9.

131 Exhibit 2-76, Adelaide Hearing 2, Statement of Ruth Harris, 12 March 2019, WIT.0074.0001.0001 at 0004 [37]–[40].

132 Transcript, Craig Gear, Adelaide Hearing 1, 12 February 2019 at T0141.13–15.

133 Exhibit 2-76, Adelaide Hearing 2, Statement of Ruth Harris, 12 March 2019, WIT.0074.0001.0001 at 0005 [43].

134 Transcript, Paul Sadler, Adelaide Hearing 2, 18 March 2019 at T0733.24–33.

Conclusion

The Royal Commission will make recommendations on how to improve the experience of older people and their families in navigating the system in our Final Report. This chapter outlines our early observations based on the extensive feedback these issues have generated so far.

My Aged Care has been a costly exercise in attempting to consolidate information on a complex system in one place. Where Government surveys and evaluations have depicted the gateway positively, evidence before the Royal Commission has indicated that older people have trouble using the contact centre and website, they face confusing and duplicative assessments and they are not supported to connect to services. This could be improved with access to:

- information to enable people to make comparisons of the quality safety and cost of services in their local area
- information about where to go to get help, including appropriate advocacy services
- accurate information about the length and progress on home care waiting lists, including well informed call centre staff, and plain and direct language in letters.

Navigating aged care requires an older person and their carer to make difficult emotional, financial, health and housing-related decisions, often under stress and time pressures, and with limited prior exposure to the system. It is obvious to us that there should be more services made available to people to navigate aged care. Having a single front door to the aged care system is a positive change, but help to find that door and then navigate the labyrinth beyond is required. People need integrated, face-to-face support and linking services, with local knowledge, to help them access the right service.

6. The Lottery

And probably because we've kind of sat back and waited, my husband would say nothing – nothing has come yet, nothing has come yet. But watching TV and hearing the radio and different people ringing in about Home Care Packages and how long they've had to wait, I was coming to the realisation, we've just got to wait. We've got no option to do anything.¹

Introduction

The current generation of people we refer to as 'older' is used to waiting. Many of them waited for the Second World War to end, waited for their loved ones to come home and for their families to join them from overseas.

Older people wait for children to grow up, embark on their own lives, and set up households of their own. They may wait to reach retirement age, so that they have more free time.

Older people are still waiting. Waiting for care. These are patient people and they do not deserve to wait anymore. Some of them die while they are waiting for care. Surely:

They should not die waiting. No one should die waiting for an essential service.²

Like the generations before and after them, today's older people may have bought lottery tickets or played (and still play) the lottery. But they do not 'wait' to win the lottery. People get on with their daily lives, even if they may hope to strike it lucky.

One of the inconvenient truths brought to light by the Royal Commission is that, in fact, many older people do wait for the lottery: the lottery of the waiting list for aged care services. For that is in effect what the current system of prioritising and managing waiting lists is: a cruel lottery in which some people can die before they ever find out if they have, in fact, 'won'.

This chapter examines the issues surrounding waiting times in the Australian aged care system: when people are asked to wait for services and how long people wait. It considers the physical and emotional costs of waiting for care are for people and their families, and explores what it will take to reduce or remove waiting times.

While it is generally accepted in Australia that it is reasonable for people to have to wait for a limited time to receive some types of health and social care, access to aged care is critical for older people who may be struggling to remain independent or who are reliant on informal care that is not sustainable. It can make the difference between living a safe life and being highly dependent in older years.

1 Transcript, Kay Warrenner, Adelaide Hearing 1, 21 February 2019 at T600.8-12.

2 Submission AWF.001.00012

The impact of waiting is not a new concern. As long ago as 1998 the issue of waiting times for residential aged care was raised in the Report on Government Services³ as an important measure of the effectiveness of the aged care system. Nonetheless, significant attention has recently been given to waiting times for aged care, with the Royal Commission hearing many stories of long waits—and of people waiting up to two years for services at home.⁴

In the 2015-16 Federal Budget, the Australian Government changed the process for allocating Home Care Packages so that, from February 2017, older people would have control over their funds and be able to direct them to the provider of their choice. However, the Government continued to limit the number of Home Care Packages that were available, so it was necessary to introduce a new process to prioritise access to home care—the national prioritisation queue.⁵

The national queue allocates Packages in a way that considers priority, within a system that rations the number of available Packages of support. This has made transparent for the first time how many older people are waiting for home care and for how long. So, as Catholic Health Care Australia has argued:

Obtaining better information about demand was one of the side benefits of the policy change whose primary objective was to increase consumer control by giving package holders choice of service provider. The question now is what policy issues flow from this data, and how best to respond.⁶

When do people wait?

Even before a person seeks formal aged care services, they may be waiting—waiting to see how long they can endure without seeking support, or waiting to see how long their spouse, child or friends can provide the level of care they need.

3 Steering Committee for the Review of Commonwealth/State Service Provision, *Report on Government Services*, 1999, p 740.

4 C Knaus, 'Two-year wait for home aged care 'unacceptable', advocates say', *The Guardian Australia*, May 17 2018, <https://www.theguardian.com/australia-news/2018/may/17/two-year-wait-forhome-aged-care-unacceptable-advocates-say>, viewed 24 September 2019.

B Brown, 'Wait for home-care packages pushing elderly into nursing homes', *Sydney Morning Herald*, April 12 2018, <https://www.smh.com.au/money/planning-and-budgeting/wait-home-care-packages-elderly-nursing-homes-20180411-p4z92u.html>, viewed 24 September 2019.

Submission AWF.001.01224; Exhibit 1-11, Adelaide Hearing 1, Statement of Sue Elderton, 2 February 2019, WIT.0003.0001.0001 at 0005; Exhibit 1-8, Adelaide Hearing 1, Statement of Craig Gear, 31 January 2019, WIT.0007.0001.0001 at 0003 [21]; Exhibit 1-4, Adelaide Hearing 1, Statement of John McCallum, 31 January 2019, WIT.0004.0001.0001 at 0014.

5 Australian Government, *Budget 2015-16: Budget Measures: Paper No. 2*, 2015, p 147, https://archive.budget.gov.au/2015-16/bp2/BP2_consolidated.pdf, viewed 9 September 2019.

6 Catholic Health Care Australia, *Aged Care Update: What does the queue for Home Care Packages mean for aged care reform?*, 20 August 2018, <https://www.cha.org.au/images/agedcare/2018/Aged%20Care%20Update%20-%20200818.pdf>, viewed 9 September 2019

When finally they decide that they must seek help, they need to navigate the maze that is the aged care system:

I am 51 and highly educated and still had trouble understanding all the options. I can't imagine what an elderly person without support would do trying to understand all of this. It is extremely overwhelming.⁷

The first time an older person will generally be asked to wait formally is when they contact My Aged Care. It begins with waiting for someone to answer the phone and to return your call. From 1 July 2017 to 30 June 2018 a total of 32,715 calls to the My Aged Care consumer line were not answered. Although most calls are answered within 30 seconds, about 2.6% of total calls made to the line are not answered at all.⁸ Even when the call is answered, the caller still finds themselves waiting, or having to call back. A respondent to a survey conducted by National Seniors Australia indicated that the outcome was dependent on the person who answered the call:

The effectiveness of My Aged Care is heavily dependent on the training and attitude of the staff. Any successful assistance occurred usually after several phone calls to find the right person with the right knowledge and the right attitude.⁹

Another respondent to the National Seniors Australia survey was more succinct:

Call centre...long wait, unfriendly. ¹⁰

Once a person has decided they need to ask for help and has navigated My Aged Care, the first hurdle they will encounter within the system is the time it takes to obtain an Aged Care Assessment Team or Regional Assessment Service assessment. After being assessed over the phone, they may be assigned to either of these services for a face-to-face interview in their home. The older person will need to wait for this face-to-face interview well before any of their aged care services are delivered. The Royal Commission has heard of significant waits for face-to-face assessments.¹¹

The Australian Department of Health's Key Performance Indicator for Aged Care Assessment Teams requires them to complete 95% of assessments within 75 days.¹² The Secretary of the Victorian Department of Health and Human Services told the Royal Commission that the average waiting time for an assessment in Victoria was 19.7 days, and that one in 20 older people waited more than 69 days for an assessment.¹³

7 Submission AWF.001.02253.

8 Senate Community Affairs Committee, Budget Estimates 2018-19, Answers to Estimates Questions on Notice, reference number SQ18-000751, answered 21 August 2018.

9 K Rees, J Maccora, and J McCallum, 'You don't know what you don't know: The current state of Australian aged care service literacy', *National Seniors Australia*, 2018, p 26.

10 K Rees, J Maccora, and J McCallum, 'You don't know what you don't know: The current state of Australian aged care service literacy', *National Seniors Australia*, 2018, p 25.

11 Exhibit 1-56, Adelaide Hearing 1, Statement of Anthony Bartone, 18 February 2019, WIT.0015.0001.0012 at 0012 [68]; Submission AWF.001.01013; Submission AWF.001.02176.

12 Australian Department of Health, *My Aged Care Assessment Manual For Regional Assessment Services and Aged Care Assessment Teams*, 2018, p 108.

13 Exhibit 9-22, Melbourne Hearing 1, Statement of Kym Lee-Anne Peake, 29 March 2019, WIT.0039.0001.0001 at 0046 [264].

This waiting can be frustrating, particularly for people who have struggled for a long time before asking for help and because needs often change rapidly.

Following face-to-face assessment, an older person may be granted access to either the Commonwealth Home Support Programme or a Home Care Package, or be recommended to enter full-time residential care while still being given the option to access a Home Care Package.

Of the three main aged care programs, there is no published data on waiting times for the Commonwealth Home Support Programme, despite it being the largest in terms of the number of people supported (over 850,000 people).¹⁴ Upon being approved for home support, the onus falls on the person to contact providers and arrange for services. This can result in further waiting. For example, people may experience a wait when searching for a provider—‘provider waiting’—and then potentially have to wait for the provider to become available to deliver the service—‘service waiting’.

For example, three respondents to the National Seniors survey reported similar experiences:

I can't get any help because they don't have anyone in my area who can come in and assist me.

The assessment met the needs of my husband but the providers did not deliver what was required.

What is assessed may not be what the PROVIDER can deliver.¹⁵

When an Aged Care Assessment Team advises an older person of their eligibility for a Home Care Package, that person has passed a key hurdle to receive subsidised aged care. Unfortunately, at that point the next steps become entirely opaque. The Royal Commission has heard that older people and their carers are left alone and problems with health and wellbeing are often exacerbated while they wait for the actual Package to become available.¹⁶ Many people who have made submissions have expressed their frustration about the waiting lists. One person wrote:

My mother has been waiting for a Level 2 (Home Care Package) for more than 12 months and we are being told it will be another 6–12 months. In the meantime her care level has increased. She has dementia. This is simply not good enough.¹⁷

14 Australian Institute of Health and Welfare, *Aged Care Data Snapshot 2018 – sixth release*, 2018.

15 K Rees, J Maccora and J McCallum, ‘You don’t know what you don’t know: The current state of Australian aged care service literacy’, *National Seniors Australia*, 2018, p 31.

16 Exhibit 1-4, Adelaide Hearing 1, Statement of John McCallum dated 31 January 2019, WIT.004.0001.0001.

17 Submission AWF.001.02383

Within the national prioritisation queue, there are currently two streams—medium and high—and people are allocated to a *stream* and a *Package level* based on their face-to-face assessment.¹⁸ The high stream is reserved for those at ‘immediate risk’ to their safety or imminent risk of admission to residential care and moves more quickly than the medium stream. Carer crisis is a factor that can influence priority.¹⁹ On average, there are longer waits for higher level Packages.²⁰ As Table 6.1 shows, this effectively leaves those with greatest need waiting longest, and represents an immediate priority for the Australian Government:

One of the common scenarios I face in the My Aged Care years is having a community client with dementia and unmet needs where the system has approved them for Level 3 or 4 Home Care Package, but they are waiting for unconscionable periods on the National Priority List.²¹

Waiting is not restricted to those on the medium priority stream. The Royal Commission heard of lengthy waiting times from people on the high priority queue. For example, Home Care Package recipient Ms Gwenda Darling told us:

I had an [Aged Care Assessment Team] reassessment over the telephone about 15 months ago and I was assessed as high priority for a Level 4 package. I have been on the high priority list since then I was told by My Aged Care in July 2019 that they estimate it will be a further three to six months before I might receive a Level 4 package.²²

The impact of waiting for a Package can have lasting effects on families and carers. During the Royal Commission’s second Adelaide Hearing, Ms Ruth Harris reflected on her mother’s wait for a Home Care Package which was so long that her mother had no choice but to enter into residential care. Ms Harris felt that the system ‘comes to basically a dead stop once you’re on the list’ and that the national prioritisation queue lacks transparency.²³ The frustrations with the system extend beyond hearings, with the Royal Commission also receiving evidence from public submissions:

It is extremely tiring, draining, stressful and emotional for us all. It’s simply not good enough, if we have been approved this package, then we shouldn’t have to be waiting so long for it. We need the help now.²⁴

18 Submission AWF.001.01668.01

19 Exhibit 2-91, Adelaide Hearing 2, Department of Health -Guidance on Priority for Home Care Services, CTH.0001.1000.4838.

20 Exhibit 2-89, Adelaide Hearing 2, Statement of Fiona Buffinton, 11 March 2019, WIT.0058.0001.0001 at 0021 [63].

21 Submission AWF.001.00383.

22 Exhibit 8-24, Brisbane Hearing, Statement of Gwenda Noelene Darling, WIT.0329.0001.0001 at 0002 [10].

23 Transcript, Ruth Harris, Adelaide 2 Hearing, 21 March 2019 at T951:40-41

24 Submission: AWF.001.00239

As with the Commonwealth Home Support Programme, even after an older person has been assigned a Home Care Package, they can continue to wait for support while they find an appropriate provider and until services commence. When a Home Care Package becomes available, My Aged Care writes to the recipient, giving them 56 days (8 weeks) to select a provider to deliver their Package.

We also heard evidence that people in regional and remote areas have to wait longer for the services that they need.²⁵ This is especially the case in residential aged care, but there is emerging evidence that people seeking Home Care Packages also have to wait longer in regional areas than in the city, even though the prioritisation queue is meant to be national.²⁶ Put simply, in areas where there are no or fewer providers people wait longer for the care that they need. This ‘thin market’ issue will not be solved by a single prioritisation queue, as that does nothing in and of itself to encourage providers to establish services in undersupplied regions. This is a serious void in the current arrangements for Home Care Packages.

People have a strong preference to age in their own home. Entry to residential aged care is often a last resort and preceded by a significant shock or incident.²⁷ However, the need to access residential care does not relieve the older person of waiting. Those requiring residential care have preferences about their living arrangements, location and culture, and want to base care decisions on these preferences.²⁸ Older people and their families must then begin a detailed search for an appropriate care facility reflecting their preferences, while trying to find information to support their decision. This can be a lengthy and daunting task:

In all, I visited approximately 15 aged care facilities and other rehabilitation centres while Michael was at the Rehabilitation Unit but the facilities I saw were entirely unsuitable, too expensive or full.²⁹

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- 25 Submission AWF.001.00612; Exhibit 7-10, Mildura Hearing, Statement of Bonney Heather Dietrich, 25 July 2019, WIT.0314.0001.0001 at 0004 [22].
 - 26 S Yu and J Byles, ‘Waiting times in aged care: What matters?’, *Australasian Journal on Ageing*, 2019, p 7, in press, DOI: 10.1111/ajag.12665.
 - 27 Exhibit 7-2, Mildura Hearing, Statement of Elaine Maree Gregory, 25 July 2019, WIT.0315.0001.0001 at 0004 [33]; Exhibit 2-76, Adelaide Hearing 2, Statement of Ruth Harris, 12 March 2019, WIT.0074.0001.0001 at 0002 [14].
 - 28 SD Pizer, and JC Prentice, ‘Time is money: outpatient waiting times and health insurance choices of elderly veterans in the United States’, *Journal of Health Economics*, 2011, Vol 30, pp 626–636.
RT Anderson, FT Camacho, and R Balkrishnan, ‘Willing to wait? The influence of patient wait time on satisfaction with primary care’, *BMC health services research*, 2007, Vol 7, p 31. L Trigg, S Kumpunen, J Holder, H Maarse, MS Juves, and J Gil, ‘Information and choice of residential care provider for older people: a comparative study in England, the Netherlands and Spain’, *Ageing & Society*, 2018, Vol 38, pp 1121–1147. E Shapiro, RB Tate, and E Tabisz, ‘Waiting times for nursing-home placement: the impact of patients’ choices’, *Canadian Medical Association Journal*, 1992, Vol 146, p 1343.
 - 29 Exhibit 9-4, Melbourne Hearing 1, Statement of Catherine Eileen Roche, 29 August 2019, WIT.1238.0001.0001 at 0005 [33].

It is important to understand that the size and shape of aged care in Australia is constrained by the Australian Government through controls on the supply of aged care places, rather than being driven by demand.³⁰ Understandably, waiting for aged care services that are in limited supply has become a focal point in criticism of the current system. The unclear measures of waiting and the need to wait for assessment, approval, allocation and service delivery has created a dysfunctional arrangement in which some people are waiting years to access services. Others wait long periods to receive less than what they need or, in some cases, nothing at all.³¹ This is clearly unsafe, especially as many die while waiting.

The quote below illustrates one family's frustrations with waiting and the vague information surrounding the aged care system when seeking care for their mother:

I have spent hours and days on the phone being fed into a loop from My Aged Care to Assessment Team to care providers and back again till I want to scream. I fear that while all this is happening my mother will die before we are able to get her support to live at home.³²

Waiting for a Home Care Package³³

When her husband died in 2000, Ms Joyce Edwards stayed active in her church community and social groups. She remained living independently at home.

In 2017, Ms Edwards started to experience episodes of unconscious collapse due to her fluctuating blood pressure. After several hospitalisations, Ms Edwards and her family agreed it was time to get extra help.

In December 2017, Ms Edwards was approved for a Level 3 Home Care Package. She was told she would receive her help in three to six months. Six months later, Ms Edwards contracted an infection and, after a fall in the shower, was admitted to hospital. Even though Ms Edwards hadn't received the Level 3 Package, she was re-assessed. The assessor found that she now needed a Level 4 Package.

Ms Edwards's daughter, Ruth Harris, tried every avenue she could think of to accelerate the process. She made countless calls to My Aged Care, registered two formal complaints, and even wrote letters to several members of parliament. No one could help.

30 D Tune, *Aged Care Legislated Review*, 2017, p 34.

31 For example Submission AWF.001.01337, Submission AWF.001.01522, Submission AWF.001.01528.

32 Submission AWF.001.01570.

33 Based on the evidence of Ruth Harris: Exhibit 2-76, Adelaide Hearing 2, Statement of Ruth Harris, 12 March 2019, WIT.0074.0001.0001; Transcript, Ruth Harris, Adelaide Hearing 2, 21 March 2019 at T.947.25–957.44.

In December 2018, Ms Edwards was assessed for a third time and was assigned to the high priority queue of the waiting list. It had now been over year since her first assessment and Ms Edwards still hadn't received a Home Care Package. Mere days after her third assessment, Ms Edwards received a letter to inform her that a package would arrive soon. It contained no indication of exactly when the Package would start. Several weeks passed with no update.

Ms Edwards heard that a bed was becoming available at a residential care facility she was familiar with. She decided that 'she couldn't wait forever for help to come' and made the decision to enter permanent residential care in January 2019.

Dissatisfied by what had taken place, Ms Harris investigated the situation. She discovered that a Level 3 Home Package had been assigned to Ms Edwards back in December 2018. No one had bothered to follow up the offer, even though My Aged Care had Ms Edwards's phone number, and Ms Harris's phone number and email.

Ms Edwards waited over a year and she never received a Home Care Package.

How long are people waiting?

The Royal Commission was keen to understand the extent to which people are waiting for aged care services. To shed some light on this, we have used records from the national prioritisation queue and data on 'elapsed time'. Often used in research projects, elapsed time is data recorded by the Australian Government through the aged care assessment program and is defined as 'the time elapsed between an assessment approval and entry into a residential care service or commencement of home care'.³⁴ As indicated above, waiting actually starts well before this. The following section uses the national prioritisation queue and elapsed time (noting its limitations in capturing the total time someone has waited) to assess the extent of waiting for Home Care Packages and residential care.³⁵

The Royal Commission has heard that waiting times for Home Care Packages are often confusing and frightening. According to My Aged Care, the estimated wait time is around three to six months for a Level 1 Home Care Package and more than 12 months for a Level 4 Package.³⁶ Disturbingly, this indicates that people with the greatest need are waiting the longest, even for an interim Package.

34 Productivity Commission, 'Part F, Chapter 14 - Aged Care Services', *Final Report on Government Services 2019*, 2019, p 8.

35 The elapsed time only commences once a person has entered the queue; it does not take account of time before that such as waiting for an ACAT or an ACAT decision.

36 Australian Department of Health, *Assessment decision: Home Care Packages*, 2019, <https://www.myagedcare.gov.au/help-home/home-care-packages/accessing-home-care-package>, viewed 26 September 2019.

All the estimated waiting times, as of 30 June 2018 and 30 June 2019, for a person with a medium priority approval are shown in Table 6.1, with increases over that time period highlighted in red. Waiting times for an interim (first) Package have increased, which says that even individuals with lower needs are being forced to wait longer. As for the individuals with greater needs—Levels 2, 3 and 4—it is understandable that being advised of a ‘more than 12 month’ wait for your approved Package would leave a person unclear about how long they are likely to wait, regardless of whether they can manage during that time and how safe they will be living at home.

Table 6.1: Estimated waiting times for people entering the Home Care Package program by Package level (My Aged Care)

30 JUNE 2018			
Package Level	Interim Package assigned	Time to interim Package	Time to approved Package
Level 1	Level 1	1-3 months	1-3 months
Level 2	Level 1	1-3 months	9-12 months
Level 3	Level 1	1-3 months	12+ months
Level 4	Level 2	9-12 months	12+ months

30 JUNE 2019			
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 Package Program Quarterly Data Report

These estimated waiting times are also to be found in the Australian Department of Health’s quarterly report on the Home Care Package program. This report has been published since the adoption of the national prioritisation queue in 2017.

The estimated waiting times in Table 6.1 show the approved Package level, an interim Package level, the estimated wait time for an interim Package, and the estimated wait time for the approved Package level. Interim Packages enable people to receive a lower level Package to commence care as early as possible.

The existence of interim Packages in fact creates another form of waiting. While services do become available via interim Packages, ultimately the recipients are still waiting. This is because they are receiving a lower level Package that will not fully meet their assessed level of need. The Royal Commission has heard many instances of the frustrations with interim Packages and their lack of services³⁷ and the impact on informal carers of not providing care and support at the right level:

At the time she was living at her home, and had support for about 4 hours a week on a Level 2 Package. If she had access to a Level 4 Package earlier when she was first assessed as needing one perhaps she would not have become so vulnerable so quickly.³⁸

The Royal Commission has learnt that the reality of waiting times for home care differs significantly from that presented on My Aged Care. A public submission provided evidence of a daughter's fears when discovering the true waiting times for home care:

In July 2018 I telephoned (My Aged Care) to enquire as to progress. I was told it was a 12 month wait, which I found astonishing. In December 2018, I called again and was told it was a 12 month+ wait from the time of the original approval. I consider this to be an artifice of language. I have been told unofficially that the current wait is 2–3 years. I doubt my father will still be alive when this package becomes available.³⁹

In fact, many people die waiting. This is the hidden impact of waiting and it is terrible. During the 12 month period ending in June 2018, more than 16,000 people died waiting for a Package on the national prioritisation queue.⁴⁰ We regard this as totally unacceptable.

Despite the estimated waiting times published on the My Aged Care website and in the Australian Department of Health's quarterly report, data reflecting actual waiting times submitted to the Royal Commission is much more revealing.⁴¹ It shows the actual waiting times for Home Care Packages rather than the much more vague references to periods such as '12-plus months'. Table 6.2 shows the more accurate data held by the Australian Department of Health, indicating, for example, that the mean waiting time for a Level 4 Package in 2017–18 was in fact 22 months.

37 For example see Submission AWF.001.01522, Submission AWF.001.01528, Submission AWF.001.01644, Submission AWF.001.01152 and Submission AWF.001.00737.

38 Submission AWF.001.00012.

39 Submission AWF.001.01224.

40 Exhibit 2-89, Adelaide Hearing 2, Statement of Fiona Buffinton, WIT.0058.0001.0001 at 0024 [76].

41 Exhibit 2-89, Adelaide Hearing 12, Statement of Fiona Buffinton WIT.0058.0001.0001 at 0021 [63].

Table 6.2: Mean and median distribution of time (in months) since people were approved for their level of Home Care Package

2017-2018				
Package Level	25 th percentile	Median	75 th percentile	Mean
Level 1	3	7	11	7
Level 2	9	10	11	13
Level 3	6	18	23	16
Level 4	7	18	31	22

Source: Statement of Fiona Buffinton WIT.0058.0001.0001 at .0021 [63]

There is a concerning lack of transparency within the Home Care Package program; in effect, misleading information is being delivered to older people and the broader Australian public.

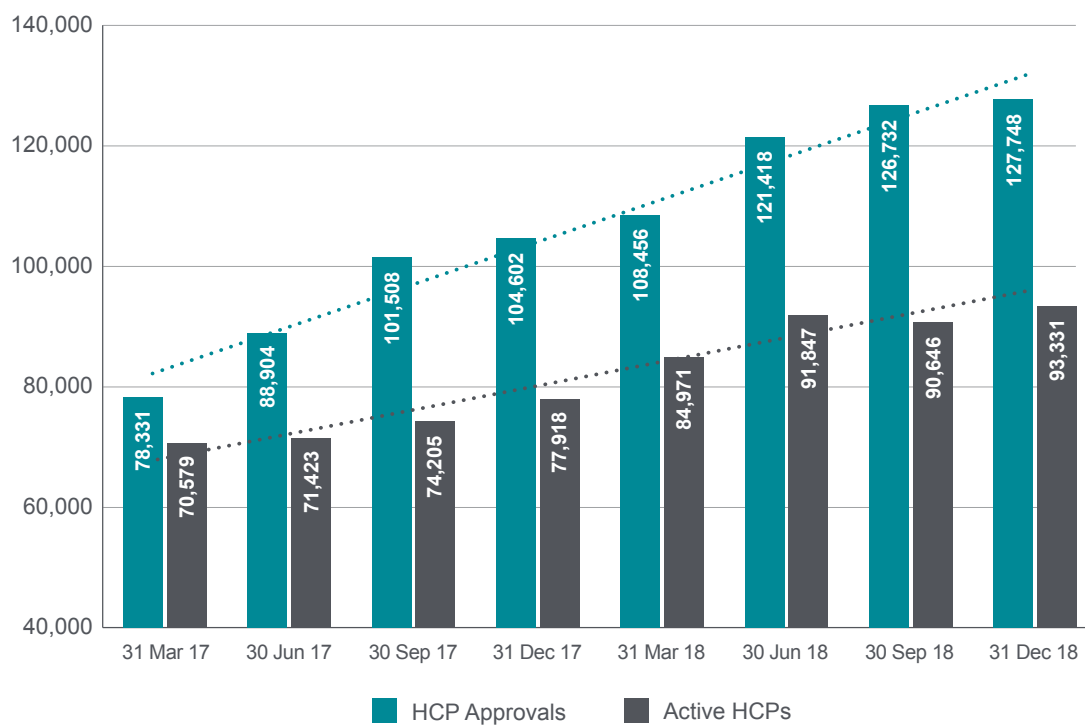
The growing waiting times for Home Care Packages are largely due to the growing number of people on the waiting list. In 2017, the Australian Government reported that 53,750 people were in the national queue. At the same time, a further 35,154 people were receiving an interim Package at a lower level while waiting for their approved care—over 63% of these people were waiting for a level four Home Care Package.⁴²

As of June 2019, there were 119,524 people on the waiting list. Of this group, 72,062 people (about 60%) were waiting for a Package at their approved level and had not yet been offered access to a lower level Package. The remaining 47,462 people (40%) had been offered an interim Home Care Package. However, of the 72,062 people waiting for a Package at their approved level, 68,900 (about 96%) had been granted access to the Commonwealth Home Support Programme.⁴³

42 Australian Department of Health, *Home Care Packages Program: Data Report 27 February – 30 June 2017*, 2017.

43 Australian Department of Health, *Home Care Packages Program: Data Report 1 April – 30 June 2019*, 2019

Figure 6.1: Number of Home Care Package approvals and active Packages: March 2017 to December 2018



Source: Leading Aged Services Australia, third home care provider survey report—March 2019⁴⁴

We find it particularly disturbing that only 91,847 people were receiving Home Care Packages as at 30 June 2018, while more than 120,000 were waiting for Packages. Figure 6.1 reinforces this point by showing the number of Home Care Package approvals against the number of active Packages from March 2017 to December 2018. The figure indicates that demand for Home Care Packages has far outstripped supply. Although this disparity pre-dates 2017, it has become more easily measurable since the adoption of the national prioritisation queue.

The Productivity Commission reports annually on waiting times for Home Care Packages and residential aged care following approval by an aged care assessment team.⁴⁵ It shows that the waiting time for a Home Care Package has been steadily increasing since 2014 in line with demographics and aspirations for care to be provided as long as possible in older people's homes. Even more striking is the sharp increase in waiting times since the adoption of the national prioritisation queue in 2017. For example, 77% of people were waiting more than one month for a Package in 2016–17 which increased to 86% of people waiting more than one month in 2017–18.

⁴⁴ Leading Aged Services Australia, *Third home care provider survey report*, March 2019, pp 4–6.

⁴⁵ Productivity Commission, 'Part F, Chapter 14 - Aged Care Services', *Final Report on Government Services 2019*, 2019, p 8.

Waiting for home care often precipitates entry into residential care. This in itself can result in further and more debilitating waiting. The Royal Commission has heard of the challenges that drive the decision to enter residential care. One witness told the Royal Commission of the impact of being deemed eligible for home care and it not being available, ultimately resulting in admission to residential care:

She was assessed, and we were told by her case supervisor that she was Level 4. We were delighted, but as the caseworker said, the money is not available in the government funds to provide those extra hours. So, we went from joy to sadness very quickly.⁴⁶

The same Productivity Commission report on Government services also shows that the waiting time for residential aged care has been increasing since 2008. This data shows that older people assessed as needing residential care are more likely to wait longer than they did in previous years. Most notably, the largest shift has been occurring in the 'greater than nine months' category—5.4% of people were waiting more than nine months to enter residential care in 2008–09 compared with 35% of people in 2017–18.⁴⁷ This is despite increasing vacancy levels in residential care, a phenomenon that requires further analysis but may be explained to some extent by people who are willing to wait for a residential care place that they consider is right for them.

The Director of the Global Centre for Modern Ageing, Dr Mike Rungie, illustrates the correlation between home and residential aged care waiting times:

Strong preference to not move is expressed by many older people, and now being demonstrated by growing waiting lists for Home Care and dropping occupancy rates in [residential aged care facilities].⁴⁸

Much like Home Care Packages, since the introduction of the national prioritisation queue in 2017, elapsed time between approval for residential care and entry into residential care has significantly increased. This is illustrated by the sharp increase across all the waiting times in the 2017–2018 period. It seems the introduction and release of additional Home Care Packages delays older people from seeking entry to residential care, even if they have been approved, because they think they are more likely to be able to stay at home as more Packages are released.⁴⁹ There is a caveat to be applied to any attempt to reduce waiting times without longer-term changes also being made. In other words, an attempt only to reduce waiting times for home care may deter entry to residential care, which may end in more people waiting for Home Care Packages.

46 Transcript, Johanna Aalberts-Henderson, Cairns Hearing, 15 July 2019 at T3456:16-19.

47 Productivity Commission, 'Part F, Chapter 14 - Aged Care Services', *Final Report on Government Services 2019*, 2019, Table 14A.26.

48 Exhibit 5-29, Perth Hearing, Statement of John Michael Rungie, WIT.0158.0002.0001 at 0004 [15e].

49 Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, 2019, p 42.

What is the impact of waiting?

Since [I was] assigned a Level 2 Package in May then Level 3 in December 2018, I am still waiting for essential equipment and home modifications that are needed NOW—not when I am dead!⁵⁰

This section explores the impact of waiting for care on an older person's likelihood of entering residential or acute care, and their health care and general wellbeing. There are also fiscal implications for the Australian Government in the current regime under which people wait.

There are personal costs associated with waiting for care. The Royal Commission has heard that time waiting for high level Packages (Levels 3 and 4) has caused severe suffering.⁵¹ Evidence also shows that the delay in accessing the right level of care at home can result in admission into residential care.⁵² Delays have led to hospitalisations that may have otherwise been avoided had adequate care at home been available.⁵³ Home services, therefore, not only provide supportive care but are also important in providing a preventative or restorative approach.⁵⁴ In her statement to the Royal Commission, home support worker Ms Anna Hansen illustrated the harsh results of delaying access to home:

The result is that those people will be forced to go into residential care because they can't look after themselves without help, and there's no [Home Care Packages] available for them.⁵⁵

The Royal Commission also notes a recently published study showing that longer wait times were associated with higher mortality in the longer term. More specifically, compared with individuals who waited less than 30 days for a Home Care Package, individuals who waited more than six months for a Package had a 20% higher risk of death within two years of receiving the Package. The same study also found that individuals who waited more than six months had a 10% higher risk of transitioning into residential aged care within two years.⁵⁶

50 Submission AWF.001.01637

51 For example, Exhibit 2-04, Adelaide Hearing 2, Statement of Raelene Ann Ellis, 12 March 2019, WIT.0083.0001.0001 at 0005 [41].

52 Exhibit 2-76, Adelaide Hearing 2, Statement of Ruth Harris, 12 March 2019, WIT.0074.0001.0001 at 0004 [35]–[36]. Exhibit 2-28, Adelaide Hearing 2, Statement of Anna Hansen, 7 March 2019, WIT.0081.0001.0001 at 0002 [20].

53 Exhibit 1-09, Adelaide Hearing 1, Statement of Paul Versteeg, WIT.0009.0001.0001 at 0004 [22]. Transcript Paul Versteeg, Adelaide Hearing 1, 12 February 2019, T164.3-39. Transcript Paul McCallum, Adelaide Hearing 1, 11 February 2019, T324.25-27.

54 Australian Department of Health and Ageing, *Home Care Package Guidelines*, August 2013.

55 Exhibit 2-28, Adelaide Hearing 2, Anna Gabrielle Hansen, 7 March 2019, WIT.0081.0001.0001 at 0002 [20].

56 R Visvanathan, AT Amare, S Wesselingh, R Hearn, S McKechnie, J Mussared, and MC Inacio, 'Prolonged Wait Time Prior to Entry to Home Care Packages Increases the Risk of Mortality and Transition to Permanent Residential Aged Care Services: Findings from the Registry of Older South Australians (ROSA)', *The Journal of Nutrition, Health & Aging*, 2019, Vol 23, pp 271–280.

There are also substantial financial costs, for the taxpayer, associated with waiting. Residential care is generally more expensive for the Government than Home Care Packages and home support programs.⁵⁷ Waiting times therefore impose a significant hidden cost on the Federal Budget via an individual's increased likelihood of entering residential care or hospital admission.

Older people often rely on family members and friends to provide informal care while waiting for services. In addition to having an impact on the health and wellbeing of carers, having to wait for services imposes a cost on the time of the informal carer:

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.⁵⁸

I had organised carers to shop, clean and shower my mother but they were never good enough, so I found it exhausting coordinating that with a full-time job. I lost my job as a consequence of my parent's demands.⁵⁹

In this case, someone became unemployed as a result of the escalating needs of a parent forced to wait for her Home Care Package. Privately-funded carers were found to be inadequate, so the daughter became her mother's full-time support. This scenario is not uncommon, nor is that of people reducing their hours of paid work, or giving up work altogether, to care for an older relative or partner at home. The person effectively forced into a caring role can feel resentment and isolation as a result, irrespective of the love they may have for the older person. Not only does someone lose income and the social and psychological benefits that accrue from working, but the Government loses tax revenue—the very same taxes that go to fund aged care.

With only four Home Care Package levels, there can be a misallocation of Packages relative to assessed need, which is only exacerbated by waiting times.⁶⁰ The longer the time between assessment of need and assignment of a Home Care Package, the more likely the older person's needs will change. The consequences of lengthy waiting times include increasing numbers of older people with unmet needs or unspent funds.

57 Australian Institute of Health and Welfare, *Aged Care Data Snapshot 2018 – sixth release*, 2018.

58 Submission AWF.001.01753.

59 Submission AWF.001.00673.

60 Leading Aged Services Australia, *Analysis: Responding to the Home Care Packages Waitlist Crisis*, September 2018, p 10.

Unspent funds are the ‘ongoing balance of funds that have not been spent or committed as part of a person’s Home Care Package’.⁶¹ When a person moves to a new home care provider, unspent funds (less any exit fee) must be transferred to the new provider. The funds transfer to the new provider must be made within 70 days after the cessation day.⁶²

Home Care Package providers were asked about the total amount of unspent funds they were holding on 1 October 2018. Across 6293 Home Care Packages that were held by just 17 providers, there was a total of approximately \$34 million in unspent funds. Extrapolating these data led to an estimate of approximately \$450 million in unspent funds nationally.⁶³ The Aged Care Financing Authority estimates that on current trends, the amount of unspent funds held by providers will top \$500 million in a couple of years.⁶⁴ In the meantime, thousands of older people are waiting to receive any care at all. These funds are simply lying idle.

The National Director of Home Care Services, Ms Amanda Bowe, said in her statement to the Royal Commission that unspent funds, although representing an inefficiency, can be largely beneficial if properly allocated:

Redirecting unspent funds would greatly assist with supporting those with unmet needs as a result of funding being assigned at a level at less than assessed need, or those waiting for funding to be assigned.⁶⁵

It is estimated that the average unspent amount is approximately \$6720 a year across all four levels of Home Care Packages.⁶⁶ In the months ahead, the Royal Commission will give further consideration to the issue of unspent funds. We have heard evidence which indicates that the reasons for underspending can include the saving mindset of older people; pressure from providers; waiting for a ‘rainy day’ or for respite care; time taken to build trust in a provider to deliver personal care; and the over-assessment of needs.⁶⁷

In the meantime, people wait.

61 Exhibit 2-89, Adelaide Hearing 2, Statement of Fiona Buffinton, WIT.0058.0001.0001 at 0018 [49].

62 Exhibit 2-89, Adelaide Hearing 2, Statement of Fiona Buffinton, WIT.0058.0001.0001 at 0018 [51].

63 Leading Aged Services Australia, *Third Home Care Provider Survey Report*, March 2019.

64 Aged Care Financing Authority, *Sixth Report on the Funding and Financing of the Aged Care Sector*, 2018, p 77.

65 Exhibit 2-88, Adelaide Hearing 2, Statement of Amanda Claire Bowe, 8 March 2019, WIT.0034.0001.0027 at 0027 [12.5.8].

66 Exhibit 1-50, Adelaide Hearing 2, Statement of Nicolas Mersiades, 31 January 2019, WIT.0011.0001.0001 at 0026 [122.21].

67 Exhibit 2-12, Adelaide Hearing 2, Statement of Paul Sadler, 11 March 2019, WIT.0078.0001.0002 at 0010 [51–52].

How can we reduce waiting?

It is important to make the distinction between waiting lists and waiting times. The aim should not be to eliminate the waiting list but to eliminate the waiting time.⁶⁸

People are accustomed to waiting for many public services, but expect the time that they wait to be as short as possible, particularly when their need is critical. Reducing waiting times is no simple task and the Australian Government has been offered many suggestions about addressing this issue. Some are presented below. As it stands, most options are directed towards the national prioritisation queue but ultimately there is no one clear answer.

Each year the Government releases new Home Care Packages. Evidence before the Royal Commission indicates that by 2021–22, there will be 153,438 Home Care Packages available with release of additional Packages to be staged over three years from 2018–19. To fund this target, the Government increased its spending on Home Care Packages from \$1.6 billion in 2016–17 to \$2.6 billion in 2018–19.⁶⁹ In the May 2018 Federal Budget, the Government allocated another \$1.6 billion over four years to support an additional 14,000 high level Packages by 2021–22.⁷⁰

In the months following the calling of the Royal Commission, the Government announced that it would bring forward future expenditure on Home Care Packages. Following the initial increase, in December 2018, the Government announced a further \$287.3 million for the release of 10,000 higher level Packages.⁷¹ This announcement was followed by an additional \$282.4 million over five years for 10,000 more Packages in February 2019.⁷²

These measures are intended collectively to reduce the waiting times from those that existed in 2017–18. However, there was an estimated 12.6% growth in the number of people waiting for the Level 3 and Level 4 Home Care Packages between June 2018 and September 2018 alone.⁷³ Given the extent of the pre-existing waiting list, it is clear that the additional Packages will not satisfy the current, and growing, demand for home care.

68 Submission AWF.001.01918.

69 Transcript, Fiona Buffinton, Adelaide Hearing 2, 22 March 2019 at T1056.21–25, T1080.42–45; Commonwealth Post-Hearing Submissions, 29 March 2019, RCD.0012.0003.0012, 0014[10].

70 Exhibit 2-89, Adelaide Hearing 2, Statement of Fiona Buffinton, 11 March 2019, WIT.0058.0001.0001 at 0015 [42].

71 Exhibit 1-30, Adelaide Hearing 1, The Hon. Greg Hunt MP and The Hon. Ken Wyatt MP, Media Release, 17 December 2018, RCD.9999.0011.2022.

72 Exhibit 2-12, Adelaide Hearing 2, Statement of Paul Sadler, 11 March 2019, WIT.0078.0001.0001 at 0007 [34].

73 Exhibit 2-92, Adelaide Hearing 2, Home Care Packages Program Report for the period 1 October 2018 to 31 December 2018 dated March 2019, RCD.9999.0028.0001 at 0005.

The Royal Commission has received some suggestions about how to clear the waiting list and potential benchmarks:

- Mr Paul Sadler (Presbyterian Aged Care) suggested that it would take 40-50,000 Packages to absorb the current waiting list.⁷⁴
- Mr Ian Yates (COTA) suggested benchmarks of no more than one month waiting times for residential care and no more than three months for Home Care Packages.⁷⁵
- Leading Aged Services Australia reinforce a benchmark waiting time of no more than three months from the time of assessment to the time an older Australian receives support in their home.⁷⁶
- The Australian Department of Health indicated that it would take some \$2-2.5 billion per annum to provide access to all people on the waiting list at the level of care they needed (or \$800 million if Level 2 Packages were offered to all people on the list).⁷⁷

Conclusion

We are in no doubt that the current aged care system is not able to deal with the level of unmet need for home care services and the demographic pressures behind it. It is clearly unacceptable for there to be more people waiting for Home Care Packages than are receiving them. It is unsafe. It is neglect.

This situation has contributed to unnecessary and premature deaths; has driven some people into residential aged care (albeit at a slower rate than before); and has placed terrible pressure on informal carers. It cannot be allowed to continue.

Moving to eliminate the waiting list may be the obvious way to reduce waiting times for home care. However, the capacity of the sector to grow so rapidly to meet demand, without risking quality, has been questioned.⁷⁸ Concerns about quality and capacity associated with the rapidly increasing home care market are highlighted in the following public submission to the Royal Commission:

Negligence by the [home care] provider resulted in food poisoning, a dramatic loss of weight, failure to comply with meal preparation tasks, plus hospitalisation following a failure to take effective action when illness was observed.⁷⁹

74 Transcript, Paul Sadler, Adelaide Hearing 2, 18 March 2019 at T731.43-45.

75 Exhibit 1-3, Adelaide Hearing 1, Statement of Ian Garth Yates, 31 January 2019, WIT.0006.0001.0001 at 0015 [62].

76 Leading Age Services Australia, *LASA outlines actions to address unacceptable home care wait times*, March 27 2019, <https://lasa.asn.au/news/lasa-outlines-actions-to-address-unacceptable-home-care-wait-times/>, verified 25 September 2019.

77 Transcript - Fiona Buffinton, 22 March 2019 at T1057-1058.

78 Exhibit 2-86, Adelaide Hearing 2, Statement of Professor Swerrisen, WIT.0085.0001.0001 at 0005 [29]; Submission AWF.001.01644, Submission AWF.001.01756.

79 Submission AWF.001.01644.

The workforce implications of rapidly increasing Package numbers cannot be ignored, particularly as the aged care sector is competing for workforce with the National Disability Insurance Scheme, which is also expanding. The Royal Commission also heard evidence from the Aged Care Quality and Safety Commission that the regulation of home care is ‘not strong’.⁸⁰ One person told the Royal Commission:

I have had five different providers of my Home Care Package since January 2017. I have chosen to change providers numerous times due to concerns about poor services and management of my package funds.⁸¹

As the Government is going to continue to promote ‘care at home in line with people’s wishes’, it must find ways to encourage a high standard of care across all home care providers. The correlation between waiting times for residential care and the releasing of Home Care Packages warrants further consideration. This correlation suggests that if Packages are released too quickly, people may delay their entry into residential care which could simply lengthen the queue as people become more willing to wait at home. Ultimately, this would result in even longer waiting times for home care.⁸²

In addition to financial levers to influence waiting times, the design of the aged care system may also contribute. In his 2017 *Legislated Review of Aged Care*, Mr David Tune AO PSM recommended several ways to address the waiting times for Home Care Packages:

- rebalancing the distribution of Home Care Packages by increasing the proportion that are high care Packages, without a change in the overall home care ratio
- increasing access to high level Home Care Packages to reflect current demand by allowing for the temporary allocation of a Package where there is a residential care place that is not being used
- introducing a Level 5 Package to allow people with higher care needs to stay at home longer, with the level of assistance being no higher than the average costs of care in residential care
- changing the Aged Care Provision Ratio to the population cohort aged 75 years and over, following achievement of the 125 places per person over 70 ratio in 2021–22, to better meet future demand.

80 Transcript, Janet Anderson, Adelaide Hearing 1, 18 February 2019 at T362.40.

81 Exhibit 8-24, Brisbane Hearing, Statement of Gwenda Noelene Darling, WIT.0329.0001.0001 at 0002 [11].

82 Exhibit 5-29, Perth Hearing, Statement of Mike Rungie, 11 June 2019, WIT.0158.0002.0001 at 0004 [15].

The Royal Commission also received a number of submissions from members of the public, academics and organisations that proposed reforms to the wait for home care. These included more localised approaches to service planning and allocation; greater transparency of the waiting list and information on the waiting list; increased flexibility in Home Care Packages; ‘uncapping supply’ of home care; combining home care with home support; and allocation of unspent funds.⁸³ These and other options will be considered further by the Royal Commission in its deliberations.

It is evident, however, not least from the long waiting lists for approved [Home Care Package] recipients that the level of subsidy currently provided by the government is inadequate to ensure that every individual receives care and/or services that optimise health, wellbeing and quality of life.⁸⁴

Clearly, the complexities of waiting times for aged care services require urgent and dedicated attention. Having implemented a positive push towards ageing in the home, it is now a matter of redefining the system to avoid harm to older Australians and increase efficiency in the aged care system. The Home Care Packages and the national prioritisation queue highlight flaws in the system, but they cannot be looked at in isolation. Overall, the entire aged care system and the points at which individuals are asked to wait must be considered at the same time, alongside the ever pressing need to protect older people’s safety by providing adequate and widely available home care services.

We are convinced that, in order to keep older people safe in their homes, significant additional funding needs to be provided for Home Care Packages both immediately and into the future in order to ensure that supply meets community expectation.

We will examine the issue of waiting times further in the context of whole-of-system reform.

83 For example Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry*, 2019, p 156; Exhibit 2-89, Adelaide Hearing 2, Statement of Fiona Buffinton, 11 March 2019, WIT.0058.0001.0001 at 0016 [45]; Exhibit 1-3, Adelaide Hearing 1, Statement of Ian Garth Yates, 31 January 2019, WIT.0006.0001.0001 at 0015 [62]; Exhibit 2-88, Adelaide Hearing 2, Statement of Amanda Claire Bowe, 8 March 2019, WIT.0034.0001.0027 at 0027 [12.5.8].

84 Exhibit 1-51, Adelaide Hearing 1, Statement of Claerwen Eleanor Little, 31 January 2019, WIT.0010.0001.0001 at 0007 [34].

7. ‘Elders are our future’

Elders are our future, our culture, and that’s who we learn off. Our Elders.¹

Diversity of people, cultures and places

There is great diversity amongst Aboriginal and Torres Strait Islander people, with over 200 nations across Australia.² The Royal Commission has heard evidence about the aged care experiences of Aboriginal and Torres Strait Islander people in the Kimberley region of Western Australia; central desert lands of South Australia, Western Australia and the Northern Territory; Top End of the Northern Territory; Torres Strait and Cape York; Bairnsdale in Victoria; and in the metropolitan settings of Melbourne, Brisbane, Darwin, Sydney and Adelaide. The Royal Commission also held a roundtable discussion in Adelaide with experts and service providers who have a focus on Aboriginal and Torres Strait Islander health and aged care services.

This chapter considers aged care for Aboriginal and Torres Strait Islander people. It explores problems with access to services, the types of programs and funding that are currently available, and what Aboriginal and Torres Strait Islander people say they need in their aged care. It describes particular experiences and concerns that apply in an urban setting as well as those that apply in regional and remote locations.

Geographical diversity presents a range of challenges for the delivery of all aged care services across remote and very remote Australia. This is particularly relevant to Aboriginal and Torres Strait Islander people who comprise 16% of remote and 46% of very remote populations.³ Despite over-representation in remote settings, over 60% of Aboriginal and Torres Strait Islander people live in major cities or inner regional areas.⁴ Further, the areas with the largest Aboriginal and Torres Strait Islander populations are urban, such as Sydney (10.2%) and Brisbane (10.9%), as well as regional areas, such as the central and north coast New South Wales (10.7%).⁵ In addressing the quality and safety of aged care delivered to

1 Transcript, Faye Dean, Broome Hearing, 17 June 2019 at T1981.14.

2 Exhibit 4-16, Broome Hearing, Statement of Venessa Michelle Curnow, 17 June 2019, WIT.0243.0001.0001 at 0007[43].

3 Australian Bureau of Statistics, ‘Census of Population and Housing: Characteristics of Aboriginal and Torres Strait Islander Australians 2016, Where People Live, 2016.’ *Australian Bureau of Statistics*, updated: 13 March 2019, <https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/2076.0Main%20Features1302016?opendocument&tabname=Summary&prodno=2076.0&issue=2016&num=&view=>, viewed 27 September 2019.

4 Australian Bureau of Statistics, ‘Estimates of Aboriginal and Torres Strait Islander Australians.’ *Australian Bureau of Statistics*, updated: 17 September 2018, <https://www.abs.gov.au/ausstats/abs@.nsf/mf/3238.0.55.001>, viewed 5 August 2019.

5 Australian Bureau of Statistics, ‘2075.0 - Census of Population and Housing - Counts of Aboriginal and Torres Strait Islander Australians, 2016.’ *Australian Bureau of Statistics*, updated: 30 August 2017, <https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/2075.0Main%20Features102016?opendocument&tabname=Summary&prodno=2075.0&issue=2016&num=&view=>, viewed 5 August 2019.

Aboriginal and Torres Strait Islander people, the Royal Commission will continue to consider experiences in metropolitan settings as well as in regional and remote areas.

Notwithstanding the diversity of communities, geography, culture, ways of living and the experiences of Aboriginal and Torres Strait Islander people, we have heard considerable evidence of unifying themes surrounding self-determination, trust, cultural safety, respect, connection to community, and connection to the land.⁶ Further, the reverence and respect shown to Aboriginal and Torres Strait Islander Elders was a unifying feature of the evidence provided.

Aboriginal and Torres Strait Islander people are not being well served by the current aged care system, which, in many respects, fails to grapple with the realities of the barriers this part of our community faces. Australia's history includes mass displacement, dispossession, cultural disruption, loss of language, and policies of assimilation for Aboriginal and Torres Strait Islander people. This has led to intergenerational trauma, a deep distrust of mainstream and government services, and pervasive inequality in life expectancy, health status, education and employment outcomes:⁷

There is a distrust of institutions and a reluctance to enter care. This distrust results from the history of marginalisation, racism and mistreatment of Aboriginal and Torres Strait Islander people, including forced removal of people from Country.⁸

Aboriginal and Torres Strait Islander people told us that they want to receive aged care services from people and organisations they know and trust, and, where possible, that are Aboriginal and Torres Strait Islander controlled and staffed.⁹

The centrality of community and Country was another forceful message. For Aboriginal and Torres Strait people, the connection to Country is deep and spiritual. Consequently, many people choose to remain on their Country rather than seek health and aged care services in other places due to the subsequent displacement from family, culture, community, ceremony and their roles as Elders in community life.¹⁰ For those people who leave Country to enter residential aged care facilities elsewhere, their wellbeing depends upon the ability to return to that Country, if only for short visits.¹¹

6 Transcript, Matthew Moore, Perth Hearing, 26 June 2019 at T2572.42-46 and T2580.44-T2581.7; Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2027.37-42.

7 Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2038.13-34 and T2045.23-46; Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0009 [63]; Exhibit 4-8, Broome Hearing, Statement of Graham Aitken, 3 June 2019, WIT.1134.0001.0001 at 0007 [57]; Exhibit 4-13, Broome Hearing, Statement of Kate Suzanne Fox, 16 June 2019, WIT.1145.0001.0001 at 0005 [30-31]; Exhibit 4-9, Broome Hearing, Statement of Ruth Crawford, 23 May 2019, WIT.0185.0001.0001 at 0012 [57].

8 Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0009 [66];

9 Transcript, Shontia Michelle Saluja-Honeysett, Mildura Hearing, 29 July 2019 at T3929.1-9. Aboriginal and Torres Strait Islander roundtable, 28 May 2019.

10 Transcript, Kim McRae, Darwin Hearing, 8 July 2019 at T2864.39-; Transcript, Roslyn Malay, Broome Hearing, 19 June 2019 at T2175.39 and T2176.2.

11 Transcript, Roslyn Malay, Broome Hearing, 19 June 2019 at T2176.8; Exhibit 4-16, Broome Hearing, Statement of Venessa Michelle Curnow, 17 June 2019, WIT.0243.0001.0001 at 0009 [54]; Exhibit 4-2, Broome Hearing, Statement of Faye Dean, June 2019, WIT.1142.0001.0001 at 0005 [35]; Transcript, Madeleine Jadai, Broome Hearing, 17 June 2019 at T1985.36.

Witnesses gave evidence of aged care and health services that understand how to deliver services to Aboriginal and Torres Strait Islander people. These services innovate and make things work despite the barriers inherent in the system. They initiate and develop relationships of trust to provide holistic wrap-around services, and they take the time necessary to do so.¹² They find ways to assist people to navigate the aged care system that avoids the online My Aged Care processes.¹³ They support people through Aged Care Assessment Team and Regional Assessment Service assessments and support them in a myriad of other ways. Much of this work is done without aged care funding and is dependent upon the goodwill and flexibility of committed people.¹⁴

Access to aged care

Aboriginal and Torres Strait Islander people experience disproportionate levels of illness and disability and are more likely to require aged care services at a younger age.¹⁵ In the Broome and Darwin Hearings, witnesses gave evidence about high rates of diabetes, renal failure, heart disease, chronic obstructive pulmonary disease, dementia and other multiple complex health problems in the Aboriginal and Torres Strait Islander populations.¹⁶ Recent data from the Australian Institute of Health and Welfare supports this.¹⁷ Because of the need for functional assistance at an earlier age, aged care planning is undertaken and services are available for Aboriginal and Torres Strait Islander people aged 50 years and over.¹⁸ The equivalent age for other people is 65.

The Royal Commission heard that despite poorer health, higher levels of disability and earlier access to aged care, Aboriginal and Torres Strait Islander people are under-represented

12 Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2041 and T2042; Transcript, Matthew Moore, Perth Hearing, 26 June 2019 at T2574.39 and T2575.1; Exhibit 5-28, Perth Hearing, Statement of Matthew Moore, May 2019, WIT.0162.0001.0001 at 0022 [97].

13 Transcript, Graham Aitken, Broome Hearing, 18 June 2019 at T2072.17, T2073.42 and T2074.10-46 and T2084.19-42; Transcript, Ruth Crawford, Broome Hearing, 18 June 2019 at T2106.27 and T2112.19-T2113.22; Transcript, Matthew Moore, Perth Hearing, 26 June 2019 at T2583.10; Transcript, Kim McRae, Darwin Hearing, 8 July 2019 at T2859.31-34.

14 Exhibit 4-16, Broome Hearing, Statement of Venessa Michelle Curnow, 17 June 2019, WIT.0243.0001.0001 at 0007 [41-60]; Transcript of Ruth Crawford, Broome Hearing, 18 June 2019 at T2097.9; Exhibit 4-4, Broome Hearing, Statement of Craig Robin Barke, 31 May 2019, WIT.0227.0001.0001 at 0006-7 [28.2]; Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2035.23-30; Exhibit 4-2, Broome Hearing, Statement of Faye Dean, June 2019, WIT.1142.0001.0001 at 0007 [57]; Exhibit 5-28, Perth Hearing, Statement of Matthew Moore, May 2019, WIT.0162.0001.0001 at 0016 [61].

15 Productivity Commission, ‘Chapter 14 Aged Care Services.’, 2019, <https://www.pc.gov.au/research/ongoing/report-on-government-services/2019/community-services/aged-care-services/rogs-2019-partf-chapter14.pdf>, viewed 12 August 2019.

16 Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0010 [68-69], Transcript, Kim McRae, Darwin Hearing, 8 July 2019 at T2862.36-T2863.1; Transcript, Associate Professor Geoffrey Sussman, Darwin Hearing, 11 July 2019 at T3321.19.

17 Australian Institute of Health and Welfare, ‘Insights into vulnerabilities of Aboriginal and Torres Strait Islander people aged 50 and over.’, 30 June 2019, <https://www.aihw.gov.au/reports/indigenous-australians/vulnerabilities-aboriginal-torres-strait-50-full/contents/summary>, viewed 23 August 2019.

18 Productivity Commission, ‘Chapter 14 Aged care services’, *Report on Government Services*, 2019, <https://www.pc.gov.au/research/ongoing/report-on-government-services/2019/community-services/aged-care-services/rogs-2019-partf-chapter14.pdf>, viewed 27 September 2019.

in the aged care system.¹⁹ The rate at which Aboriginal and Torres Strait Islander people access various aged care programs across Australia will be further considered as the Royal Commission continues its work.²⁰

The Royal Commission was presented with evidence about the barriers that Aboriginal and Torres Strait Islander people face in accessing aged care services. These include:

- Some Aboriginal and Torres Strait Islander people are not aware of the range of aged care services to which they may be entitled.²¹
- My Aged Care is not easily accessible to those who do not have English as their first language.²² The system also assumes a level of internet and phone access, or at least a reliable mail service.²³ This is not realistic for a significant portion of Aboriginal and Torres Strait Islander people, particularly those who live in remote and very remote locations.²⁴
- Aged Care Assessment Team and Regional Assessment Services processes require an applicant to discuss intimate and personal health details. If the assessor is a stranger or does not use an interpreter or trusted cultural support worker, the applicant is unlikely to speak frankly or with the detail needed for a proper assessment.²⁵
- When Aboriginal and Torres Strait Islander people perceive that mainstream services are not culturally safe, they will avoid those services.²⁶

In relation to care in the home and community, the Royal Commission received evidence that when aged care is available to Aboriginal and Torres Strait Islander people through the Commonwealth Home Support Programme or a Home Care Package, 'in some cases, living conditions in remote locations brought about through structural factors such as poor housing, lack of maintenance and over-crowding' can make personal care or domestic services inappropriate or undeliverable.²⁷

19 Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2021.1; Productivity Commission, 'Chapter 14 Aged care services.', *Report on Government Services*, 2019, <https://www.pc.gov.au/research/ongoing/report-on-government-services/2019/community-services/aged-care-services/rogs-2019-partf-chapter14.pdf>, viewed 27 September 2019.

20 See further information in D Cullen with assistance from the Office of the Royal Commission, Background Paper 2, p 6.

21 Exhibit 4-8, Broome Hearing, Statement of Graham Aitken, 3 June 2019, WIT.1134.0001.0001 at 0010 [77]; Transcript, Shontia Michelle Saluja-Honeysett, Mildura Hearing, 29 July 2019 at T3930.6-24; Transcript, Lynette Joyce Bishop, Mildura Hearing, 29 July 2019 at T3938.4-11.

22 Transcript, Ruth Crawford, Broome Hearing, 18 June 2019 at T2114.42; Exhibit 4-8, , Broome Hearing, Statement of Graham Aitken, 3 June 2019, WIT.1134.0001.0001 at 0009 [71]; Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0010 [71-72].

23 Exhibit 4-10, Broome Hearing, Statement of Belinda Jayne Robinson, 6 June 2019, WIT.0211.0001.0001 at 0009 [48]; Transcript, Ruth Crawford, Broome Hearing, 18 June 2019 at T2114.42; Exhibit 4-8, Broome Hearing, Statement of Graham Aitken, 3 June 2019, WIT.1134.0001.0001 at 0007 [54]; Exhibit 4-4, Broome Hearing, Statement of Craig Robin Barke, WIT.0227.0001.0001 at 0008 [28.2]; Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0010 [71].

24 Transcript, Graham Aitken, Broome Hearing, 18 June 2019 at T2084.20; Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2035.25-30.

25 Transcript, Graham Aitken, Broome Hearing, 18 June 2019 at T2074.39-46; Transcript, Matthew Moore, Perth Hearing, 26 June 2019 at T2583.27.

26 Exhibit 4-6, Broome Hearing, Statement of Professor Leon Flicker, 27 May 2019, WIT.0161.0001.0001 at 0006 [21].

27 Exhibit 4-17, Broome Hearing, Statement of Jaye Alexander Smith, 10 May 2019, WIT.0128.0001.0001 at 0049 [195(a)].

We heard that aged care was being delivered in community centres or shared spaces, rather than in people’s homes. In some remote Aboriginal and Torres Strait Islander communities, aged care services assist older people by providing regular meals to improve nutrition or a place to wash their clothes or bedding, as many people do not have a washing machine. Ms Kim McRae, a Team Leader at the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women’s Council, known as the NPY Women’s Council, described how vital these services are in maintaining a level of health and to people being able to stay on Country for as long as possible.²⁸

Place-based models for the delivery of aged care services

Place-based models can be more sustainable in providing services to meet the needs identified by and for local Aboriginal and Torres Strait Islander communities.²⁹

Witnesses suggested place-based models should involve:

- consulting with the local Aboriginal and Torres Strait Islander people before establishing services in the community, as this develops trust and results in more culturally appropriate services.³⁰ As an example, the Star of the Sea facility on Thursday Island has a purpose-built ‘Ocean room’, connecting Elders to the sea and views of surrounding islands to which the Torres Strait Islander people are culturally linked³¹
- using blended models of care combining Aboriginal and Torres Strait Islander aged care and health care services to achieve the best outcomes for older people³²
- empowering the local community to deliver culturally safe care³³
- employing a local aged care workforce in order to provide culturally appropriate care.³⁴

28 Transcript, Kim McRae, Darwin Hearing, 8 July 2019 at T2862.45.

29 Place-based models generally use a collaborative process that aims to address the issues that people experience within a geographical location. In aged care, it involves the provision of integrated, multidisciplinary services that meet the varying needs of the local Aboriginal community.

30 Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0005 [39]; Exhibit 4-15, Broome Hearing, Statement of Roslyn Malay, June 2019, WIT.0174.0001.0001 at 0004 [23]; Transcript, Tamra Bridges, Broome Hearing, 17 June 2019 at T2008.20; Exhibit 4-8, Broome Hearing, Statement of Graham Aitken, 3 June 2019, WIT.1134.0001.0001 at 0008 [62].

31 Transcript, Tamra Jayde Bridges, Broome Hearing, 17 June 2019 at T2005.43–T2006.1.

32 Transcript, Graham Aitken, Broome Hearing, 18 June 2019 at T2072.17; Exhibit 4-15, Broome Hearing, Statement of Roslyn Malay, June 2019, WIT.0174.0001.0001 at 0004 [23].

33 Transcript, Madeleine Jadai, Broome Hearing, 17 June 2019 at T1988.15; Exhibit 4-13, Broome Hearing, Statement of Kate Suzanne Fox, 16 June 2019, WIT.1145.0001.0001 at 0004 [23]; Exhibit 4-15, Broome Hearing, Statement of Roslyn Malay, June 2019, WIT.0174.0001.0001 at 0004 [23].

34 Exhibit 4-8, Broome Hearing, Statement of Graham Aitken, 3 June 2019, WIT.1134.0001.0001 at 0008 [62]; Exhibit 4-13, Broome Hearing, Statement of Kate Suzanne Fox, 16 June, 2019, WIT.1145.0001.0001 at 0007 [43].

According to Ms Ruth Crawford, the Manager of Kimberley Aged and Community Services, which is part of WA Country Health Service, a partnership model of aged care has operated throughout the Kimberley since 1993 and largely replaced independent community services that failed due to lack of expertise and government support.³⁵ This involves Kimberley Aged and Community Services partnering with a number of community organisations to provide aged care in communities. In Bidyadanga, a coastal Aboriginal community located 200 kilometres south of Broome, Kimberley Aged and Community Services supports a community centre for older people, run by local people and known as the HACC Centre.

At the Broome Hearing, the Royal Commission heard how this model had assisted people to stay on Country longer, as well as raise awareness of, and provide support for, local people living with dementia. Ms Faye Dean is a Karajarri woman who, with the assistance of Mr Ryan Hammond, manages the HACC Centre, caring for around 12 people, on Commonwealth Home Support Programme and Home Care Packages, out of a population of around 750 to 800.³⁶ Ms Dean said that:

The centre has become a positive environment, a second home for people, where they can come to talk to each other, feel safe or just have a shower. People tell me that they feel like they have friends with the centre, and that it has helped with their feelings of loneliness and depression.³⁷

This place-based model of care is designed to ensure care is provided as close to a person's home as possible and by Aboriginal and Torres Strait Islander workers who are supported to attain the requisite training and skills.³⁸ Consequently, the HACC Centre delivers care with an understanding of the person's background, maintaining what Ms Crawford referred to as their cultural security.³⁹ Ms Crawford and others argued that it is very important that Aboriginal and Torres Strait Islander people design, govern or manage these services.⁴⁰

Mr Graham Aitken, a Yankunytjatjara descendent and Chief Executive Officer of Aboriginal Community Services, the largest provider of aged care services to Aboriginal and Torres Strait Islander people in South Australia, described his organisation's delivery of care at local community centres in the very remote Anangu Pitjantjatjara Yankunytjatjara, known as the APY Lands. The process for establishing these services required a deep conversation with the local community and its Elders, including talking to the APY Executive Board

35 Exhibit 4-9, Broome Hearing, Statement of Ruth Crawford, 23 May 2019, WIT.0185.0001.0001 at 0004 [15.2.1-15.2.4].

36 Transcript, Faye Dean, Broome Hearing, 17 June 2019 at T1969.36-T1970.2.

37 Exhibit 4-2, Broome Hearing, Statement of Faye Dean, June 2019, WIT.1142.0001.0001 at 0004 [29].

38 Exhibit 4-9, Broome Hearing, Statement of Ruth Crawford, 23 May 2019, WIT.0185.0001.0001 at 0004 [15.2.2]; Exhibit 4-2, Broome Hearing, Statement of Faye Dean, June 2019, WIT.1142.0001.0001 at 0002 [13-17] and 0003 [20].

39 Exhibit 4-9, Broome Hearing, Statement of Ruth Crawford, 23 May 2019, WIT.0185.0001.0001 at 0004 [15.2.4].

40 Exhibit 4-9 Broome Hearing, Statement of Ruth Crawford, 23 May 2019, WIT.0185.0001.0001 at 0015 [81]; Transcript, Donna Ah Chee, Dr John Boffa, Dr Sarah Giles and Olga Havnen, Darwin Hearing, 8 July 2019 at T2879.42-T2881.31.

about what his organisation sought to achieve.⁴¹ Mr Aitken explained that understanding a community’s needs will likely require attention to broader issues, including the employment of local Aboriginal and Torres Strait Islander people:⁴²

We were respectful in our conversations with community about what we were wanting to achieve in terms of aged care service delivery. Talking to as many different people as possible and certainly the Elders has really helped us, not only establish our service provision, but also enabled the Elders to really understand what it is that we were trying to achieve. And by dealing with the Elders in a respectful way, asking them how they wanted us to do business, we’ve been able to get to a place now and we’re still developing and improving all the time.⁴³

Mr Aitken spoke about how the non-Aboriginal people that work on the APY Lands have been working in the community for many years and are known and trusted. Continuity and trust go hand-in-hand.

Professor Leon Flicker AO, an expert in geriatric medicine and dementia care from the University of Western Australia, told the Royal Commission about the Lungarra Ngoora Community Care model at Looma, halfway between Broome and Fitzroy Crossing. The Looma project enabled people of all ages with disability or frailty to access the supports and services required to stay at home and on Country. The Looma project pooled funding from the Commonwealth Home Support Programme, Home Care Packages, mental health services and disability services.⁴⁴ In carrying out the Looma project, Professor Flicker’s experience was that ‘if the service isn’t there, people will not identify themselves as disabled or needing assistance’.⁴⁵ When the project began, there were eight people in the community receiving meal services. As the project developed, it went from delivering around 100 to 1800 services a month. Critically, the local Community Council that led the project was interested in the problems of older people and wanted to help keep them on Country.

While the Royal Commission heard about positive examples of place-based solutions, we were advised that this is a challenging area of service delivery. It is important to put in place appropriate governance and other support for community controlled organisations moving into service delivery as they build capacity and maturity. This is particularly important where the provider is small and cannot achieve economies of scale, or where service delivery comes with additional costs such as those associated with remote locations.⁴⁶

41 Under the *Anangu Pitjantjatjara Yankunytjatjara Land Rights Act 1981* (SA), the Executive Board is the governing body of APY. The APY Executive Board is responsible for carrying out the function and day-to-day business of the APY.

42 Transcript, Graham Aitken, Broome Hearing, 18 June 2019 at T2069.24.

43 Transcript, Graham Aitken, Broome Hearing, 18 June 2019 at T2072.17.

44 Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2029.27-29 and T2032.12-18.

45 Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2026.41.

46 Transcript, Dr Michael Preece, Broome Hearing, 18 June 2019 at T2146.

Aged care services, programs and funding

Most Aboriginal and Torres Strait Islander people do not have access to residential aged care services specifically tailored or targeted to them. Of those who access residential aged care, 78% obtain services from a mainstream provider due to the lack of tailored services.⁴⁷ In contrast, of those who access home care, 61% do so from Aboriginal and Torres Strait Islander-focused organisations, demonstrating greater availability of targeted services for this aspect of aged care.⁴⁸

There are a number of Aboriginal and Torres Strait Islander-specific programs and funding sources aimed at assisting services to provide flexible aged care to Aboriginal and Torres Strait Islander people, particularly if the service is delivered in a remote location where there are additional costs or the size of the service impacts on viability. The main programs are discussed here.

The first is the National Aboriginal and Torres Strait Islander Flexible Aged Care Program, commonly referred to as NATSIFACP, which provides aged care to Aboriginal and Torres Strait Islander people over 50 years of age close to their homes and communities. It delivers a mix of high care residential, low care residential and Home Care Packages.⁴⁹ The majority of the program's 35 operational aged care services are located in very remote areas.⁵⁰ As of 30 June 2018, a total of 453 residential places, 11 respite places and 396 home care places were funded through the program nationally.⁵¹ The program is not funded under the *Aged Care Act 1997* (Cth). Instead, it is block funded with providers receiving direct grants to deliver programs.

Block funding is a mechanism that provides funding for a particular number of places whether or not individual places are filled.⁵² This is intended to support service viability. The Royal Commission heard evidence that aged care providers who deliver services for Aboriginal and Torres Strait Islander people value the flexibility afforded by block funding.⁵³

The National Aboriginal and Torres Strait Islander Flexible Aged Care Program has been limited to smaller providers faced with issues of economies of scale or those in remote locations who have additional costs associated with the distances that goods, services and staff must travel. One provider pointed out the very existence of this program is an

47 Australian National Audit Office, *Indigenous Aged Care, Report No.53*, 2017, p 24 https://www.anao.gov.au/sites/default/files/ANAO_Report_2016-2017_53a.pdf viewed 30 September 2019.

48 Australian National Audit Office, *Indigenous Aged Care, Report No.53*, 2017, p 24 https://www.anao.gov.au/sites/default/files/ANAO_Report_2016-2017_53a.pdf viewed 30 September 2019.

49 Australian Government Department of Health, *National Aboriginal and Torres Strait Islander Flexible Aged Care Program*, Program Manual 2019, <https://agedcare.health.gov.au/national-aboriginal-and-torres-strait-islander-flexible-aged-care-program-natsifacp-guidelines> viewed 30 September 2019;

50 Australian Institute of Health and Welfare, 'Aged care data snapshot', 2019, <https://www.gen-agedcaredata.gov.au/Resources/Access-data/2019/September/Aged-care-data-snapshot—2019> viewed 30 September 2019.

51 Exhibit 4-17, Broome Hearing, Statement of Jaye Alexander Smith, 10 May 2019, WIT.0128.0001.0001 at 0016 [78]; Exhibit 4-1, Broome Hearing, General Tender Bundle, Tab 85, CTH.0001.1000.6769 at 6772.

52 Exhibit 4-17, Broome Hearing, Statement of Jaye Alexander Smith, 10 May 2019, WIT.0128.0001.0001 at 0015 [74].

53 Exhibit 4-10, Broome Hearing, Statement of Belinda Jayne Robinson 6 June 2019, WIT.0211.0001.0001 at 0010 [52-53a]; Transcript, Matthew Moore, Perth Hearing, 26 June 2019 at T2578.45-T2579.1.

indication there is a problem with the design of the mainstream aged care system when it comes to service delivery to Aboriginal and Torres Strait Islander people.⁵⁴

The second is the Multi-Purpose Services program, which is a partnership between Commonwealth and State and Territory governments. It provides combined health and aged care services for some regional and remote communities. This allows services to be offered in regions that cannot afford to support standalone hospitals or aged care homes. The arrangements are usually managed by a State or Territory Health Department.⁵⁵ As at 30 June 2018, there were 179 services delivering 3640 flexible aged care places.

Additionally, there is the Dementia and Aged Care Services Fund which aims to support older people who are suffering frailty or disability. It seeks to respond to existing and emerging challenges, including dementia care. It also supports services targeting people from diverse social and cultural backgrounds, including special measures for Aboriginal and Torres Strait Islander people.⁵⁶ In 2017–18, it allocated grants totalling almost \$4 million to improve the quality of aged care services delivered to Aboriginal and Torres Strait Islander people in remote communities.⁵⁷

Aged Care Service Development Assistance Panel supports capacity building and improving the quality of aged care. It is targeted at culturally appropriate local solutions to the challenges of maintaining and delivering quality aged care services, including to Aboriginal and Torres Strait Islander communities and people living in remote areas.⁵⁸

Service providers of both residential and home care, as well as providers of the Multi-Services Program and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program, in regional, remote and very remote areas, may also receive the viability supplement. The supplement is paid in recognition of the higher costs of providing care due to the location, size and client mix of a service.⁵⁹

Irrespective of these targeted programs and funds, a number of concerns associated with the shift to consumer-directed care have been raised with us. Firstly, in remote or very remote areas, and even in more populated regions where there are fewer or no trusted organisations, there is little or no market within which to make a choice about services. In this setting, the idea of having funds available to be spent on whatever services an

54 Transcript, Dr Michael Preece, Broome Hearing, 18 June 2019 at T2147.30-38.

55 Exhibit 4-17, Broome Hearing, Statement of Jaye Alexander Smith, 10 May 2019, WIT.0128.0001.0001 at 0023 [104-106].

56 Australian Department of Health, ‘DACS research and innovation – funding round: questions & answers’, updated 6 March 2018, <https://agedcare.health.gov.au/funding/dacs-research-and-innovation-funding-round-questions-answers>, viewed 22 June 2019.

57 Australian Department of Health, *2017-18 Report on the Operation of the Aged Care Act 1997*, 2018, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%e2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%e2%80%931997.pdf, viewed 13 May 2019.

58 Exhibit 4-17, Broome Hearing, Statement of Jaye Alexander Smith, 10 May 2019, WIT.0128.0001.0001 at 0036 [143(b)(iii)] and [144].

59 Exhibit 4-17, Broome Hearing, Statement of Jaye Alexander Smith, 10 May 2019, WIT.0128.0001.0001 at 0036 [143(b)(iv)] and 0052 [203].

Aboriginal or Torres Strait Islander person wishes to procure is impractical.⁶⁰ Secondly, individualised funding means home and community care providers are no longer able to pool home care funds and use them to equitably distribute costs. In remote settings where a provider may have to travel vast distances to see a few clients, this can mean very little of the funds in the Home Care Package are left for actual services or equipment.⁶¹

Important considerations in Aboriginal and Torres Strait Islander aged care

Aboriginal and Torres Strait Islander culture

Aboriginal and Torres Strait Islander identity is underpinned by connection to community and the land. As 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.⁶²

Aboriginal and Torres Strait Islander people's care needs are intimately connected to family, community and culture, to Country and to language, including sign language.⁶³

The Royal Commission was impressed by evidence of the valued position Elders hold within Aboriginal and Torres Strait Islander communities and families, including holding and passing on, among other things, culture, rituals, law, songs, language, and knowledge about Country.⁶⁴ Aboriginal and Torres Strait Islander people see Elders as central to the future of culture. They deserve respect and should be looked after with dignity.⁶⁵

60 Transcript, Michelle McKay, Darwin Hearing, 8 July 2019 at T2916.1-12.

61 Transcript, Ruth Crawford, Broome Hearing, 18 June 2019 at T2111.12-22.

62 Transcript, Venessa Curnow, Broome Hearing, 19 June 2019 at T2186.16-26.

63 Transcript, Yvonne Grosser, Broome Hearing, 17 June 2019 at T1997.27-28 and Tamra Bridges, Broome Hearing, 17 June 2019 at T2014.25-28 discuss the use of sign language and hand gestures to overcome language barriers; Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0008 [63]; Exhibit 4-16, Broome Hearing, Statement of Venessa Michelle Curnow, 17 June 2019, WIT.0243.0001.0001 at 0007 [43].

64 Exhibit 4-16, Broome Hearing, Statement of Venessa Michelle Curnow, 17 June 2019, WIT.0243.0001.0001 at 0005 [31]; Transcript, Venessa Curnow, Broome Hearing, 19 June 2019 at T2186.13-46; Transcript, Madeleine Jadai, Broome Hearing, 17 June 2019 at T1988.27-44; Exhibit 4-15, Broome Hearing, Statement of Roslyn Malay, June 2019, WIT.0174.0001.0001 at 0010 [54]; Transcript, Matthew Moore, Perth Hearing, 26 June 2019 at T2579.23-30.

65 Transcript, Faye Dean, Broome Hearing, 17 June 2019 at T1974.22-26;; Transcript, Graham Aitken, Broome Hearing, 18 June 2019 at T2065.17-21.

There are real opportunities for the wider Australian community to learn from this deep appreciation of older people. Miss Madeleine Jadai, a Mangala woman from Bidyadanga in Western Australia, described her Elders as having:

given so much to us, you know, and showing us Country and teach us the right way, so it's time to give—give them back something.⁶⁶

Languages play an important role in Aboriginal and Torres Strait Islander people's connection to culture, kinship, land and family. Languages are the foundation upon which the capacity to learn, interact and to shape identity is built.⁶⁷ This importance of language has not been reflected in Australian aged care policy. The Royal Commission heard evidence that while the aged care sector can access free translating and interpreting services for people from culturally and linguistically diverse backgrounds, this does not extend to Aboriginal languages.⁶⁸ We were told that this situation is 'a shameful inequity'.⁶⁹ It impacts on the quality and safety of care provided to Aboriginal and Torres Strait Islander people.⁷⁰ We agree.

Cultural safety

Cultural safety is a critical issue for Aboriginal and Torres Strait Island people. Evidence from the hearings in Darwin, Perth, Mildura and Broome reinforced the importance of cultural safety and its consideration in the provision of aged care services.

At the Darwin Hearing, Ms Olga Havnen, a Western Arrente descendent and Chief Executive Officer of Danila Dilba, the Aboriginal Health Service in Darwin, described the concept of cultural safety. According to Ms Havnen, a culturally safe environment is where people feel safe and secure in their identity, culture and community. Most importantly, the care recipient, not the provider, determines if cultural safety has been achieved.⁷¹

As the Royal Commission heard in Darwin, some providers operating in remote areas with Aboriginal and Torres Strait Islander care recipients are continuing to develop their cultural sensitivity. The evidence of Dr John Boffa, Chief Medical Officer of Public

66 Transcript Madeleine Jadai, Broome Hearing, 17 June 2019 at T1988.14-15.

67 House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs, 2012, *Our Land Our Languages: Language Learning in Indigenous Communities*; Exhibit 4-1, Broome Hearing, General Tender Bundle, – Tab83, VCU.0001.0001.0002..

68 Exhibit 4-9, Broome Hearing, Statement of Ruth Crawford, 23 May 2019, WIT.0185.0001.0001 at 0012 [56].

69 Exhibit 6-6, Darwin Hearing, Statement of Olga Havnen concurred in by Dr Sarah Giles, 4 July 2019, WIT.0263.0001.0001 at 0012 [54].

70 Transcript, Dr Sarah Giles, Darwin Hearing, 8 July 2019 at T2890.1-29.

71 Exhibit 6-6, Darwin Hearing, Statement of Olga Havnen concurred in by Dr Sarah Giles, 4 July 2019, WIT.0263.0001.0001 at 0003 [15-16]

Health, Central Australian Aboriginal Congress, echoed that of Professor Flicker, when he described cultural safety as being paramount:

If you wanted people to come and see you, you had to demonstrate that you were different. You weren't part of that previous health system. You were different. You could empathise with people. You understood their culture, you understood the importance of language, the importance of traditions that had been around a very long time, to gain respect, to gain trust, and you've got to stay a while to do that. So if you want people to come and see you when they are sick and particularly if you want them to come and see you when they are well, which we do, we want people to come and see us for health screening, they are not going to do that if they don't have absolute [trust].⁷²

Dr Boffa went on to emphasise that non-Aboriginal staff need to work to make the effort to be sure they know how to care in a way that shows empathy and compassion:

you've got to know what has led to the way people are, otherwise you victim blame and anyone who victim blames shouldn't work in Aboriginal health.⁷³

Dr Boffa also spoke about the need for services to Aboriginal and Torres Strait Islander people to be trauma-informed.⁷⁴

In its future work, the Royal Commission will continue to consider aspects of cultural safety and how to facilitate the provision of aged care services that are culturally safe.

The Royal Commission notes that from 1 July 2019, approved providers are required to meet new Aged Care Quality Standards. Standard 1 on consumer dignity and choice requires providers to demonstrate that their care and services are culturally safe. The standards also require providers to treat residents with dignity and respect, and value their identity, culture and diversity.

The Aged Care Quality and Safety Commission explains cultural safety as follows:

the consumer defines what cultural safety is. It's their experience of the care and services they are given and how able they feel to raise concerns. The key features of cultural safety are: understanding a consumer's culture, acknowledging differences, and being actively aware and respectful of these differences in planning and delivering care and services.⁷⁵

72 Transcript, Dr John Boffa, Darwin Hearing, 8 July 2019 at T2885.21-29.

73 Transcript, Dr John Boffa, Darwin Hearing, 8 July 2019 at T2886.13-4.

74 Transcript, Dr John Boffa, Darwin Hearing, 8 July 2019 at T2886.10-11. A trauma informed approach is one that seeks to recognise how trauma affects people's lives and service needs, and seeks to avoid retraumatising people, noting that usual operations may inadvertently trigger or exacerbate trauma symptoms: Australian Institute of Family Studies, *Trauma informed care in child/family welfare services*, CFCA Paper No 37, 2016, p 9; Substance Abuse and Mental Health Services Administration, *SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach*, 2014, p 9.

75 Aged Care Quality and Safety Commission, *Guidance and Resources for Providers to support the Aged Care Quality Standards*, September 2019, p 7.

Trusted relationships

Hand-in-hand with cultural safety, Aboriginal and Torres Strait Islander people place great value on relationships of trust. Without trust, communities and/or individuals may not engage with a provider.⁷⁶ According to Ms Crawford:

if you don't have the trust of the communities...the communities...won't let you visit; they won't listen to you when you go, and...they don't want to work together with you. So having the trust of people in the communities is really important. We're very fortunate in KACS. We have—out of our 31 staff we've got nine that have been there for 10 years or longer.⁷⁷

Several witnesses spoke of the time it takes to build trust with communities. Aged care workers need to build a rapport with individuals, which requires continuity of care and a consistent workforce.⁷⁸ As one provider put it:

a high touch, low impact sort of approach is taken...for us...we tell the clients enough information, that they need to mull it over, think about it, talk to people to come back and ask for the next bit...then down the path, three, four, six months down the track is when they're actually—when the trust is built and that's when you can actually get to the real issues of what's happening.⁷⁹

Multiple witnesses spoke about the importance of trusted relationships between aged care and other service providers. They also observed the benefits of different types of service providers sharing information.⁸⁰ For example, Ms Donna Ah Chee, a Bundjalung woman and Chief Executive Officer of the Central Australian Aboriginal Congress, discussed the benefits of health and aged care services having joint visibility of those who had approval for Commonwealth Home Support Programme and Home Care Packages such as better integration of health and aged care services for people.⁸¹

Staying on and returning to Country

Country is a critical concept for Aboriginal and Torres Strait Islander people. Beyond describing a physical place, it encompasses the emotional connection Aboriginal and Torres Strait Islander people have with their environment and its interrelationship with family and community.⁸² Aboriginal and Torres Strait Islander people have a strong preference to receive care in their community and to stay on Country.⁸³

76 Exhibit 5-28, Perth Hearing, Statement of Matthew John Moore, May 2019, WIT.0162.0001.0001 at 0009-0010 [37].

77 Transcript, Ruth Crawford, Broome Hearing, 18 June 2019 at T2096.39-44.

78 Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0014 [87.2]; Exhibit 4-6, Broome Hearing, Statement of Professor Leon Flicker, WIT.0161.0001.0001 at 0005 [20].

79 Transcript, Matthew Moore, Perth Hearing, 26 June 2019 at T2576.35-36 and T2577.8-13.

80 Transcript, Dr John Boffa, Darwin Hearing, 8 July 2019 at T2897.23-47 and T2898.1-15.

81 Transcript, Donna Ah Chee, Darwin Hearing, 8 July 2019 at T2896.44-47 and T2897.1-21; .

82 Exhibit 4-1, Broome Hearing, General Tender Bundle, Tab 82, VCU.0001.0001.0001 at 0001.

83 Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2024.32-38; Transcript Kim McRae, Darwin Hearing, 8 July 2019 at T2866.1-25.

Mrs Mildred Numamurdirdi, an Aboriginal Elder and traditional owner from the remote Northern Territory community of Numbulwar, perhaps provided the clearest example of the impact of leaving Country. Mrs Numamurdirdi described her experience of having to move 800 kilometres away from Country, family and community to enter residential aged care in Darwin:

my heart is crying, yes. My heart is crying because I far away from my family... Because if I pass away here, I've got my spirit, my culture, my ceremony way back... at home and my family, they don't want that way, because we've got everything there in the home. And if we pass away, culture there, our spirit. That is my family, because I'm the eldest out of my family and that's my mother land Numbulwar. Yes, I'm the eldest out of my family and so they worry.⁸⁴

Ms Roslyn Malay, a Yurriyngem Taam Kija woman from Wadamun, in the east Kimberley, Co-Chair of the Aboriginal and Torres Strait Islander, Australian Association of Gerontology Ageing Advisory Group, and Project Officer and Researcher at University of Western Australia's Centre for Health and Ageing, put it like this:

Well, older Aboriginal people, what they're saying about the residential care is pretty much a death sentence to them. It's not where they want to end up. They prefer to stay on Country, to be able to continue their leadership in their role that they play in the community...And the thing is their comment is you go there to die...They would rather stay on Country and to die, if that makes any sense.⁸⁵

Ms McRae described the dilemma associated with honouring the wishes of people to remain on Country. Her organisation supports what the client and their family want, even though other service providers may take a different view:

We support what the client and their family wants, and sometimes, yes, that can cause some conflict but that's okay. We still say that people should have a choice. They shouldn't be forced to live in town. We try to build as much of the support that they need. It might be that the family can be trained to provide some additional care. It may be that there are services around who can be engaged in supporting that client. We look at providing regular respite because that can be a way to maintain the care in the community...to actually bring the client into town for a while and give the family a break from their caring role. We look at all the ways we can continue to support a person to live on Country.⁸⁶

Where respite is available, models that support family to visit the resident, along with communication options that enable the resident to remain in contact with family, are crucial.⁸⁷ However, respite care is not widely available.

84 Transcript, Mildred Numamurdirdi, Darwin Hearing, 8 July 2019 at T2851.11-18.

85 Transcript, Roslyn Malay, Broome Hearing, 19 June 2019 at T2173.36-46.

86 Transcript, Kim McRae, Darwin Hearing, 8 July 2019 at T2866.4-12.

87 Transcript, Madeleine Jadai, Broome Hearing, 17 June 2019 at T1987.40-46; Exhibit 4-2, Broome Hearing, Statement of Faye Dean, June 2019, WIT.1142.0001.0001 at 0005 [35]; Transcript, Dr Kate Suzanne Fox, Broome Hearing, 19 June 2019 at T2165.18-33.

There are significant gaps in service availability where Aboriginal and Torres Strait Islander people live.⁸⁸ The limited availability of residential aged care on Country leads to questions about the population levels required in order to provide aged care services within the community. Dr Boffa challenged the lack of access to residential aged care services for a number of significant populations in the Northern Territory. He pointed out that while one community of 500 people in a very remote location had a residential aged care facility, another that was also in a remote location had 750 people and often more, but did not have that type of service. In comparison, he pointed to established primary health care population ratios and the planning that routinely goes on to ensure access to general practitioners, nurses and health care workers across the Territory.⁸⁹

Ms Havnen echoed these remarks and observed in her experience there are 13 communities across the Top End with populations of 1200 to 1500, including surrounding outstations and catchment areas, in which there is no residential aged care.⁹⁰

Witnesses at several hearings suggested that integrated place-based models across a range of health and social services were the best way to meet the needs of these communities, adding that local services enabled people to stay on Country for longer.⁹¹ When people do have to leave their community, this can often mean disconnection from culture. According to Ms McRae:

They get stranded in town, and sometimes they’re thousands of kilometres away from family. There is important cultural business goes on and people want to return to community. There are funerals. Those senior people often have really critical cultural knowledge that they need to be passing on to younger people in the community. They play a really important role in their community, and when they’re removed from the community, there’s a huge breach. There’s a huge hole.⁹²

Providing culturally safe care to Aboriginal and Torres Strait Islander people includes consideration of how they can return to Country. We heard of the lack of funding in residential aged care to support cultural activities, including returning to Country, along with the need to be innovative and creative in how to maintain a connection to Country.⁹³

88 Transcript, Dr Kate Suzanne Fox, Broome Hearing, 19 June 2019 at T2163.44–T2164.7. Transcript, Dr Meredith Hansen-Knarhoi, Darwin Hearing, 8 July 2019 at T2848.19–34 and T2853.32–36; Transcript, Ms Kim McRae, Darwin Hearing, 8 July 2019 at T2857.5–9; Transcript, Olga Havnen, Darwin Hearing, 8 July 2019 at T2899.17–T2900.19.

89 Transcript, Dr John Boffa, Darwin Hearing, 8 July 2019 at T2898.35–T2899.9.

90 Transcript, Olga Havnen, Darwin Hearing, 8 July 2019 at T2899.17–24.

91 Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2030.46–T2031.12; Exhibit 4-5 Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0016 [102] and 0017 [109]; Exhibit 4, Broome Hearing, Statement of Ruth Crawford, 23 May 2019, WIT.0185.0001.0001 at 0002 [8] and 0004 [15.2]; Transcript, Matthew Moore, Perth Hearing, 26 June 2019 at T2574.26–T2575.19; Exhibit 4-2, Broome Hearing, Statement of Faye Dean, June 2019, WIT.1142.0001.0001 at 0002 [13–17] and 0003 [20]; Exhibit 4-8, Broome Hearing, Statement of Graham Aitken, 3 June 2019, WIT.1134.0001.0001 at 0004 [30–33]; Transcript, Olga Havnen, Darwin Hearing, 8 July 2019 at T2899.17–37; Transcript, Michelle McKay, Darwin Hearing, 8 July 2019 at T2922.15–33.

92 Transcript, Kim McRae, Darwin Hearing, 8 July 2019 at T2866.33–39.

93 Transcript, Sarah Brown, Darwin Hearing, 8 July 2019 at T2862.20–28 and T2867.27–29; Exhibit 4-10, Broome Hearing, Statement of Belinda Jayne Robinson, 6 June 2019, WIT.0211.0001.0001 at 0010 [52] and [53a]; Transcript of Kim McRae, Darwin Hearing, 8 July 2019 at T2866.30–T2867.9; Transcript, Roslyn Malay, Broome Hearing, 19 June 2019 at T2173.36–41.

Caring for family in Bidyadanga⁹⁴

Miss Madeleine Jadai is a Mungala woman who lives in the Aboriginal community of Bidyadanga, 200 kilometres from Broome. For the last eight years, Miss Jadai, who is 55 years old, has been the primary carer for her sister, Betty Barney, who is in her early 60s and living with dementia. Miss Jadai also cares for the children and grandchildren of another sister, who died in a car accident. Although Miss Jadai is really proud of herself for looking after her family, she told the Royal Commission that she is tired all the time because of her caring responsibilities.

Miss Jadai explained that after their mother passed away, Ms Barney 'got distressed', 'her spirit went really down', and she could not look after herself anymore. Miss Jadai is also Ms Barney's interpreter.

Ms Barney visits the Home and Community Care Centre (HACC Centre), an aged care service provider in Bidyadanga, most mornings to eat and spend time with other older people in the community. Sometimes Ms Barney goes on fishing trips or trips on Country. Miss Jadai considers that Ms Barney is well looked after at the HACC Centre and it means Miss Jadai can 'take a break'. Sometimes Ms Barney does not go to the HACC Centre because she is sick or her 'mood changed', and other times Miss Jadai asks the HACC Centre to keep Ms Barney longer so she has more time to take care of other responsibilities.

Despite the assistance of the HACC Centre, and support from the local medical clinic, Miss Jadai explained that it is challenging to care for Ms Barney. She said 'people in Bidyadanga do not understand dementia very well' and Ms Barney would get angry with people when they tried to help her.

Miss Jadai would like better access to respite care. Respite care in Broome is full and the next nearest option is Derby, which is 300 kilometres away. Miss Jadai does not want to send Ms Barney so far away alone. Once, because she could not get respite, she had to take Ms Barney to a funeral 1000 kilometres away. Ms Barney got sick during that trip and required antibiotics.

Miss Jadai said that 'being around families and being together, especially our Elders' is what makes Aboriginal people in Bidyadanga happy. Miss Jadai is working with some Elders in the Bidyadanga community to get funding to establish an Elders Cultural Centre, so that people can maintain a connection to Country. She is also working on a movie about the history of Bidyadanga, so younger generations can be 'proud of themselves, their family, their connection to Country, and...their old people'.

94 Based on the evidence of Miss Madeleine Jadai: Transcript, Madeleine Jadai, Broome Hearing, 17 June 2019 at T1986.38–T1993.20.

Stolen Generations: trauma-informed care

Around 17,150 Aboriginal and Torres Strait Islander people are part of the Stolen Generations. These are people who, when they were children, were taken away from their families and communities as the result of government policies.⁹⁵ The largest populations live in New South Wales (30%), Western Australia (22%) and Queensland (21%). In 2014–15, 66% of the Stolen Generations were aged 50 years and over, and by 2023 all of this cohort will be eligible for aged care.⁹⁶

For these people, issues of trust are fundamental. Professor Flicker observed practices of the past give ‘stark reminders of why Aboriginal and Torres Strait Islander people won’t necessarily trust non-Aboriginal and Torres Strait Islander people’.⁹⁷ Ms Tamra Bridges echoed this theme.⁹⁸

Culturally safe care for this population involves awareness that they may have lost or been disconnected from many fundamental elements of their cultural identity, such as language and culture, as well as connections to Country.⁹⁹ Service providers and their staff should not assume anything about the cultural status of members of the Stolen Generations. Members of the Stolen Generations may be without extended supports and kinship relationships.¹⁰⁰ Further, people may or may not wish to have ongoing connection with, or receive services from, organisations that were involved in the removal of children, such as religious organisations.¹⁰¹ Going into care can be re-traumatising, so care must be properly trauma-informed.¹⁰²

95 Australian Institute of Aboriginal and Torres Strait Islander Studies, *Stolen Generations*, 2018, <https://aiatsis.gov.au/research/finding-your-family/before-you-start/stolen-generations>, viewed on 2 September 2019.

96 Australian Institute of Health and Welfare, *Aboriginal and Torres Strait Islander Stolen Generations and Descendants*, 2018, p vii, <https://healingfoundation.org.au/app/uploads/2018/08/AIHW-REPORT-Stolen-Generations-and-descendants.pdf>, viewed on 12 August 2019.

97 Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2045.36-38.

98 Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0009 [66].

99 Transcript, Graham Aitken, Broome Hearing, 18 June 2019 at T2085.43–T2086.2; Transcript, Venessa Curnow, Broome Hearing, 19 June 2019 at T2180.35-36; Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, WIT.0166.0001.0001 at 0009, para [66].

100 Exhibit 4-1, Broome Hearing, General Tender Bundle, Tab 74, RCD.9999.0084.0001 – The Healing Foundation and AAG’s Aboriginal and Torres Strait Islander Ageing Advisory Group Joint Statement – 7 June 2019.

101 Aboriginal and Torres Strait Islander Roundtable, 28 May 2019.

102 Transcript, Graham Aitken, Broome Hearing, 18 June 2019 at T2085.43–T2086.2; Transcript, Craig Gear, Adelaide Hearing 2, 12 February 2019 at T143.32–T144.7; Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2038.23-34; Transcript, Ruth Crawford, Broome Hearing, 18 June 2019 at T2109.14-21; Transcript, Shontia Saluja-Honeysett, Mildura Hearing, 29 July 2019 at T3929.5–T3930.16; Exhibit 4-1, Broome Hearing, General Tender Bundle, Tab 74, RCD.9999.0084.0001 – The Healing Foundation and AAG’s Aboriginal and Torres Strait Islander Ageing Advisory Group Joint Statement – 7 June 2019.

End of life and palliative care in residential aged care

We also heard evidence that in remote and very remote Australia, ceremonies surrounding death are extremely important to Aboriginal and Torres Strait Islander people and may take precedence over other activities.¹⁰³ These practices vary widely across different communities, and may include singing ceremonies before and after death, smoking ceremonies to cleanse the place where the person died, and sorry camps.¹⁰⁴ The Royal Commission heard that it is important for providers to understand local practices or ask for advice from local communities on appropriate practices.¹⁰⁵

Ms Bridges gave evidence about the Australian Regional and Remote Community Services facility at Mutijulu in the Northern Territory and its separate palliative care module constructed adjacent to the residential care facility. It allows external access for the community to be with their Elder as they are dying and thereby enables the completion of necessary cultural practices.¹⁰⁶ Professor Flicker spoke of the importance of the physical infrastructure accommodating these practices, given the need for a smoking ceremony in most cases. He also spoke of the need for support and counselling for both the people providing that palliative care service and the community using it.¹⁰⁷

When Aboriginal and Torres Strait Islander people reach the end of their lives, some providers respond by:

- inviting the community to be a part of the care planning and seeking advice on the protocols required with the death of a person
- involvement in supporting sorry camps
- being aware of, and following, local cultural protocols and conventions, particularly those concerning death and dying
- using an Aboriginal Liaison Officer to provide a bridge between the cultures involved and ensure appropriate communication and understanding.¹⁰⁸

¹⁰³ Transcript, Tamra Bridges, Broome Hearing, 17 June 2019, at T2014.34–T2015.38; Exhibit 6-6, Darwin Hearing, Statement of Olga Havnen concurred in by Dr Sarah Giles, 4 July 2019, WIT.0263.0001.0001 at 0005 [20] – 0006 [26].

¹⁰⁴ McGrath P, and Phillips E, *Insights on end-of-life ceremonial practices of Australian Aboriginal peoples*, Collegian, Volume 15, Issue 4, 2008, pp125-133.

¹⁰⁵ Transcript, Tamra Bridges, Broome Hearing, 17 June 2019 at T2014.34–T2015.38.

¹⁰⁶ Transcript, Tamra Bridges, Broome Hearing, 17 June 2019 at T2015.18-25.

¹⁰⁷ Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2040.4-6.

¹⁰⁸ Transcript, Tamra Bridges, Broome Hearing, 17 June 2019 at T2014.36–T2015.5; Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2040.43–T2041.9.

Ms McRae identified the importance of returning to Country as a consideration for culturally appropriate palliative care:

if someone knows that they have a life-shortening illness, being able to build supports around that person and their family [and]...providing supports for people to go home and die on Country is probably a really big issue that we hear about again and again.¹⁰⁹

Experiences in urban locations

Many of the barriers that face Aboriginal and Torres Strait Islander people who live in regional and remote areas also apply to the increasing numbers of Aboriginal and Torres Strait Islander people who live in urban locations.¹¹⁰

Mr Matthew Moore, General Manager Aged and Disability Services at the Institute for Urban Indigenous Health Limited (the Institute), gave evidence at the Perth Hearing. The Institute is an Aboriginal Community Controlled Health Service that delivers an integrated, multi-disciplinary, whole-of-life service that includes aged care.

Mr Moore observed that the greatest increase in the Aboriginal and Torres Strait Islander population has occurred in South East Queensland. However, as he explained, proximity to mainstream services has not translated into better health or aged care access for urban Aboriginal and Torres Strait Islanders.¹¹¹

Across Australia, for Aboriginal and Torres Strait Islander people, the availability of trusted, culturally safe providers is key—if there are no such providers, Aboriginal and Torres Strait Islander people may not engage with mainstream services.¹¹² This was illustrated by the situation the Institute encountered when it commenced its home care services in 2013–14.

when we first rolled services out into the northern suburbs of Brisbane there was no community-controlled aged care providers. There was a couple of welfare programs run by some faith-based organisations but less than 50 Aboriginal people out of a population of 35,000 in that catchment were receiving care. The scary part was the 12 months prior there was only four ACAT assessments for Aboriginal people in that same catchment and only two of them were actually approved for a service. So there was significant lack of services there.¹¹³

109 Transcript of Kim McRae, Darwin Hearing, 8 July 2019 at T2870.23-26.

110 Aboriginal and Torres Strait Islander Roundtable, 28 May 2019.

111 Exhibit 5-28, Perth Hearing, Statement of Matthew Moore, May 2019, WIT.0162.0001.0001 at 0003 [19]. Exhibit 4-1, Broome Hearing, Tab 71, RCD.9999.0079.0001; Transcript, Matthew Moore, Perth Hearing, 26 June 2019 at T2572.42-43 and T2581.20-21.

112 Transcript, Matthew Moore, Perth Hearing, 26 June 2019 at T2572.36-46.

113 Transcript, Matthew Moore, Perth Hearing, 26 June 2019 at T2578.9-15.

Half a decade on, and the Institute services more than 1800 Aboriginal and Torres Strait Islander people with a staff of just under 100 employees across five aged care planning regions.¹¹⁴

Mr Moore also highlighted the importance of an Aboriginal and Torres Strait Islander workforce in an urban setting, including as part of Aged Care Assessment Teams:

If you don't understand...those cultural nuances...I think that whilst the ACAT teams and the assessment teams are really quite a professional workforce...[if] there's no inherent understanding of these cultural barriers first, I don't think they understand that these clients will tell them what they think they want to hear to get them out of their face, to get them out. The result of that is inappropriate assessments, lower levels of care that are approved or the clients walk away from the system altogether.¹¹⁵

The Royal Commission will hear more about urban Aboriginal and Torres Strait Islander aged care at future hearings.

Particular challenges for regional and remote locations

The delivery of services to remote and very remote geographical regions in Australia is complex and influenced by a wide range of social and environmental determinants.¹¹⁶

One of the factors impacting access to aged care services of all types in remote and very remote communities is population density and the small numbers of older people who may require support.¹¹⁷ This means that services can be limited in scope, or simply unavailable. Where there are services, they are difficult to access and costly. We heard about the high cost of goods and services, utilities, transport, fuel, food, vehicles that fit the environment, insurance, repairs and maintenance, and translators.¹¹⁸

The impact of these costs was illustrated by Juniper, a Uniting Church Community (Juniper) organisation which operates five facilities with 116 beds in four locations in the Kimberley Aged Care Planning region. It is funded under both the Aged Care Act and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program. Its beds comprise more than half of the 197 funded residential places delivered by not-for-profit providers in that region. According to Dr Michael Preece, the Executive Director of Operations for Juniper

114 Exhibit 5-28, Perth Hearing, Statement of Matthew Moore, May 2019, WIT.0162.0001.0001 at 0001 [5].

115 Transcript, Matthew Moore, Perth Hearing, 26 June 2019 at T2576.44–2577.6; See Transcript, Shontia Michelle Saluja-Honeysett, Mildura Hearing, 29 July 2019 at T3932.1-9 concerning similar experiences in Melbourne.

116 Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0004 [33].

117 Exhibit 4-9, Broome Hearing, Statement of Ruth Crawford, 23 May 2019, WIT.0185.0001.0001 at 0006 [23].

118 Exhibit 4-10, Broome Hearing, Statement of Belinda Jayne Robinson, 6 June 2019, WIT.0211.0001.0001 at 0009 [48] and [50-51], 0010 [55] and 0011 [61]; Exhibit 4-4, Broome Hearing, Statement of Craig Robin Barke, 31 May 2019, WIT.0227.0001.0001 at 0005 [26]; Exhibit 4-12, Broome Hearing, Statement of Dr Michael Stephen Preece, 13 June 2019, WIT.0256.0001.0001 at 0006 [41]; Exhibit 4-17, Broome Hearing, Statement of Jaye Alexander Smith, 10 May 2019, WIT.0128.0001.0001 at 0033 [140-141].

in Western Australia, these beds are cross-subsidised by more than \$2 million by Juniper’s aged care operations in Perth.¹¹⁹ There is no residential aged care delivered by for-profit providers in the region at all.¹²⁰

At the Broome Hearing, Ms Bridges spoke about remoteness and the impact that aged care services provided by Australian Regional and Remote Community Services have in Docker River in the Northern Territory. The facility there is small and very remote: three hours by dirt road west of Yulara. Ms Bridges described how all of the nursing and personal care staff:

do 10 weeks on, two weeks off, on a rotating roster...to get to Docker River requires a flight into Alice Springs and then a flight to Yulara and then from Yulara it’s what we call the bush bus where staff travel for three hours on a dirt road to get to the location.¹²¹

Unsurprisingly, staff travel costs in the 2018–19 financial year were in excess of \$100,000.¹²² Locally engaged staff would be more culturally aware and enable costs such as this to be reduced if not entirely removed.

In remote areas, high rates of socio-economic disadvantage may mean people have lower levels of education and literacy, limited access to good quality housing stock, experience food insecurity and poor health. This can sometimes result in the prioritisation of the necessities of life, such as food and housing, over health expenses.¹²³ Where people are unable to access services to meet their health needs, there may be earlier and increased risk of deterioration resulting in entry into the aged care system.¹²⁴ At the Broome Hearing, the Chief Executive Officer of the Royal Flying Doctors Service, Dr Martin Laverty, stated that:

Primary care and aged care are interdependent, they are reliant on each other... primary care, that is, access to doctors, to nurses, to allied health professionals, to dentists, to geriatricians, and primary care plays an essential role in keeping older Australians, and indeed all Australians, well and healthy, and the longer you are able to maintain your health...the longer you are likely to avoid the necessity of access to the formal aged care setting...once an older Australian enters an aged care environment... access to ongoing primary care is essential to that citizen receiving appropriate care... Access to geriatricians, to dentists, to mental health professionals, to palliative care specialists. This is the interdependency between primary care and aged care.¹²⁵

119 Exhibit 4-12, Broome Hearing, Statement of Dr Michael Stephen Preece, 13 June 2019, WIT.0256.0001.0001 at 0004 [26-28].

120 Australian Institute of Health and Welfare, ‘My aged care region’, <https://www.gen-agedcaredata.gov.au/My-aged-care-region>, viewed 20 September 2019.

121 Transcript, Tamra Bridges, Broome Hearing, 17 June 2019 at T2012.28-31.

122 Exhibit 4-4, Broome Hearing, Statement of Craig Robin Barke, 31 May 2019, WIT.0227.0001.0001 at 0007 [31].

123 Exhibit 4-13, Broome Hearing, Statement of Dr Kate Suzanne Fox, 16 June 2019, WIT.1145.0001.0001 at 0005 [33].

124 Exhibit 4-16, Broome Hearing, Statement of Venessa Michelle Curnow, 17 June 2019, WIT.0243.0001.0001 at 0003 [21]; Transcript of Kim McRae, Darwin Hearing, 8 July 2019 at T2859.20-24.

125 Transcript of Dr Martin Laverty, Broome Hearing, 18 June 2019 at T2050.15-28.

Much closer collaboration between systems is vital to ensure better primary health, housing and infrastructure, and better access to education, economic and social opportunities in remote communities.¹²⁶ The delivery of multidisciplinary care that promotes communication and collaboration across service systems is critical for people living in remote and very remote areas who more often present with complex health and wellbeing needs.¹²⁷

The Royal Commission has heard about the use of technology, in particular telehealth, to facilitate access to health care in remote areas.¹²⁸ Dr Fox hoped that telehealth might be a useful tool to access primary care, but noted that currently it did not work well owing to language barriers and the need for relationships of trust.¹²⁹ Dr Boffa echoed this view during the Darwin Hearing.¹³⁰ However, there are numerous issues for Aboriginal and Torres Strait Islander people, including those living in regional and remote areas, which will likely reduce the effectiveness of telehealth for this population. In addition to those raised by Dr Fox, these include issues with connectivity, infrastructure and maintenance, as well as health and technological literacy.¹³¹

Workforce

Staffing is one of the main and ongoing challenges for providers in regional and remote locations. Witnesses described cultural and geographical barriers to providing a quality aged care workforce, including limited access to training providers in remote locations, limited career progression opportunities, restrictions on flexible staffing between residential and home care services, and negative perceptions of the aged care sector.¹³² Difficulties arise in identifying, recruiting, training and retaining suitable skilled staff.¹³³

We heard that, in very remote areas, a stable workforce is difficult to achieve. Where staff cannot be recruited at all or are unwilling to base themselves locally, the cost of flying them in and out and providing accommodation while they are on site is high. Agency staff are expensive and often not interested in working in aged care services.

126 Exhibit 4-13, Broome Hearing, Statement of Dr Kate Suzanne Fox, 16 June 2019, WIT.1145.0001.0001 at 0007 [41]; Transcript, Dr Martin Laverty, Broome Hearing, 18 June 2019 at T2055.36–T2056.3.

127 Exhibit 4-13, Broome Hearing, Statement of Dr Kate Suzanne Fox, 16 June 2019, WIT.1145.0001.0001 at 0007 [41]; Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0016 [100];

128 Transcript, Ruth Crawford, Broome Hearing, 18 June 2019 at T2111.37–T2112.8; Transcript of Dr Martin Laverty, Broome Hearing, 18 June 2019 at T2051.11–18.

129 Exhibit 4-13, Broome Hearing, Statement of Dr Kate Suzanne Fox, 16 June 2019, WIT.1145.0001.0001 at 0003 [20].

130 Transcript, Dr John Boffa, Darwin Hearing, 8 July 2019 at T2898.35–36.

131 Exhibit 4-10, Broome Hearing, Statement of Belinda Jayne Robinson, 6 June 2019, WIT.0211.0001.0001 at 0009 [48]; Exhibit 4-8, Broome Hearing, Statement of Graham Aitken, 3 June 2019, WIT.1134.0001.0001 at 0007 [54] and 0009 [71]; Exhibit 4-4, Broome Hearing, Statement of Craig Robin Barke, 31 May 2019, WIT.0227.0001.0001 at 0006 [28.2]; Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0010 [71–72]; Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2035.23–49; Transcript, Ruth Crawford, Broome Hearing, 18 June 2019 at T2111.37–47, T2112.19–39 and T2113.16–22; Exhibit 5-28, Perth Hearing, Statement of Matthew Moore, May 2019, WIT.0162.0001.0001 at 0021 [95].

132 Exhibit 4-11, Broome Hearing, Statement of Rejane Le Grange, 6 June 2019, WIT.0212.0001.0001 at 0003 [12.1] and 0007 [18.1] – [18.2]; Exhibit 4-2, Broome Hearing, Statement of Faye Dean, June 2019, WIT.1142.0001.0001 at 0005 [38] – [40].

133 Exhibit 4-10, Broome Hearing, Statement of Belinda Jayne Robinson, 6 June 2019, WIT.0211.0001.0001 at 0008 [44].

The evidence of Ms Belinda Robinson, who manages the Juniper Ngamang Bawoona and Numbala Nunga in Derby, indicated that replacing staff who leave can take months and funding does not meet the actual cost of employing staff in remote locations.¹³⁴

Dealing with the cultural obligations of staff can be a difficult issue, as they may need to be away from work for extended periods of time. Mr Aitken explained he has:

to be flexible quite often...staff will need to take off for various reasons...
it can be for cultural reasons, such as men’s business or women’s business.
It can also be for sorry business.¹³⁵

He described his approach as being tied up in the broader aspect of gaining and retaining the trust of the community, as he understands this trust could be undermined within the community and amongst Elders if the cultural obligations of staff were not honoured.¹³⁶ Ms Robinson accepted the need to plan around such matters.¹³⁷

The Royal Commission also heard about the need to support the training of local Aboriginal and Torres Strait Islander staff members. A number of witnesses suggested a need for local employment strategies and culturally safe aged care training.¹³⁸ Bringing these skills and knowledge into the community may also improve health literacy levels.¹³⁹ One Aboriginal Community Controlled Health Organisation noted that it always looks for Aboriginal and Torres Strait Islander nurses and has introduced programs to offer a variety of experiences for newly graduated Aboriginal and Torres Strait Islander nurses.¹⁴⁰

Providers also noted the importance of understanding a local community’s culture and environment. If staff do not know what to expect, working in a remote community can be confronting. To support new staff, organisations undertake a variety of orientation, activities including basic information, buddy shifts, cultural awareness training and staff exchanges.¹⁴¹

134 Exhibit 4-10, Broome Hearing, Statement of Belinda Jayne Robinson, 6 June 2019, WIT.0211.0001.0001 at 0011 [56-60].

135 Transcript, Graham Aitken, Broome Hearing, 18 June 2019 at T2080.14-15.

136 Transcript, Graham Aitken, Broome Hearing, 18 June 2019 at T2080.25-27.

137 Transcript, Belinda Robinson, Broome Hearing, 18 June 2019 at T2128.36–T2129.15.

138 Exhibit 4-13, Broome Hearing, Statement of Dr Kate Suzanne Fox, 16 June 2019, WIT.1145.0001.0001 at 0007 [43]; Exhibit 4-8, Broome Hearing, Statement of Graham Aitken, 3 June 2019, WIT.1134.0001.0001 at 0008 [61-62]; Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0016 [104-105]; Exhibit 4-9, Broome Hearing, Statement of Ruth Crawford, 23 May 2019, WIT.0185.0001.0001 at 0015 [85]; Exhibit 4-17, Broome Hearing, Statement of Venessa Michelle Curnow, 17 June 2019, WIT.0128.0001.0001 at 0005 [27].

139 Transcript, Dr Kate Suzanne Fox, Broome Hearing, 19 June 2019 at T2164.26-32.

140 Transcript, Dr John Boffa, Darwin Hearing, 8 July 2019 at T2893.6-16.

141 Transcript, Tamra Bridges, Broome Hearing, 17 June 2019 at T2014.10-19; Exhibit 4-9, Broome Hearing, Statement of Ruth Crawford, 23 May 2019, WIT.0185.0001.0001 at 0015 [85]; Transcript of Graham Aitken, Broome Hearing, 18 June 2019 at T2081.13-18; Transcript of Sarah Brown, Darwin Hearing, 8 July 2019 at T2861.43–T2862.3.

Dr Boffa gave evidence that integrating service systems in regional and remote locations, particularly in relation to the nursing component of aged care in the home, may support staff retention. He suggested that aged care nurses should be placed within primary health services. This would enable the development of multidisciplinary teams, decrease professional isolation and provide opportunities for professional development and training.¹⁴²

There are numerous barriers to employing local Aboriginal and Torres Strait Islander staff in remoter locations. These can include limited English literacy; a lack of work experience and readiness; people being shy or lacking confidence; poor previous work experiences; and no acculturation into more mainstream employment.¹⁴³ Some community members have expressed their fear to providers about retribution if an Elder passes away after they have been involved in aged care service delivery.¹⁴⁴ Additionally, those people who lack a current driver's licence, have ongoing family responsibilities or have limited mobility may find it difficult to commit to long-term work in a specific location. The evidence also pointed to specific difficulties obtaining criminal history clearances. There is a problem with the over-representation of Aboriginal and Torres Strait Islander people in the criminal justice system.¹⁴⁵ It can also be the case that some people with minor offences may be daunted by the process or a sense of shame.¹⁴⁶ Additionally, people do not always have the requisite identification documents, such as birth certificates, which are needed to get clearances.¹⁴⁷

However, some witnesses stated that local employment was possible if the barriers were overcome. For example the NPY Women's Council has 60% Aboriginal and Torres Strait Islander staff,¹⁴⁸ and Purple House (Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation), as well as Star of the Sea in the Torres Strait, have around 80% Aboriginal and Torres Strait Islander employment in their aged care workforce.¹⁴⁹

142 Transcript, Dr John Boffa, Darwin Hearing, 8 July 2019 at TT2883.3-13, T2894.1-14 and T2901.18-31.

143 Transcript, Kim McRae, Darwin Hearing, 8 July 2019 at T2861.8-28.

144 Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0005 [39.2].

145 The Australian Law Reform Commission found that, in 2016, Aboriginal and Torres Strait Islander people were seven times more likely than others to be charged with a criminal offence and appear before the courts. See *Pathways to Justice – Inquiry into the Incarceration Rate of Aboriginal and Torres Strait Islander Peoples*, 2018, <https://www.alrc.gov.au/publication/pathways-to-justice-inquiry-into-the-incarceration-rate-of-aboriginal-and-torres-strait-islander-peoples-alrc-report-133/executive-summary-15/overview-of-the-report-3/>, viewed 25 August 2019.

146 Transcript, Graham Aitken, Broome Hearing, 18 June 2019 at T2083.22-25.

147 Transcript, Ruth Crawford, Broome Hearing, 18 June 2019 at T2013.14-35; Transcript, Graham Aitken, Broome Hearing, 18 June 2019 at T2083.21.

148 Transcript, Kim McRae, Darwin Hearing, 8 July 2019 at T2860.40-41.

149 Transcript, Sarah Brown, Darwin Hearing, 8 July 2019 at T2861.36; Exhibit 4-5, Broome Hearing, Statement of Tamra Jayde Bridges, 31 May 2019, WIT.0166.0001.0001 at 0004 [31].

Ms Sarah Brown, Chief Executive Officer of Purple House, told us Purple House has waiting lists for nurses that want to work with them, despite a shortage of dialysis nurses:

we provide lots of cultural safety training and mentoring, lots of support. We’ve never refused anyone’s annual leave. We put a lot of effort into helping non-Indigenous employees from other places to have a really great experience and build up strong relationships with people. And then in terms of our Indigenous workforce, we work really hard to be as flexible as we can to encourage people to come, even if they’ve got other carer and family responsibilities. And so really flexible casual contracts that recognise people’s strengths and create job descriptions around those people, and what they want to be doing with their lives.¹⁵⁰

Contrary to the national trend, Ms Michelle McCall, Aged and Disability Program Manager, Larrakia Nation Aboriginal Corporation (Larrakia Nation), gave evidence about their success in recruiting young male staff to their aged care workforce. She said their success came from ‘looking for passion’ and explaining to potential employees that ‘you’re making a difference to the quality of people’s lives...you’re supporting people to remain in their homes’.¹⁵¹

This passion was evident in the evidence of Ms Sharai Johnson, a Larrakia descendent and Aged Care Coordinator with Larrakia Nation, who said of working in aged care:

What makes it so rewarding is that you know that you’re...having a positive impact on each individual’s life, daily life...and if you can be that one person to make that change on a daily basis, then that’s a wonderful outcome, not only for my personal satisfaction, my professional development, and giving that back to the community, giving that back to the workforce and also mentoring younger staff members, just the younger generation in general, showing them that aged care is— it’s a great place to be. It is a wonderful place to be. It is so rewarding...¹⁵²

This evidence highlights that it is possible to recruit, train and sustain an aged care workforce in regional and remote locations. Working with local communities to deliver aged care services in regional and remote locations offers unique and rewarding experiences. If these experiences and accommodation and other infrastructure are provided, it is possible to attract and retain staff even in the most remote locations.

While aged care services in regional and remote locations have a tougher time building and maintaining stable workforces, the approach of these successful services warrants detailed consideration by the members of Remote Aged Care Workforce Accord that was announced by the Australian Government in late 2018.¹⁵³

150 Transcript, Sarah Brown, 8 July 2019, T2861.46–2862.9.

151 Transcript, Michelle McCall, Darwin Hearing, 12 July 2019 at T3424.37–41.

152 Transcript, Sharai Johnson, Darwin Hearing, 12 July 2019 at T3425.34–41.

153 The Hon Ken Wyatt AM, MP, Media Release, 6 November 2018, at <https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22media%2Fpressrel%2F6317819%22;src1=sm1>, viewed on 24 August 2019.

In the development of our Final Report, we will give further consideration to many matters relating to aged care for Aboriginal and Torres Strait Islander people. Controversially, the Royal Commission heard that there may not be a strong evidence base for the notional age of 50 being the relevant reference for aged care planning purposes. Professor Flicker referred to this age being ‘plucked from the air’ with ‘virtually no access to data’. He noted that ‘whether that’s equivalent to the population over the age of 70, non-Aboriginal, the needs basis for those two groups is really unknown’.¹⁵⁴

Professor Flicker also suggested that service streams other than aged care, such as the National Disability Insurance Scheme, may be a more appropriate response for Aboriginal and Torres Strait Islander people under 65 years of age. Nonetheless, he acknowledged other service streams are often not available or can be difficult to access.¹⁵⁵

Conclusion

The Royal Commission will carefully consider these complex issues, and others, in the months ahead.

The evidence and submissions received to date show that aged care for Aboriginal and Torres Strait Islander people needs to be delivered in ways that are flexible, adaptable and culturally safe. Key features include:

- providing accessible aged care assessment pathways
- integrating aged care with other services, such as primary health, mental health and disability services, including services provided by Aboriginal Community Controlled Health Organisations and other existing Aboriginal health and community organisations
- devising culturally appropriate assessment processes to access aged care
- facilitating aged care provision on Country and ‘return to Country’ where that is not possible
- greater provision of Aboriginal and Torres Strait Islander-specific services in cities and regional areas
- providing easier access to respite care.

¹⁵⁴ Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2026.14-15. See also PR Cotter et al, ‘Do Indigenous Australians aged prematurely? The implications of life expectancy and health conditions of older Indigenous people for health and aged care policy’, *Australian Health Review*, 2012, Vol 36, 1, pp 68-74; PR Cotter et al, *Indigenous aged care service use and need for assistance: How well is policy matching need?*, *Australasian Journal on Ageing*, 2011, Vol 30, 2, 38-44.

¹⁵⁵ Transcript, Professor Leon Flicker, Broome Hearing, 17 June 2019 at T2028.41-42.

Workforce matters will also be an area for further consideration. We will explore ways to support aged care services to be staffed and managed by Aboriginal and Torres Strait Islander people, including those that have been suggested:

- targeted programs in career and pre-employment to support and prepare Aboriginal and Torres Strait Islander people for entry into the aged care workforce
- national and local workforce strategies to attract and retain Aboriginal and Torres Strait Islander people and culturally safe trained non-Aboriginal and Torres Strait Islander staff
- tailored training and access programs, including programs for Aboriginal and Torres Strait Islander people wishing to work in aged care
- ongoing access to training and development on Country to sustain development and education, with a focus on supporting more Aboriginal and Torres Strait Islander people to move into management and leadership positions within aged care.

8. Restrictive Practices

Unfortunately chemical and physical restraint is the easiest ‘care’ practice for many, but it is a pathway for people with dementia that is not in line with our human rights or best practice.¹

Introduction

The Royal Commission’s inquiry has revealed instances where the use of restrictive practices in aged care has been inhumane, abusive and unjustified. Restraining a person, whether through physical or pharmacological means, is dehumanising and disempowering. It is an affront to dignity and personal autonomy. The overwhelming weight of evidence confirms that restrictive practices have questionable success in minimising so-called ‘challenging behaviours’. They also carry risks of serious physical and psychological harm, including health complications and premature death.

This chapter outlines evidence we have received about the use of restrictive practices in residential aged care in Australia, why they are being used, and preliminary observations and future directions for reform. It is not exhaustive but highlights key points.

In general, restraint should be used only in very narrow circumstances and be subject to safeguards. The expert evidence is that physical restraint should be used only where it is absolutely necessary to protect a person from a serious and imminent risk of harm, and that medicines that have the effect of restraining a person be used in accordance with clinical criteria and guidelines. Despite this evidence and the global trend promoting ‘restraint-free’ environments in aged care,² restrictive practices are common in Australia.

In many instances, restraints are used as a first-line response to manage behaviours that are challenging for staff and others in residential aged care, contrary to available guidance and evidence. As recently as June 2019, the provider of the Earle Haven aged care facilities on the Gold Coast disclosed, when asked, that 71% of its care recipients received psychotropic medication and 50% were physically restrained.³

1 Exhibit 3-84, Sydney Hearing, Statement of Kate Swaffer, 16 May 2019, WIT.0127.0001.0001 at 0026 [210].

2 See, for example, Exhibit 3-2, Sydney Hearing, General tender bundle, tab 2, CTH.0001.4000.4879.

3 Exhibit 8-1, Brisbane Hearing, Earle Haven tender bundle, tab 95, 29 April 2019, CTH4010.2000.0707 at 0712.

Restrictive practices have been identified as a problem 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.⁴ Meanwhile, the disability sector has adopted a framework and strict procedures to regulate restrictive practices, which incorporate a human rights-based approach. In contrast, there has been little progress in aged care. The indiscriminate use of restrictive practices on older people in Australia is unacceptable.

Defining restrictive practices

The term restrictive practices generally refers to activities or interventions, either physical or pharmacological, that have the effect of restricting a person's free movement or ability to make decisions.⁵ They may involve restricting people with wrist restraints, abdominal and pelvic straps, vests, bed rails or deep recliner chairs, confining a person to their room or a section of a facility, or sedating them with particular medication.⁶

Restrictive practices are commonly, but not exclusively, used in residential aged care for people who exhibit what are sometimes referred to as 'challenging behaviours'.⁷ These behaviours can be symptoms of cognitive impairment, including dementia, and can include physical or verbal aggression, agitation, restlessness and not following social and/or sexual rules. The behaviours tend to be unique to the person and their circumstances and can be made worse by factors such as pain, fear, feelings of being threatened, or stress. We refer to these as 'changed behaviours' throughout this chapter, consistent with the guidelines developed for describing the behavioural and psychological symptoms of dementia.⁸ We acknowledge that what a residential aged care provider may consider 'challenging' or 'changed' behaviour will vary, and in some cases, its approach to care may exacerbate these behaviours and result in a decision to use restraint. We also acknowledge that restrictive practices may be used in people's homes or other care settings, such as hospitals. Our inquiry so far has predominately focused on those used in residential aged care.

4 See, for example, Australian Law Reform Commission, *Elder Abuse – A National Legal Response*, Report No 131, 2017, <https://www.alrc.gov.au/publication/elder-abuse-a-national-legal-response-alrc-report-131/>, verified 27 September 2019; Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Report No 124, 2014, <https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/>, viewed 27 September 2019; K Carnell and R Paterson, *Review of national aged care quality regulatory processes*, 2017.

5 See, for example, Exhibit 3-2, Sydney Hearing, General tender bundle, tab 2, CTH.0001.4000.4879 at 4883.

6 Exhibit 3-70, Sydney Hearing, Statement of Joseph Elias Ibrahim, 23 April 2019, WIT.0115.0001.0001 at [184].

7 For further detail about the behavioural and psychological symptoms associated with dementia, see Royal Commission into Aged Care Quality and Safety, *Background Paper 3 – Dementia in Australia: nature, prevalence and care*, 2019.

8 Dementia Australia, *Dementia Language Guidelines*, 2018, <https://www.dementia.org.au/files/resources/dementia-language-guidelines.pdf>, viewed 16 August 2019.

There is no consistent understanding within the aged care sector about what constitutes restrictive practices.⁹ A view of restrictive practices that focuses on restraints attached or adjacent to a person's body might fail to recognise other limitations on free movement, such as secured doors, as restrictive practices. Definitions of 'restrictive practices' used in legislation and guidance also vary.¹⁰ This creates issues with identifying, measuring and responding to the issue.

There are specific challenges defining 'chemical restraint'. Particular medicines can restrict people's movements or ability to make decisions. Psychotropic medications affect the mind, emotions and behaviours of a person.¹¹ Within the broad cluster of such medications, the ones most commonly used to provide chemical restraint in aged care are antipsychotics (often referred to as tranquilisers) and benzodiazepines (minor tranquilisers or sleeping pills).¹² At the Sydney Hearing, Scientia Professor at the Centre for Healthy Brain Ageing at the University of New South Wales, Professor Henry Brodaty AO, explained the distinction between using medication for treating psychotic symptoms, such as delusions or hallucinations, and restraining a person through sedation. In his view, the boundary between treatment for an illness and restraint can become blurred, which makes defining 'chemical restraint' difficult.¹³ The Australian Commission on Safety and Quality in Health Care contends that there is a lack of consensus on the definition of chemical restraint because of the difficulties in determining whether a clinician's intent is primarily to treat a person's symptoms or to control their behaviour.¹⁴

Registered pharmacist and senior lecturer in dementia care at the University of Tasmania, Dr Juanita Breen (formerly Westbury), gave evidence about the difficulties in explaining clearly what constitutes chemically restraining an aged care resident. Her opinion was that the focus should be on whether medication prescribed for any resident is used appropriately, 'that is, in accordance with professional or government guidelines and publications'.¹⁵

9 Transcript, Professor Joseph Ibrahim, Sydney Hearing, 16 May 2019 at T1797.42-45; Exhibit 3-49, Sydney Hearing, Statement of Professor Elizabeth Beattie, 30 April 2019, WIT.0119.0001.0001 at 0028 [98]-[99]; Exhibit 3-48, Sydney Hearing, Statement of Professor Constance Dimity Pond, 6 May 2019, WIT.0118.0001.0001 at 0016 [69]. For further detail, see Royal Commission into Aged Care Quality and Safety, *Background Paper 4 – Restrictive practices in residential aged care in Australia*, 2019.

10 For further detail, see Royal Commission into Aged Care Quality and Safety, *Background Paper 4 – Restrictive practices in residential aged care in Australia*, 2019.

11 Psychotropic medication include stimulants, antidepressants, antipsychotics, mood stabilizers and anti-anxiety agents.

12 Exhibit 3-55, Sydney Hearing, Statement of Professor Brendan Francis Murphy, 24 April 2019, WIT.0129.0001.0001.

13 Exhibit 3-80, Sydney Hearing, Statement of Professor Henry Brodaty, 16 May 2019, WIT.0116.0001.0001 at 0011 [52].

14 Australian Commission on Safety and Quality in Health Care, *National Safety and Quality Health Service Standards guide for multi-purpose services and small hospitals*, 2017, p 172, <https://www.safetyandquality.gov.au/sites/default/files/migrated/National-Safety-and-Quality-Health-Service-Standards-Guide-for-Multi-Purpose-Services-and-Small-Hospitals.pdf>, viewed 27 September 2019.

15 Exhibit 3-61, Sydney Hearing, Statement of Dr Juanita Westbury (now Breen), 29 April 2019, WIT.0117.0001.0001 at 0018 [27].

What the Royal Commission has heard about the use of restrictive practices

During the Sydney Hearing, we heard evidence from family members who witnessed a loved one being inappropriately restrained in residential aged care. They described their distress and shock at the practices, and the negative impact on their family member's health and wellbeing.

Ms Eresha Dilum Dassanayake told us that her mother's mobility aid was removed for 'safety', despite the benefit of regular walking for the management of her osteoporosis:

one incident which shocked me...my mum complained that the walker gets taken away from her...when I asked one of the carers they said, well, we're sick of, you know, having to give it to her because she's walking around all the time, and I've taken it away to keep her safe.¹⁶

A witness known as 'DM' explained that her mother had been prescribed 'Axit' (containing antidepressant Mirtazapine) because she had anxiety and agitation, which was causing her to 'wander'. DM said:

Neither [my sister] nor I were told by staff at Brian King Gardens what the side effects of Axit might be. [The doctor] never spoke to either of us about the medication and [she] never mentioned that Axit could have been the reason why Mum was out of it so long.¹⁷

16 Transcript, Eresha Dilum Dassanayake, Sydney Hearing, 6 May 2019 at T1174.47–T1175.4.

17 Exhibit 3-20, Sydney Hearing, Statement of 'DM', 17 April 2019, WIT.0099.0001.0001 at 0009 [69].

‘He never came back 100 per cent’¹⁸

Mr Terance Reeves was diagnosed with Alzheimer’s disease in 2010. As Mr Reeves’s condition declined, he continued to live in his own home cared for by his wife, Lillian Reeves. The decision in 2018 to seek respite care for Mr Reeves was a difficult one for Mrs Reeves and her family.

Mr Reeves was in respite care at Garden View Aged Care from 1 May 2018 to 7 July 2018.

Mr Reeves’s care plan at the time of his admission did not include strategies for addressing his care needs relating to behaviours associated with his dementia.

At the request of a nurse at the facility, a general practitioner prescribed Mr Reeves the antipsychotic drug risperidone, to be taken three times a day as required for unsettled behaviour. Although risperidone can have severe adverse side effects, Mr Reeves was given the antipsychotic drug without the informed consent of either Mr Reeves or his wife, Mrs Reeves.

Mr Reeves’s daughter, Michelle McCulla, was ‘shocked’ and ‘confused’ when she visited her father on 8 May 2019 and found him physically restrained by a belt across his lap. Ms McCulla recalled Garden View’s explanation that the restraints had been used because Mr Reeves had been aggressive and that he was not being cooperative. Mrs Reeves recalled she was later asked to give her consent to Mr Reeves being physically restrained so that he did not walk around during shift changes. As Ms McCulla recalled, ‘every single time I visited he was in a restraint except for one day when he was completely unconscious in a bed’. Describing one such visit, she said she ‘found him in the East Wing, sitting in a lap belt, head hanging in his chest, drooling’. Describing another occasion, Ms McCulla told us:

We went through a keypad locked door. I found a small room, perhaps 11m by 5m or 6m. I found several patients across from me. There was a line of chairs and everyone was restrained in lap belts along that side of the wall. My father was in a chair with his back towards me restrained in the chair. He had another resident next to him restrained in a chair and there were...maybe two or three in tub beds also restrained.

Records provided to the Royal Commission by the facility revealed that Mr Reeves had been physically restrained most days and sometimes for as long as 13 hours a day.

When Mrs Reeves made the decision to remove Mr Reeves from Garden View earlier than planned, she observed that he was less capable of walking and speaking than he was when he had arrived at the facility and that he had become completely incontinent.

Mrs Reeves described the facility where Mr Reeves now resides as a ‘wonderful’ place where Mr Reeves is not restrained and is free to walk around, having recovered his ability to walk very well. She added, however, that ‘he never came back 100 per cent after being at Garden View; never came back’.

18 Based on material in the Garden View Case Study, Sydney Hearing, described in detail in Volume 2 of this Interim Report.

The prevalence of restrictive practices

These examples are not isolated instances. They are part of a widespread practice affecting the care of many older Australians. While some providers strive to deliver restraint-free environments, there is both empirical and anecdotal evidence to show that the use of restraints is common in aged care.¹⁹

The prevalence of physical restraint in residential aged care in Australia is very poorly documented²⁰ and there is a lack of recent empirical data.²¹ However, the Royal Commission received substantial anecdotal evidence during the Sydney Hearing of the continuing use of physical restraint in residential aged care. In particular, Associate Professor Stephen Macfarlane, Head of Clinical Services, Dementia Centre at HammondCare, who also leads the team of Clinical Associates who work with the Severe Behaviour 'Response Team and the Dementia Behaviour Management Advisory Service, gave evidence about the experience of the team and service, both of which deliver specialist dementia services to aged care facilities to manage changed behaviours. Associate Professor Macfarlane said that he hears anecdotally and on a weekly basis from consultants of stories where restraint has been inappropriately applied.²² Witnesses with experience working in residential care described having seen physical restraint being used often in the care homes where they have worked.²³

Professor Joseph Ibrahim, the Head of Health Law and Ageing Research at Monash University, told us that 'the use of restraints generally is sadly still widely accepted, though people will all react abhorrently when they hear it but it's still used'.²⁴

There is significant empirical data concerning the use of psychotropic medications. Research dating back to the 1990s has shown that the rate of prescription of psychotropic medication in residential aged care substantially exceeds the reasonably expected clinical needs of the people receiving care.²⁵

More recent data supports this point. Important research carried out by Dr Breen and others over the last decade shows a significant use of chemical restraint across Australia, with minor variations depending on the State or Territory. The result of her major national

19 See, for example, Transcript, Jennifer Lawrence, Sydney Hearing, 14 May 2019 at T1596.36; Transcript, Lucy O'Flaherty, Sydney Hearing, 14 May 2019 at T1597.14; Exhibit 3-2, Sydney Hearing, General tender bundle, tab 16, CTH.0001.1000.5385 at 5459-5460.

20 Exhibit 3-2, Sydney Hearing, General tender bundle, tab 16, CTH.0001.1000.5385 at 5459.

21 Some older research provides some indication of the prevalence of physical restraint in residential aged care facilities in Australia. For example, a study carried out in a high care facility in Western Australia in 2005 found that 40% of residents were restrained. See J Timmins, 'Compliance with best practice: implementing the best available evidence in the use of physical restraint in residential aged care', *International Journal of Evidence Based Health Care*, 2008, Vol 6, 3, p 345.

22 Transcript, Associate Professor Stephen Macfarlane, Sydney Hearing, 15 May 2019 at T1756.28-29.

23 Transcript, Margaret Bain 15 May 2019 at T1711; Transcript, Jennifer Lawrence, 14 May 2019 at T1596.36; Transcript, Lucy O'Flaherty, 14 May 2019 at T1597.14.

24 Transcript, Professor Joseph Ibrahim, Sydney Hearing, 16 May 2019 at T1798.3-5.

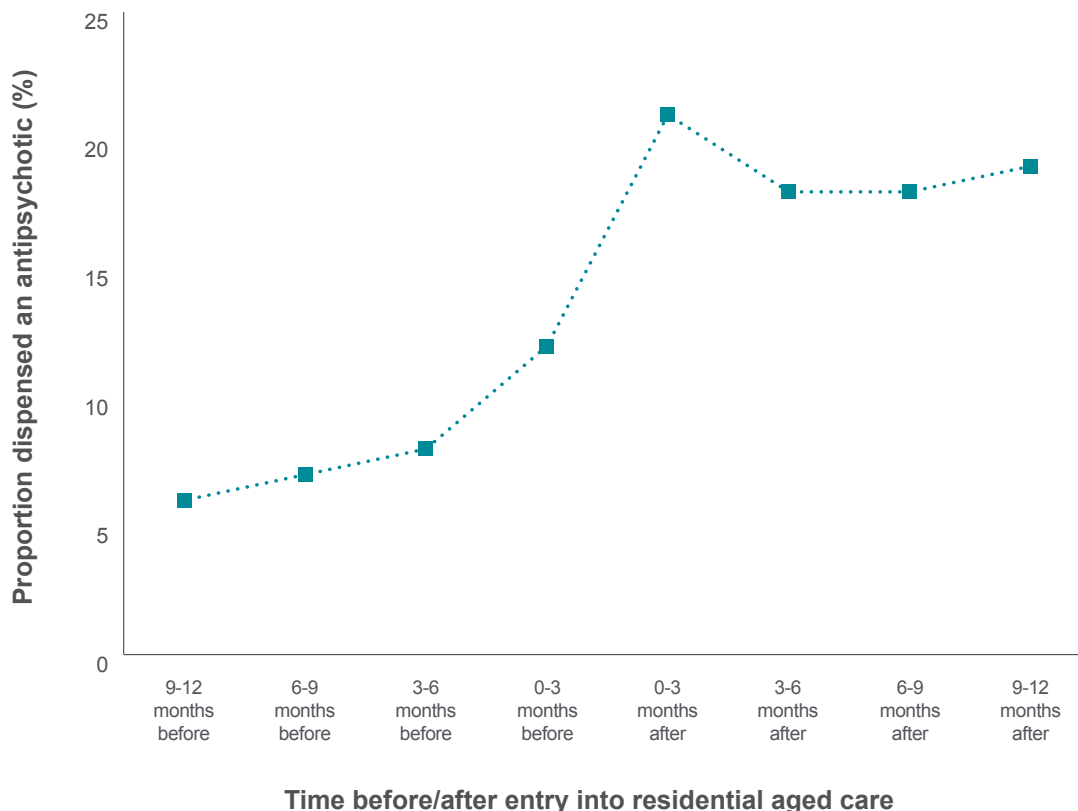
25 See, Royal Commission into Aged Care Quality and Safety, *Background Paper 4 – Restrictive practices in residential aged care in Australia*, 2019.

study of 11,368 residents across 139 residential aged care facilities, published in 2018, demonstrated, among other things, that:

- 21.8% of residents were administered antipsychotics, 41.4% antidepressants and 21.6% benzodiazepines on a regularly charted basis and that risperidone accounted for half of all antipsychotic prescribing—11.4% of all residents.
- 11.1% of residents were prescribed ‘as needed’ (prn) antipsychotics and 30.5% were charted for ‘prn’ benzodiazepines. In addition, 47% of regular benzodiazepine users were also prescribed these agents on a ‘prn’ basis, as were 29% of regular antipsychotic users
- with both regular and prescribed as needed prevalence taken into account, 54.1% were prescribed antipsychotic and/or benzodiazepine agents.²⁶

Figure 8.1 shows the prevalence of antipsychotic dispensing among nearly 98,000 people prior to and after entering residential aged care in Australia between 2013 and 2015. It was compiled by the Registry of Older South Australians Research Team using data from the National Historical Cohort of the Registry of Older South Australians.

Figure 8.1 – Prevalence of antipsychotic dispensing prior to and after entering residential aged care



Source: Exhibit 6-1, Darwin and Cairns Hearing, General tender bundle, tab 129, RCD.9999.0103.0001 at 0007.

26 Exhibit 3-2, Sydney Hearing, General tender bundle, tab 49, RCD.9999.0032.0128 at 0128.

Dr Janet Sluggett, a consultant pharmacist and a National Health and Medical Research Council Early Career Research Fellow at the Centre for Medicine Use and Safety at Monash University, gave evidence at the Darwin Hearing. Dr Sluggett has been closely involved in the research conducted into the National Historical Cohort of the Registry of Older South Australians. She outlined the data sources and methodology adopted, and made some reflections about the implications of the findings. As Figure 8.1 shows, the transition to residential care is associated with a significant rise in initiation of antipsychotics, building on the increased use of antipsychotics immediately before entry. Dr Sluggett explained that:

the transition from home to residential aged care may cause stress or distress, and so that may present as—more people may present with some sort of behavioural symptoms of dementia during that time, particularly if they're unable to communicate verbally...it indicates to me as well that non-pharmacological techniques to manage the behavioural and psychological systems of dementia are going to be particularly important during those—that transition time and during those first few months of stay in a residential aged care facility.²⁷

It is concerning that the high level of prescription of antipsychotics remains constant after that transition.

While it is difficult to ascertain the precise extent to which the prevalence of psychotropic medication dispensing correlates with the use of chemical restraint, it appears that prescription rates for people in residential aged care are significant and well above what might be expected. 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 10% of antipsychotics 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.²⁸ In the opinion of Professor Ibrahim, the overprescribing of antipsychotics as a first line treatment for behavioural and psychological symptoms of dementia is 'a major, systemic industry-wide issue'.²⁹

The serious impacts of restrictive practices

The Royal Commission's concern about restrictive practices in Australia stems not only from the fact that they can violate the fundamental rights of older Australians, but also from their serious impact on physical and psychological health. Research demonstrates that physical restraints can cause premature death as well as other serious physical and psychological consequences, such as falls and cognitive decline.³⁰

27 Transcript, Dr Janet Sluggett, Darwin Hearing, 12 July 2019 at T3364.30-34.

28 Exhibit 3-2, Sydney Hearing, General tender bundle, tab 104, CTH.1007.1007.0374 at 0378.

29 Exhibit 3-70, Sydney Hearing, Statement of Professor Joseph Elias Ibrahim, 23 April 2019, WIT.0115.0001.0001 at 0015 [78].

30 E Bellenger, J Ibrahim, J Lovell and L Bugeja, '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.

Physical restraints have other impacts on older people, apart from the most severe ones of injury and death.³¹ As ‘Elizabeth’, a registered nurse who gave evidence in the Sydney Hearing, told us:

If you sit for an excessive period of time you lose muscle mass, you lose your condition, you lose the ability to walk. And people who are elderly are already in a compromised condition for that.³²

In his evidence, Professor Brodaty explained that the risks associated with use of pharmaceuticals with psychotropic and sedative effects include falls, fractures, increased confusion, and extra-pyramidal side effects (Parkinson-like effects), such as a slow shuffling gait, slowing of movements and increased muscle rigidity.³³ In its guidance on the treatment of behavioural and psychological symptoms of dementia, the Royal Australian & New Zealand College of Psychiatrists notes that antipsychotic medicines are associated with increased risk of respiratory complications (such as pneumonia), stroke and heart rhythm abnormalities, cerebrovascular events (including stroke) and increased risk of death.³⁴

A particularly troubling example of the misuse of chemical restraint is the Victorian coronial case of Barton. Oxazepam was prescribed in response to behaviours of an 83-year-old aged care resident with advanced Alzheimer’s dementia, including agitation, biting, spitting, scratching, hitting and kicking. Staff reassurance, redirection and one-on-one time with the resident had not achieved a sustained effect. An excessive medication regimen involving the over-prescription of the psychotropic benzodiazepine Oxazepam was found to have contributed to the resident’s physical decline and death.³⁵

Restrictive practices are not effective in managing changed behaviour

The Royal Commission has also received evidence that physical restraints have questionable success in minimising risk of changed behaviours and the management of behavioural and psychological symptoms associated with dementia.

A recent study into the nature and extent of physical restraint-related deaths in residential aged care facilities affirmed the view that individuals can still experience falls even when restrained to prevent them.³⁶ The research evidence also suggests that physical restraints are not effective in preventing serious injury which may occur because of

31 Exhibit 3-70, Sydney Hearing, Statement of Professor Joseph Elias Ibrahim, 23 April 2019, WIT.0115.0001.0001 at 0037 [188], 0038 [193]-[194].

32 Transcript, ‘Elizabeth’, Sydney Hearing, 15 May 2019 at T1710.40-43.

33 Exhibit 3-80, Sydney Hearing, Statement of Professor Henry Brodaty, 16 May 2019, WIT.0116.0001.0001 at 0009 [44] – 0010 [46].

34 Exhibit 3-2, Sydney Hearing, General tender bundle, tab 15, RCD.9999.0032.0087 at 0087.

35 Exhibit 3-2, Sydney Hearing, General tender bundle, tab 27, RCD.0010.0001.0022 at 0040 [47].

36 E Bellenger, J Ibrahim, J Lovell and L Bugeja, ‘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 1031.

aggressive behaviour. In many cases, the agitation, discomfort and anxiety of the person is only increased.³⁷ During the Sydney Hearing, Professor Ibrahim concluded: ‘There is no evidence I’m aware of—and I’m happy to be proven wrong—that physical restraints improve your life or protect you from anything.’³⁸ According to the Australian and New Zealand Society for Geriatric Medicine, the use of physical restraints attached to or near a person’s body is not supported by evidence of efficacy or safety.³⁹

The Royal Commission heard that the effectiveness of psychotropic medication in managing the behavioural and psychological symptoms of dementia depends largely on the nature of the symptoms. Associate Professor Macfarlane explained that if a person is hallucinating, an antipsychotic like risperidone can be highly effective and clinically appropriate. Similarly, if a person has insomnia or severe anxiety disorder, then a benzodiazepine such as ‘Valium’ or ‘Librium’ may be effective and clinically appropriate.⁴⁰ However, there is no psychotropic medication that can address behaviour such as ‘calling out’ or so-called ‘wandering’ other than by means of sedating the person to the point where they are no longer able to engage in it.⁴¹ Chief Medical Officer for the Australian Government, Professor Brendan Murphy, gave evidence that, with the exception of psychotic manifestations of dementia or risks of self-harm, antipsychotic and benzodiazepine medications do not alleviate behavioural and psychological symptoms of dementia and can make them worse.⁴²

What we heard about why restrictive practices are used

A key question, given the adverse impacts and lack of efficacy of restrictive practices, is why they continue to be used in the aged care sector on such a wide scale.

During our Sydney Hearing, ‘Elizabeth’ suggested that:

[chemical restraint is] anonymous, [so that] everyone looks fine...they’re all clean and tidy and they’re not crying out. But they’re not actually getting... the care they need and being treated like a person with needs.⁴³

37 C Gastmans and K Milisen, ‘Use of physical restraint in nursing homes: clinical-ethical considerations’, *Journal and Medical Ethics*, 2006, Vol 32, p 148.

38 Transcript, Professor Joseph Ibrahim, Sydney Hearing, 16 May 2019 at T1798.8-10.

39 Exhibit 3-2, Sydney Hearing, General tender bundle, tab 4, CTH.1007.1003.4677 at 4677 [3].

40 Exhibit 3-68, Sydney Hearing, Statement of Associate Professor Stephen Robert MacFarlane, 24 April 2019, WIT.0125.0001.0001 at 0022 [112].

41 Ibid, 0022 [109].

42 Exhibit 3-55, Sydney Hearing, Statement of Professor Brendan Francis Murphy, 24 April 2019, WIT.0129.0001.0001 at 0009 [25].

43 Transcript, ‘Elizabeth’, Sydney Hearing, 15 May 2019 at T1708.6-10.

The Royal Commission has received evidence that the ‘drivers’ behind the use of restrictive practices are complex and involve multiple factors across the aged care and health systems. In many cases, people involved in the decision to restrain have good intentions, whether that be mitigating risk to the person or giving the person relief. Research shows that restrictive practices may be used with the intention of ensuring a person’s safety and for preventing harm to others, reducing the risk of liability to the service provider, or at times for the convenience of the staff.⁴⁴ However, from what we have heard to date, it is our view that the perceived need to restrain rarely aligns with the actual need.⁴⁵

A focus on symptoms rather than cause

The evidence suggests that an overarching reason for the use of restraint in residential aged care is a care model that focuses on managing symptoms, rather than addressing people’s underlying needs and concerns. Associate Professor Macfarlane illustrated this point with the following example: a person with dementia may be unsafe walking and may be at extreme risk of falls. If that person is making repeated attempts to rise from their chair and walk, staff may be concerned about the risk of falls and fracture and may apply a physical restraint to prevent that person from rising. This approach treats the symptom (attempting to rise) rather than cause (considering why the person is attempting to rise and focusing interventions around that).⁴⁶

According to Associate Professor Edward Strivens, President of the Australian and New Zealand Society for Geriatric Medicine, the changed behaviours associated with dementia are often an expression of unmet need, including untreated pain, a desire to interact with the physical environment, and/or unmet psychosocial needs.⁴⁷ Psychosocial needs of people in residential care can include loneliness and anxiety.

Professor Ibrahim’s evidence was that the use of physical restraint means that staff are not employing evidence-based interventions to address the risk of falls or behavioural and psychological symptoms of dementia.⁴⁸ He elaborated in his oral evidence: ‘The use of physical restraint means that you’ve not sufficiently examined, worked up the resident with sufficient help from other professionals, to work out why that person is agitated or distressed for you to initiate restraint.’⁴⁹

44 See, for example, R Möhler and G Meyer, ‘Attitudes of nurses towards the use of physical restraints in geriatric care: A systematic review of qualitative and quantitative studies’, *International Journal of Nursing Studies*, 2014, Vol 51, 2, pp 274–288; Exhibit 3-68, Sydney Hearing, Statement of Associate Professor Stephen Robert Macfarlane, 24 April 2019, WIT.0125.0001.0001 at 0021 [106]; Exhibit 3-49, Sydney Hearing, Statement of Professor Elizabeth Beattie, 30 April 2019, WIT.0119.0001.0001 at 0028 [100].

45 Exhibit 3-68, Sydney Hearing, Statement of Associate Professor Stephen Robert MacFarlane, 24 April 2019, WIT.0125.0001.0001 at 0021 [105] – 0022 [107].

46 Ibid, 0021-0022 [107].

47 Exhibit 1-14, Adelaide Hearing 1, Statement of Edward Strivens, 28 January 2019, WIT.0021.0001.0001 at 0007 [63].

48 Exhibit 3-70, Sydney Hearing, Statement of Professor Joseph Elias Ibrahim, 23 April 2019, WIT.0115.0001.0001 at 0038 [194].

49 Transcript, Professor Joseph Ibrahim, Sydney Hearing, 16 May 2019 at T1799.20-23.

In oral evidence, Associate Professor Macfarlane told us that service providers may feel behaviour is effectively managed through a restraint. His response to this approach was that it might be effective, but it was ‘not necessarily appropriate, safe, or empowering for the person living with dementia’.⁵⁰ He explained that providers may perceive it as easier to implement a medication-based solution, rather than devote time and effort to getting to know and understand the person.⁵¹

According to Dr Breen, before any psychotropic medication is prescribed, there should be a comprehensive behavioural and psychological assessment identifying triggers for the changed behaviour, and the combined effect of other medications should be considered. Consent from the resident or person responsible for the resident should be obtained.⁵²

In addition, the Australian Commission on Safety and Quality in Healthcare’s *Third Atlas of Healthcare Variation* stresses that non pharmacological interventions should be prioritised over psychotropic medications. This is consistent with the Australian Department of Health’s policy guidance.⁵³ Clinical practice guidelines also recommend assessment of causative factors and a range of person-centred strategies to support people who develop behavioural and psychological symptoms of dementia.⁵⁴

There is significant research on person-centred strategies and interventions to negate or mitigate the need for restraint by managing the underlying causes of changed behaviour, spanning environmental, psychosocial, and physiological factors.⁵⁵ The use of these strategies and interventions was a key theme arising from the evidence of a panel of specialist dementia providers during the Sydney Hearing. Ms Tamar Krebs, Co-Chief Executive Officer of Group Homes Australia, told us that her organisation seeks to find alternative solutions to using restraints. They focus on identifying strategies to support the resident and assist with their unmet needs through various forms of engagement.⁵⁶ Ms Lucy O’Flaherty, Chief Executive Officer of Glenview Community Services Inc., gave evidence that their approach involves trying to understand ‘what staff are not responding to, which creates the behaviour in the first place’.⁵⁷

50 Transcript, Associate Professor Stephen Macfarlane, Sydney Hearing, 15 May 2019 at T1759.42-43.

51 Exhibit 3-68, Sydney Hearing, Statement of Associate Professor Stephen Robert MacFarlane, 24 April 2019, WIT.0125.0001.0001 at 0025 [127]-[128].

52 Exhibit 3-61, Sydney Hearing, Statement of Dr Juanita Westbury (now Breen), 29 April 2019, WIT.0117.0001.0001 at 0016 [24].

53 Exhibit 3-2, Sydney Hearing, General tender bundle, tab 74, CTH.1007.1003.2494 at 2494; Exhibit 3-80, Sydney Hearing, Statement of Professor Henry Brodaty, 16 May 2019, WIT.0116.0001.0001 at 0009 [45]; Exhibit 3-68, Sydney Hearing, Statement of Associate Professor Stephen Robert MacFarlane, 24 April 2019, WIT.0125.0001.0001 at 0024 [120]-[122]; Exhibit 3-2, Sydney Hearing, General tender bundle, tab 2, CTH.0001.4000.4879.

54 Exhibit 3-2, Sydney Hearing, General tender bundle, tab 14, RCD.9999.0031.0002 at 0014.

55 See, for example, Exhibit 3-80, Sydney Hearing, Statement of Professor Henry Brodaty, 16 May 2019, WIT.0116.0001.0001 at 0003 [13].

56 Exhibit 3-45, Sydney Hearing, Statement of Tamar Chayen Krebs, 30 April 2019, WIT.0124.0001.0001 at 0462.

57 Exhibit 3-47, Sydney Hearing, Statement of Lucille (Lucy) Claire O’Flaherty, 26 April 2019, WIT.0122.0001.0001 at 0011 [58].

Retired diversional therapist Ms Margaret Bain's approach was also instructive:

We use techniques such as approaching the person quietly, if they're agitated or if they're upset. We go about it in a different way to the clinical—clinical restraint or anything like that. What we do is we would just sit with them. Once we've approached them we would sit with them. We might hold their hand, we might offer a hand massage. We might just listen to what they have to say. If they can't speak, then we just sit with them and we take into us what they are feeling, really. We use many different techniques to calm any agitated or wandering resident.⁵⁸

Focusing on the person and assessing and managing the underlying causes of behaviour can mitigate or eliminate the need for restrictive practices. However, these approaches do not appear to be consistent across residential aged care and many providers struggle to deal with the range of complex needs associated with dementia and other cognitive impairment. This is illustrated, in part, by Dr Breen's research, which demonstrated that some residential aged care facilities were able to operate with minimal antipsychotic use, whereas others were giving these medications to over 40% of their residents.⁵⁹ Notably, facilities specialising in changed behaviours and mental illness were excluded from the research.

Inadequate knowledge and skills

The overwhelming evidence before the Royal Commission is that there is a lack of knowledge about restraints and their impacts, alternatives to their use and the safe and appropriate management of the behavioural and psychological symptoms of dementia. This affects personal care workers, nurses and general practitioners.

Many witnesses have suggested that the limited training in the care of people living with dementia contributes to substandard care, including restraint use.⁶⁰ For example, at the Sydney Hearing, 'Elizabeth' said:

if somebody starts lashing out at you and if you don't understand the issues around dementia, you then—you start attributing blame...When they...simply don't have the capacity to make those decisions. If you are sitting there, expecting them to have the capacity to behave in what you perceive as a normal way, then that just builds resentment and that comes into poor care.⁶¹

58 Transcript, Margaret Bain, Sydney Hearing, 15 May 2019 at T1697.2-8.

59 Exhibit 3-61, Sydney Hearing, Statement of Dr Juanita Westbury (now Breen), 29 April 2019, WIT.0117.0001.0001 at 0010 [15].

60 Exhibit 3-49, Sydney Hearing, Statement of Professor Elizabeth Beattie, 30 April 2019, WIT.0119.0001.0001 at 0028 [100]; Exhibit 3-68, Sydney Hearing, Statement of Associate Professor Stephen Robert MacFarlane, 24 April 2019, WIT.0125.0001.0001 at 0018 [86].

61 Transcript, 'Elizabeth', Sydney Hearing, 15 May 2019 at T1701.45-T1702.4.

‘Elizabeth’s’ comments were echoed by Ms Susan Walton, an assistant in nursing, who said education and training around dementia is critical to managing changed behaviour. However, Ms Walton told us that where she is employed, care staff are not trained to seek out strategies other than restrictive practices when confronted with ‘challenging behaviours’.⁶² Associate Professor Macfarlane told us that current training is inadequate if the expectation is that such training ‘can adequately equip carers to manage the complex spectrum of dementia care needs within a one size fits all environment’.⁶³

Associate Professor Macfarlane went on to explain a common scenario where inadequate knowledge and skills result in inappropriate prescriptions of psychotropic medication. Personal care workers are often confronted with the changed behaviours of residents, and make incident reports which are escalated to nurses and then general practitioners, who are then expected ‘to do something’.⁶⁴ General practitioners may have little preparation or training in the management of changed behaviours, and the only strategy at their disposal is the prescription of psychotropic medications to sedate the person. Professor Constance Dimity Pond, Professor of General Practice at the University of Newcastle said that general practitioners do not have a full understanding of the symptoms and needs of people living with dementia.⁶⁵

There are also misconceptions about the prescription and effects of psychotropic medications among general practitioners. Dr Breen said that, as part of her PhD studies, she conducted a survey to help her understand why psychotropic medications are being prescribed. She found that general practitioners have a strong belief that psychotropic medications are more effective and the potential side effects are less significant than the evidence suggests. Dr Breen said some of the doctors she surveyed told her that the risks were ‘overblown and overpublicised’. She also noted that pharmacists who worked in the sector had said that they encountered real resistance to reduce the overall use because a lot of the aged care staff were quite concerned that behaviour would return or be escalated if medication was reduced.⁶⁶

In her research, Dr Breen found nursing and personal care workers could influence the decision to prescribe psychotropic medications the most and many believed the medications to be more beneficial than is in fact the case. Staff often expressed the view that medications improve a resident’s quality of life by calming and comforting them. Staff reported that relatives often asked them to ‘do something’ about behavioural symptoms. Nurses were often unaware of the side effects associated with use, wrongly attributing side effects such as falling, drowsiness or movement effects to the resident ‘getting old’.⁶⁷

62 Exhibit 3-59, Sydney Hearing, Statement of Susan Marie Walton, 11 May 2019, WIT.0153.0001.0001 at 0014 [56].

63 Exhibit 3-68, Sydney Hearing, Statement of Associate Professor Stephen Robert MacFarlane, 24 April 2019, WIT.0116.0001.0001 at 0018 [86].

64 Exhibit 3-68, Sydney Hearing, Statement of Associate Professor Stephen Robert MacFarlane, 24 April 2019, WIT.0116.0001.0001 at 0018 [86].

65 Exhibit 3-48, Sydney Hearing, Statement of Professor Constance Dimity Pond, 6 May 2019, WIT.0118.0001.0001 at 0017 [71].

66 Transcript, Dr Juanita Westbury (now Breen), Sydney Hearing, 15 May 2019 at T1730-T1731.

67 Exhibit 3-61, Sydney Hearing, Statement of Dr Juanita Westbury (now Breen), 29 April 2019, WIT.0117.0001.0001 at 0013 [20].

Inadequate staffing and workload pressures

Despite availability of a range of non-restrictive ways to manage changed behaviour, workload pressures can often mean that there is no time to do anything other than to restrain older people. Even where staff members are adequately trained, they may not be supported to deliver alternatives and restraint may be used as a way of managing workload.

For example, ‘Elizabeth’ gave evidence that there are many alternatives available to restraining a person, but that they all take ‘skill, time and patience’.⁶⁸ Explaining the difficult workloads confronting nurses in residential aged care facilities, she said:

And when you’ve got 60 people...how can you even see them when you divide that by a shift?...If you’re lucky you will get a break...so you’re coming down to minutes and then something else will go wrong and you’ve got nothing and there are days and days and days with those workloads when you don’t actually set eyes on a person.⁶⁹

Other witnesses explained that staff often lack the time to manage changed behaviour. Ms Walton told us that people with changed behaviours often require a one-on-one carer who understands their needs to support them. She said that: ‘Care workers have to be able to listen to what they have to say. You can’t physically do this when you are with 20 other residents with similar problems.’⁷⁰ Ms Bain said that, in her view, restraint arises from a ‘lack of knowing the person as an individual person’ and that staff do not currently have the time to do this faithfully.⁷¹

‘Elizabeth’ told us that because there are not enough staff, and it is confronting and unsavoury to physically restrain people, people are often sedated so ‘they’re not annoying you’.⁷²

General practitioners, too, may be affected by workload pressures. Professor Brodaty gave evidence that general practitioners may rely on information from the staff of an aged care residence about a person’s behaviours and prescribe on that basis, rather than analysing those behaviours and why they might be occurring, which is more time-consuming.⁷³ Dr Breen told us that in her research, most general practitioners assumed that assessment and trial of non-drug strategies had occurred *before* they were asked to prescribe.⁷⁴ The general view of experts during the Sydney Hearing was that remuneration for general practitioners for attending patients in residential aged care was insufficient, thus providing no incentive for them to take the extra time needed to do an adequate

68 Exhibit 3-57, Sydney Hearing, Statement of Elizabeth [full name known to the Commission], 14 May 2019, WIT.0152.0001.0001 at 0015 [93].

69 Transcript, ‘Elizabeth’, Sydney Hearing, 15 May 2019 at T1720.31-T1721.2.

70 Exhibit 3-59, Sydney Hearing, Statement of Susan Marie Walton, 11 May 2019, WIT.0153.0001.0001 at 0010 [38].

71 Transcript, Margaret Bain, Sydney Hearing, 15 May 2019 at T1697.14-15.

72 Transcript, ‘Elizabeth’, Sydney Hearing, 15 May 2019 at T1707.44-46.

73 Transcript, Professor Henry Brodaty, Sydney Hearing, 17 May 2019 at T1914.20-30.

74 Exhibit 3-61, Sydney Hearing, Statement of Dr Juanita Westbury (now Breen), 29 April 2019, WIT.0117.0001.0001 at 0013 [20].

assessment of the person they are called in to see.⁷⁵ In Associate Professor Macfarlane's view, the overall limitations on medical practitioners' time also makes it 'impractical' for them to be able to adequately assess people displaying behavioural and psychological symptoms of dementia.⁷⁶

A lack of informed consent

Laws relating to informed consent are complex, different in each State and Territory, and do not appear to be properly understood or applied in aged care.⁷⁷ During the Sydney Hearing, we found that risperidone was prescribed to Mr Terance Reeves at the Garden View Nursing Home without informed consent having first been obtained in accordance with the *Guardianship Act 1987* (NSW).⁷⁸ Failing to obtain informed consent where required by law ignores the rights of older Australians.

In her evidence, Dr Breen observed that all professional guidelines stress the importance of obtaining informed consent from the person or, in the event that they lack the capacity to make decisions, from their authorised substitute decision maker. 'Informed consent' means the prescriber or clinical nurse has advised the person or their legal representative of the benefits that can be expected as well as the adverse effects and risks that taking a medication may confer.⁷⁹

Dr Breen told us that relatives she had spoken to in the course of her research often said they had not been consulted before psychotropic medications were started. Many of them said the first time they were aware their relative was taking the medications was when they received the pharmacy bill.⁸⁰ Professor Brodaty referred to a further research study which showed that only one in 13 surveyed people receiving psychotropic medication in residential care who lacked capacity to give informed consent had documented consent from a legal representative, while another one in 13 had documented oral consent.⁸¹

In relation to physical restraints, Professor Ibrahim told the Royal Commission that a key issue contributing to their unjustified use is inconsistent approaches to obtaining informed consent from the resident or their appointed substitute decision maker before physical restraint is used.⁸²

75 Exhibit 3-80, Sydney Hearing, Statement of Professor Henry Brodaty, 16 May 2019, WIT.0116.0001.0001 at 0010 [47]; Exhibit 3-48, Sydney Hearing, Statement of Professor Constance Dimity Pond, 6 May 2019, WIT.0118.0001.0001 at 0006 [21]; Exhibit 3-68, Sydney Hearing, Statement of Associate Professor Stephen Robert MacFarlane, 24 April 2019, WIT.0125.0001.0001 at 0028 [143]-[146].

76 Exhibit 3-68, Sydney Hearing, Statement of Associate Professor Stephen Robert MacFarlane, 24 April 2019, WIT.0125.0001.0001 at 0015 [70].

77 See Royal Commission into Aged Care Quality and Safety, *Background Paper 4 – Restrictive practices in residential aged care in Australia*, 2019.

78 See Garden View Case Study, Sydney Hearing, described in detail in Volume 2 of this Interim Report.

79 Exhibit 3-61, Sydney Hearing, Statement of Dr Juanita Westbury (now Breen), 29 April 2019, WIT.0117.0001.0001 at 0016 [24].

80 Transcript, Dr Juanita Westbury (now Breen), Sydney Hearing, 15 May 2019 at T1731.9-12.

81 Exhibit 3-80, Sydney Hearing, Statement of Professor Henry Brodaty, 16 May 2019, WIT.0116.0001.0001 at 0011 [50].

82 Exhibit 3-70, Sydney Hearing, Statement of Professor Joseph Elias Ibrahim, 23 April 2019, WIT.0115.0001.0001 at 0039 [196].

The point at which informed consent should be obtained is a critical juncture for the person and their family. To be done correctly, it requires a shared understanding of the person's needs and wishes, exploring how those might best be addressed and providing information about the benefits as well as potential harm associated with physical restraint or medications. Enforcing these requirements help to ensure that any decision to use a physical restraint, or prescribe a particular medication, is robust and supported by the right considerations, starting with the person's best interests.

A lack of effective rules and regulation

A range of Australian Government, State and Territory laws, and non-statutory policies and guidance, impact on restrictive practices in residential aged care.⁸³ These include the aged care regulatory framework and guidance, health and medication regulation and guidance, medicine regulation, and legal frameworks relating to consent to care and treatment. Despite this plethora of guidelines, it is clear that there are insufficient limitations on the use of restrictive practices, especially in residential aged care.

The regulation of the aged care sector is not at all robust in the area. Until January 2019, with the introduction of the *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019* (Cth) (the Principles), the Australian Government had not sought to directly and explicitly regulate the use of restraints in residential aged care. Before 1 July 2019, the operative regulatory regime (which expired on 30 June 2019) under the *Aged Care Act 1997* (Cth), including the applicable Accreditation Standards,⁸⁴ did not expressly refer to the use of physical restraint or the prescription of psychotropic medications. During her evidence, Assistant Secretary of the Australian Department of Health, Ms Amy Laffan, accepted that these requirements, including voluntary guidance provided in the *Decision-Making Tool: Supporting a restraint free environment in residential aged care* (2012), were not effective in reducing restraint in residential aged care facilities.⁸⁵

Expert witnesses at our Sydney Hearing did not express confidence that the Principles would reduce the use of psychotropic medications, not least because they do not purport to regulate the behaviour of prescribing medical practitioners.⁸⁶ The Principles add to, rather than overcome, concerns regarding regulation of physical and chemical restraint, including on issues of consent.

On 29 July 2019, the Parliamentary Joint Committee on Human Rights resolved to conduct an inquiry into the Principles, examining the instrument's compatibility with human rights, the outcome of which remains unknown at the time of this Interim Report.

83 See, Royal Commission into Aged Care Quality and Safety, *Background Paper 4 – Restrictive practices in residential aged care in Australia*, 2019.

84 *Quality of Care Principles 2014* (Cth), sch 2.

85 Transcript, Amy Elizabeth Laffan, Sydney Hearing, 16 May 2019 at T1859.18-30.

86 See, Exhibit 3-61, Sydney Hearing, Statement of Dr Juanita Westbury (now Breen), 29 April 2019, WIT.0117.0001.0001 at 0020 [30]; Exhibit 3-68, Sydney Hearing, Statement of Associate Professor Stephen Robert MacFarlane, 24 April 2019, WIT.0116.0001.0001 at 0026-0027 [137]; Transcript, Professor Joseph Ibrahim, Sydney Hearing, 16 May 2019 at T1799.25-38.

A further example of weak regulation can be found in medicines regulation. Dr Breen explained that in her view, clinical guidelines are not used by many prescribers in aged care to base decisions about which medications to prescribe, doses and duration of use.⁸⁷ Her research referred to one in five doctors being able to identify a guideline or information source they referred to when prescribing.⁸⁸ In her view, the current regulation of the requirements under the Pharmaceutical Benefits Scheme ‘offers no disincentive to inappropriate psychotropic use’.⁸⁹

Preliminary observations and future focus

We acknowledge that the drivers behind the use of restrictive practices are complex. This is an issue that we will consider in the context of systematic reform, so that the recommendations we make in the Final Report can be the most effective in reducing and eliminating reliance on restrictive practices. However, we wish to make several preliminary observations and identify areas for reform.

Training and education

Training in understanding dementia, the safe and appropriate management of behavioural and psychological symptoms, and restraints and their impacts, is insufficient for both aged care staff and general practitioners. There is a critical lack of knowledge throughout the health and aged care sectors which can have serious, even catastrophic, consequences for people in aged care facilities. As ‘Elizabeth’ said:

the big problem with people with dementia is that...they can no longer communicate with you...so you then have to be their eyes and ears....You can precipitate all sorts of difficult behaviours because somebody is not being cared for physically. If somebody can't tell you, for example, that they've got a pain in their tooth, if they can't tell you that they're constipated, all of these things, or they're being forced to sit in the chair and they're not being moved, then they just get agitated. What you need is good, basic nursing care and then layered over the top of that you need the good emotional care on top of it.⁹⁰

If personal care workers and nurses are to be able to effectively respond to the complex behavioural and psychological symptoms of dementia, they must be trained and supported to do so as part of both core competencies and ongoing training. Allied health professionals engaged in assessment, care planning and treatment of people in residential aged care also require appropriate training. Similarly, general practitioners

87 Exhibit 3-61, Sydney Hearing, Statement of Dr Juanita Westbury (now Breen), 29 April 2019, WIT.0117.0001.0001 at 0005 [10].

88 Exhibit 3-61, Sydney Hearing, Statement of Dr Juanita Westbury (now Breen), 29 April 2019, WIT.0117.0001.0001 at 0015 [23].

89 Exhibit 3-61, Sydney Hearing, Statement of Dr Juanita Westbury (now Breen), 29 April 2019, WIT.0117.0001.0001 at 0020 [28].

90 Transcript, ‘Elizabeth’, Sydney Hearing, 15 May 2019 at T1701.2-14.

are being asked to exercise clinical judgement outside the scope of their education and training. They, too, must be trained and supported in the safe and appropriate management of changed behaviours in residential aged care.

Regular and targeted review of people taking psychotropic medication

Too many people in aged care are being prescribed psychotropic medications and remaining on them for extended periods of time, contrary to clinical guidelines and criteria. Regular and targeted reviews of residents taking psychotropic medications (and other medications) is an evidence-based way of reducing psychotropic use, preventing medical complications that can arise from polypharmacy (that is, the use of multiple medications at the same time) and promoting the quality use of medicines.⁹¹

Australia has had a national, Government-funded collaborative medication review service in residential aged care facilities since 1997, the Residential Medication Management Review program (often known as an 'RMMR'). The program enables people living in residential aged care, referred by their general practitioner, to receive a review from an accredited consultant pharmacist. All things being equal, the Residential Medication Management Review should provide an effective mechanism for safer medication review. However, the Royal Commission considers that current remuneration arrangements applying to the conduct of these reviews could restrict people's access to them.

Since 1990, a series of Community Pharmacy Agreements between the Australian Government and the Pharmacy Guild of Australia have determined a range of payments for dispensing medicines listed on the Pharmaceutical Benefits Scheme and professional pharmacy programs and services, including Residential Medication Management Review. Under current arrangements, a benefit is payable under the Medicare Benefits Schedule for a general practitioner participating in a Residential Medication Management Review for an aged care resident once in any 12-month period, or where there has been 'a significant change to the resident's condition or medication regimen'.⁹² However, an accredited pharmacist is only funded under the Community Pharmacy Agreement to perform a review every two years, or where there has been a significant change as per the criteria above.⁹³

At the Darwin Hearing, Dr Sluggett said that there is an urgent need for a mechanism for residents to receive a medicines review and other clinical input from a pharmacist more frequently than every two years. While a review is available where there has been a significant change to the resident's condition or medication regimen, Dr Sluggett noted

91 Exhibit 6-32, Darwin and Cairns Hearing, Statement of Dr Janet Kathleen Sluggett, 27 June 2019, WIT.0251.0001.0001 at 0021 [39].

92 Australian Department of Health, *Medicare Benefits Schedule - Item 903*, <http://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&q=ItemID&q=903>, viewed 29 August 2019.

93 Pharmacy Programs Administrator, *Program Rules – Residential Medication Management Review and Quality Use of Medicines*, 2019, <https://www.ppaonline.com.au/wp-content/uploads/2019/01/RMMR-and-QUM-Program-Rules.pdf>, viewed 29 August 2019.

that a previous evaluation of the program showed that one third of directors of nursing surveyed were able to identify residents who did not receive a review, despite having an unmet clinical need.⁹⁴

In 2017, the *Review of National Aged Care Quality Regulatory Processes* by Ms Kate Carnell AO and Professor Ron Paterson ONZM recommended that a Residential Medication Management Review must be conducted on admission for residents to an aged care service, after any hospitalisation, upon deterioration of behaviour or upon any change in medication regimen.⁹⁵

Further, Dr Breen's evidence during the Sydney Hearing was that service provision for Residential Medication Management Review has 'eroded markedly over the past years'. She explained that there are a 'wide range of interpretations about what adequately constitutes a review'.⁹⁶ There also appears to be a critical gap in eligibility requirements for Residential Medication Management Review. The current Patient Eligibility Criteria appears to exclude people in residential respite care, even though the number of such people is increasing, and despite the need for a strong focus on medication management as people move between the community and aged care services.

Finally, Dr Sluggett identified the need for a government-subsidised process to support pharmacists to be involved in case conferencing, monitoring the resident's response to recommendations made during the medicines review process and the implementation of the medicines management plan for each affected resident.⁹⁷

The current (sixth) Community Pharmacy Agreement expires on 30 June 2020. As part of the consideration of the seventh Community Pharmacy Agreement, we suggest that the Australian Government, the Pharmacy Guild of Australia, and the Pharmaceutical Society of Australia (who will for the first time be a co-signatory to the Agreement) should review the effectiveness of the Residential Medication Management Review program and:

- a. lift the cap on funding to enable reviews to be conducted once every year, including when a person enters a residential aged care facility, or otherwise where there is a significant change to the resident's condition or medication regimen
- b. amend the Residential Medication Management Review Patient Eligibility Criteria to incorporate people in residential respite care and transitional care

94 Exhibit 6-32, Darwin and Cairns Hearing, Statement of Dr Janet Kathleen Sluggett, 27 June 2019, WIT.0251.0001.0001 at 0022 [40].

95 K Carnell and R Paterson, *Review of national aged care quality regulatory processes*, 2017, pp xiii.

96 Exhibit 3-61, Sydney Hearing, Statement of Dr Juanita Westbury (now Breen), 29 April 2019, WIT.0117.0001.0001 at 0005 [10].

97 Exhibit 6-32, Darwin and Cairns Hearing, Statement of Dr Janet Kathleen Sluggett, 27 June 2019, WIT.0251.0001.0001 at 0022 [41].

- c. consider mechanisms to enhance the quality and consistency of reviews, including auditing of service provision
- d. consider mechanisms, including additional government-subsidised processes, to support pharmacists to be involved in the implementation and monitoring of recommendations made during the review process.

Requirements under the Pharmaceutical Benefits Scheme

We are very concerned about the significant prescription of psychotropic medication outside clinical guidelines and authority requirements under the Pharmaceutical Benefits Scheme.

The Australian Government is responsible for administering the Pharmaceutical Benefits Scheme (PBS), under the *National Health Act 1953* (Cth). Restrictions may be placed on medicines as part of the process of listing them on the PBS. This means that they can only be subsidised under the scheme for use in a specific group of patients or for a specific purpose. These restrictions are referred to as ‘authority requirements’. Restrictions are imposed on particular psychotropic medicines. Risperidone is the only antipsychotic indicated for the treatment of behavioural disturbances in patients with Alzheimer’s type dementia. The authority requirements for the use of risperidone include that the patient must have failed to respond to non-pharmacological methods of treatment, and that the treatment must be limited to a maximum duration of 12 weeks.

However, there is very limited monitoring of authority requirements under the Pharmaceutical Benefits Scheme. Professor Murphy explained that the Australian Department of Health monitors compliance with the Pharmaceutical Benefits Scheme, including authority requirements, for the purposes of ‘protecting the integrity of Australia’s health payment system’.⁹⁸ It does not seek to provide comprehensive regulation of medical practitioners’ prescribing practices by monitoring compliance with authority requirements.⁹⁹ Professor Murphy acknowledged that prescribers are not audited with regard to whether they hold evidence of compliance with prescribing under the Scheme.¹⁰⁰ He also acknowledged that there is currently no mechanism under the Pharmaceutical Benefits Scheme to stop a prescription from being written or dispensed for long durations inconsistent with guidelines and the Scheme’s requirements.¹⁰¹

98 Exhibit 3-55, Sydney Hearing, Statement of Professor Brendan Francis Murphy, 24 April 2019, WIT.0129.0001.0001 at 0014 [46].

99 Exhibit 3-55, Sydney Hearing, Statement of Professor Brendan Francis Murphy, 24 April 2019, WIT.0129.0001.0001 at 0014 [46].

100 Transcript, Professor Brendan Murphy, Sydney Hearing, 14 May 2019 at T1665.25-30.

101 Transcript, Professor Brendan Murphy, Sydney Hearing, 14 May 2019 at T1665.25-30.

While the Royal Commission understands that better monitoring and enforcement of authority requirements under the Pharmaceutical Benefits Scheme may not prevent *all* prescribing outside rules,¹⁰² we agree with Dr Breen that the current approach does not offer a disincentive to inappropriate prescribing. Greater safeguards against the inappropriate prescription of antipsychotic medications may be needed. Given what we have learned about the frequent prescription of these types of medications by general practitioners, it may be appropriate to limit their initiation in residential aged care facilities to registered psychiatrists who are likely to have greater knowledge about the diagnosis and treatment of psychiatric and psychological disorders. We will consider this area further in the context of our other recommendations.

Publication of data on physical restraint and psychotropic medication rates in facilities

The collection and publication of data on the use of physical restraint and psychotropic medication rates in residential aged care facilities has the potential to reduce use through greater transparency and increased accountability. At the Sydney Hearing, Mr Glenn Rees, Chair of Alzheimer's Disease International, said that he believed that such a system would 'sharpen the mind' of providers in terms of how people think about their facility and help consumers make decisions.¹⁰³ Quality Indicators for psychotropic use and physical restraint are currently used in the United States and Canada to benchmark use.¹⁰⁴

The provision of information to the public of every aged care residence's use of restrictive practices would be a powerful way not only of informing the community but also of holding providers to account. We will be giving specific consideration to such measures as part of broader reforms to the aged care system.

Physical and social care environments

We heard strong evidence at the Sydney Hearing to the effect that poor design of physical and social care environments—for example, large, noisy facilities with poor visual layouts and an inappropriate mix of residents—contribute to behavioural and psychological symptoms of dementia and poor care management, including restraint.¹⁰⁵ The research evidence on this topic is also strong and indicates that the environments in which people

102 See, for example, exhibit 3-55, Sydney Hearing, Statement of Professor Brendan Francis Murphy, 24 April 2019, WIT.0129.0001.0001 at 0022 [71].

103 Transcript, Glenn Eric Rees, Sydney Hearing, 13 May 2019 at T1554.14-20.

104 See, for example, Centres for Medicare & Medicaid Services, *Design for Nursing Home Compare Five-Star Quality Rating System: Technical Users' Guide*, April 2019, p 11; Health Quality Ontario, *Results from Health Quality Ontario's Benchmark Setting for Long-Term Care Indicators*, February 2017, p 2.

105 See, for example, Transcript, Tamar Chayen Krebs, Sydney Hearing, 14 May 2019 at T1580-T1581; Exhibit 3-68, Sydney Hearing, Statement of Associate Professor Stephen Robert MacFarlane, 24 April 2019, WIT.0125.0001.0001 at 0016 [71].

with dementia receive care are integral to quality and safety.¹⁰⁶ Specific design elements in the physical environment have been shown to be beneficial to people with dementia.¹⁰⁷

Many of these design elements have been reflected in voluntary guidelines and audit tools for the design and construction of new and renovation of existing residential aged care facilities, such as those available in Victoria.¹⁰⁸ Given the weight of evidence, we will give further consideration to how implementation of dementia-friendly design principles can be increased, including potentially through mandatory requirements for new residential aged care facilities, or the refurbishment of existing facilities.

A consistent approach to restrictive practices across sectors

The Australian Law Reform Commission recommended a national approach to regulating restrictive practices, incorporating disability and aged care. While the disability sector has forged ahead with a national framework and strict rules around use of restrictive practices, the aged care sector has not kept pace.¹⁰⁹

The National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018, made under the *National Disability Insurance Scheme Act 2013* (Cth), set out specific rules for the use of certain restrictive practices by particular providers under the National Disability Insurance Scheme. These include the requirement to engage a ‘behaviour support practitioner’, whom the National Disability Insurance Scheme Quality and Safeguard Commissioner approves, the development and lodgement of a behaviour support plan, and monthly reporting and oversight by a Senior Practitioner in the Quality and Safeguard Commission.¹¹⁰

The new Principles for aged care falls well short of this approach.

While rules and regulation are only one mechanism among many to reduce restrictive practices, there appears to be no justification in this case for inconsistency in protection between sectors. The aged care system has fallen behind, to the significant detriment of people who are subjected to unjustified chemical and physical restraint. In the Final Report, we will address the regulatory framework as well as other measures designed to reform this neglected area of aged care.

106 S Reilly, C Miranda-Castillo, R Malouf, J Hoe, S Toot, D Challis, and M Orrell, ‘Case management approaches to home support for people with dementia’, *Cochrane Database of Systematic Reviews*, Vol 1, 2015.

107 G Marquardt, K Bueter and T Motzek, ‘Impact of the design of the built environment on people with dementia: an evidence based review’, *Health Environments Research and Design*, 2014, Vol 8, 127–157.

108 Government of Victoria, *Dementia-friendly environments*, <https://www2.health.vic.gov.au/ageing-and-aged-care/dementia-friendly-environments>, viewed 18 July 2019.

109 Australian Law Reform Commission, *Elder Abuse – A National Legal Response*, Report No 131, 2017, p 11, <https://www.alrc.gov.au/publication/elder-abuse-a-national-legal-response-alrc-report-131/>, viewed 27 September 2019.

110 NDIS Quality and Safeguards Commission, *Behaviour support*, <https://www.ndiscommission.gov.au/providers/provider-responsibilities/behaviour-support>, viewed 29 August 2019.

Conclusion

People do not surrender their rights to mobility, personal autonomy, legal capacity and dignity when they enter residential aged care. The prevalence of restrictive practices in residential aged care is unacceptable. The Royal Commission can only conclude, on the evidence before us, that the ongoing and common use of restrictive practices in aged care represents severely substandard and unsafe care.

Behind the use of these restrictive practices lies a history of neglect: neglect to engage adequately with older people to understand their needs and their concerns; neglect in being either time-constrained or unwilling to spend the time with older people to help them manage their changing behaviours so that the need for restraint is obviated; neglect in seeking permission for the use of restraints; and a surprisingly neglectful approach to the use and prolonged use of chemical restraint, which fails to use the opportunities provided by the Residential Medication Management Review Program.

Early action by the Government in the context of current negotiations on the seventh Community Pharmacy Agreement may partly correct the latter problem.

More generally, however, significant change in medical and operational practice in residential aged care is needed to address this unsafe and substandard care regime. The Royal Commission will make recommendations on restrictive practices in its Final Report.

9. Workforce Matters

I would like to pay tribute to the aged care workers who care for my mother and who do really actually care. They are in a difficult position trying to provide the best they can in less than ideal circumstances, and they are paid less than you might be paid to work in a fast food outlet...So the status, training...and recognition by the community. You know, if the pay of people doing the important and challenging work of caring for the most vulnerable people in society like my mother...is less than someone serving hamburgers...what does that say about our society?¹

Why the aged care workforce matters

One of the most important keys to good care for older Australians is the workforce that delivers it. Older people who receive personal services and care should be confident that those who care for them will do so competently and compassionately, in a way that enhances their cognitive and physical abilities, rather than reinforcing the loss of function and strength.

This chapter outlines some of the complex issues for the aged care workforce that have been raised in our inquiry to date. This chapter was finalised prior to our third Melbourne Hearing, which examined workforce issues in more detail, so does not include the outcomes in that hearing.

The capacity, aptitude and capability of the aged care workforce are extremely important given the complexity of the work involved and the responsibility borne by those involved in providing care and support for older people. As they age, people are likely to become increasingly frail and develop one or more chronic health conditions, such as cardiovascular disease, arthritis, brittle bones (known as osteopenia), macular degeneration, and hearing loss. There is a body of scientific opinion pointing to an increase in neurological conditions that affect thinking, behaviour, motor and sensory function, mobility, and balance, all of which can contribute substantially to the increased dependency experienced by many very old people.² Notably, the Australian Institute of Health and Welfare currently estimates that 365,000 people in Australia have a diagnosis of dementia and that this will increase to around 900,000 by 2050.³

1 Transcript, Lyndall Fowler, Darwin Hearing, 9 July 2019 at T2968.40-2969.5.

2 MJ Prince, F Wu, Y Guo, LM Gutierrez Robledo, M O'Donnell, R Sullivan and S Yusuf, 'The burden of disease in older people and implications for health policy and practice', *Lancet*, 2015, Vol 385, 9967, pp 549-562; M Cutler, S Chatterji, J Byles, T Seeman and E Verdes, 'Health, Functioning, and Disability in Older Adults-Present Status and Future Implications', *Lancet*, 2015, Vol 385, 9967, pp 563-575; S Banerjee, 'Multimorbidity—older adults need health care that can count past one', *Lancet*, 2015, Vol 385, 9968, pp 587-589.

3 Australian Institute of Health and Welfare, *Australia's welfare 2017*, 2017, p xiv.

Australia needs a sufficient and stable supply of well-trained and motivated doctors, nurses, allied health professionals and personal care workers to deliver quality care and provide stability and certainty for older people. People receiving aged care should be confident about the skills and abilities of the people who are caring for them and feel secure and safe regardless of where they receive that care.

An aged care workforce which is properly trained, appropriately paid and given the opportunity for professional development will not only provide good care to older people, but also make it easier for employers to attract and retain staff.

The Royal Commission has heard that the aged care sector is grappling with how to attract, train, retain, and sustain its workforce.

A 2011 report by the Productivity Commission predicted that the aged care workforce will need to have at least doubled by 2050 to meet the projected target of 980,000 workers, and that 3.5 million Australians will be accessing aged care services every year, largely through community-based services.⁴ A coordinated approach to workforce planning is required to create a much larger workforce with the skills to care for people with forms of dementia and significant levels of frailty or impairment in home or residential settings.

Workforce planning enables organisations and industries to identify the workforce capacity and capability needed to meet their current and future objectives and to identify, monitor and respond to workforce risks. These risks can relate to attraction and recruitment, skill gaps, health, safety and performance, training and education, workplace culture and management and leadership.

Workforce issues affect every aspect of our inquiry into Australia's aged care system. The Royal Commission hearings held to date have given extensive insight into the breadth of the workforce issues that will need to be addressed in our final recommendations. Without seeking to be exhaustive, our early impressions of critical workforce issues are outlined below. These matters will be the subject of further close consideration in our Final Report.

⁴ Productivity Commission, *Caring for Older Australians, Productivity Commission Inquiry Report No 53, Volume 2*, 2011, pp 353-355; Productivity Commission, *Caring for Older Australians, Productivity Commission Inquiry Report No 53, Volume 1*, 2011, p XXII.

Preliminary observations and lines of inquiry

All the Royal Commission hearings and community meetings have featured considerable commentary on workforce issues. We have heard about the challenges faced by aged care workers and their employers, and the impact of these challenges on people who receive their care. We also heard a range of perspectives from experts who participated in a roundtable discussion on the aged care workforce in May 2019.

The Royal Commission is giving close attention to the work and recommendations of the Aged Care Workforce Strategy Taskforce. In 2017, the Government set up an independent Taskforce led by Professor John Pollaers OAM, to develop a strategy for growing and sustaining the workforce providing aged care services and support for older people.⁵ The Taskforce membership was drawn from the public sector, the aged care sector, academia, the health sector, and advocacy groups.

The Taskforce delivered its report in June 2018. The report sets out 14 ‘strategic actions’ to be implemented by the Government and the aged care sector to achieve reform. These include: creating a social change campaign to promote the sector; defining new career pathways and a qualification and skills framework; establishing an industry approach to workforce planning; and revising the workplace relations framework.⁶ The Taskforce emphasised the lack of workforce planning capability as a risk to the sector.⁷

The problems identified by the Taskforce reflect those identified in previous reviews⁸ of the aged care system and are consistent with the themes that have emerged from evidence to the Royal Commission so far. Practical solutions are needed to address these longstanding problems. Aged care providers and the Government need to be not only willing to develop these solutions but able to work together to implement them.

The sector needs to promote itself as an employer of choice to meet its future workforce demand projections and compete with other human service industries for high quality people. An employer of choice is one that can attract people by offering superior work conditions, career paths, training and professional development, and rewarding and satisfying work. At present, aged care is a very long way from being able to do this.

5 Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia’s Aged Care Workforce Strategy*, 2018, pp 102–103.

6 Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia’s Aged Care Workforce Strategy*, 2018, pp 14–17.

7 Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia’s Aged Care Workforce Strategy*, 2018, p 48.

8 Australian Law Reform Commission, *Elder Abuse – A National Legal Response, Final Report*, 2017, pp 11, 127–142; Productivity Commission, *Caring for Older Australians, Productivity Commission Inquiry Report No 53, Volume 1*, 2011, pp LXXIV–LXXV; D Tune, *Legislated Review of Aged Care 2017*, 2017, p 17.

‘Interact with them as people’⁹

Mr Anthony O’Donnell has lived at Waminda Aged Care facility in Bentley, Western Australia, since July 2013. From when he first moved into the facility until October 2018, Mr O’Donnell said, he received a minimal amount of care and didn’t need help with showering or other basic activities. In November 2018, Mr O’Donnell’s legs failed and he has since needed quite intensive care, including two carers to help him move.

Mr O’Donnell now requires lifting in and out of bed, out of his wheelchair, and in and out of the bathroom. Mr O’Donnell’s usual routine begins at around 6:30am, when carers get him out of bed and into his wheelchair. He stays in his wheelchair until breakfast at around 8:00am. Someone then takes him to the bathroom at around 8:30am, first to the toilet and then to the shower. Someone then moves him onto the bed for a nurse to dress his hip, before he is moved back into his wheelchair. He remains in his wheelchair until someone moves him onto his bed after lunch at 12:30pm.

Throughout the rest of the day, Mr O’Donnell receives less care than in the mornings. He told us that he spends most of the day reading and going up and down the outdoor ramp in his wheelchair for exercise.

Mr O’Donnell described an occasion where another resident was ‘neglected’. This resident needed ‘just some company. Somebody to talk to her’. She looked for staff around the facility. Eventually, someone told her, ‘Well, it’s Sunday, there’s nobody here.’ The resident continued asking people to talk to her, until one of the personal care workers, while delivering medication, said, ‘I will make time to talk to you.’

Mr O’Donnell has found that his care is based around tasks. He thinks that ‘actual care, as in the connecting with residents in order to see to their needs and to interact with them as people’ relies on each resident summoning a personal care worker with the call button. Mr O’Donnell considers that neither resident nor worker finds these interactions fulfilling, as the carer usually has to attend to the next urgent task or call as soon as they have satisfied a resident’s immediate needs. He said that residents need carers to understand what they want as an individual, and that this is not occurring.

Mr O’Donnell also reflected on the lack of nutritious food offered at the facility. He described having to ‘fight and fight and fight to get the idea of having fresh food, fresh fruit, less sugary things and creamy things on the menus, but most particularly to get nutritious food’.

Mr O’Donnell suggested that establishing and policing staff ratios would help in these circumstances. He told the Royal Commission that more people are needed who are trained to interact with people, including those with dementia.

9 Based on the evidence of Anthony O’Donnell: Exhibit 5-1, Perth Hearing, Statement of Anthony Patrick O’Donnell, 30 May 2019, WIT.1125.0001.0001; Transcript, Anthony O’Donnell, Perth Hearing, 25 June 2019 at T2472.5–2484.15.

Attracting and retaining the aged care workforce

Evidence from witnesses and from research indicates that the aged care sector has difficulty attracting sufficient numbers of people with the right skills.¹⁰ At the Mildura Hearing, Mr Darren Midgley, the Chief Executive Officer at Chaffey Aged Care, spoke of skills shortages in regional areas that are compounded by difficulties attracting allied health practitioners such as physiotherapists and occupational therapists.¹¹

This evidence is consistent with the findings of the 2016 Workforce Census and Survey, which indicated that skill shortages and difficulties filling positions is common, particularly in regional and remote areas. Aged care services have particular difficulties attracting registered nurses. Almost two thirds of residential facilities and one half of home care services reported skill shortages. The main reasons for skill shortages are a lack of suitable applicants and slow recruitment processes.¹² One quarter of residential facilities reporting having nurse or personal care worker vacancies, with timeframes of over four weeks to fill vacancies relatively common.¹³

There is varying evidence about turnover rates in the aged care sector. Some witnesses pointed to significant difficulties with retaining staff and the importance of attraction and retention.¹⁴

The Aged Care Workforce Census and Survey, conducted by the Australian Department of Health in 2016, showed that '[a] tenth of the residential workforce was currently seeking alternative work. Most residential workers (82%) expected to still be with their current employer after 12 months. Only 4 per cent of employees reported intentions to leave the aged care sector altogether'.¹⁵

10 Exhibit 4-4, Broome Hearing, Statement of Craig Robin Barke, 31 May 2019, WIT.0227.0001.0001 at 0005 [26] [30]; Exhibit 6-5, Darwin Hearing, Statement of Ms Donna Ah Chee concurred by Dr Boffa, 04 July 2019, WIT.0265.0001.0001 0012 [45]; Transcript, Darren Midgley, 31 July 2019, at T4097.5-10; Exhibit 1-3, Adelaide Hearing 1, Statement of Ian Yates, 31 January 2019, WIT.0006.0001.0001 at 0014 [56] [57]; Exhibit 4-13, Broome Hearing, Statement of Kate Suzanne Fox, 16 June 2019, WIT.1145.0001.0001 at 0007 [45].

11 Transcript, Darren Midgley, Mildura Hearing, 31 July 2019 at T4097.5-10.

12 Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia's Aged Care Workforce Strategy*, 2018, pp 48, 57, 107, 122.

13 National Institute of Labour Studies, *2016 National aged care workforce census and survey—the aged care workforce*, 2017, p 57. This survey was sent out to all aged care providers. While a convenience sampling method was used for the survey, the survey data was weighted to the relevant population (PAYG employees providing direct care services). Providers selected the staff to whom they would distribute it.

14 Exhibit 4-4, Broome Hearing, Statement of Craig Robin Barke, 31 May 2019, WIT.0227.0001.0001 at 0007 [26] [30]; Transcript, Dr John Boffa, 08 July 2019, Darwin Hearing, T2883.5-10; Transcript, Darren Midgley, 31 July 2019 at T4097.5-10; Exhibit 1-3, Adelaide Hearing 1, Statement of Ian Yates, 31 January 2019, WIT.0006.0001.0001 at 0014 [56] [57].

15 Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia's Aged Care Workforce Strategy*, 2018, p 11.

The Report of the Aged Care Workforce Strategy Taskforce identifies high employee turnover as a challenge for the industry.¹⁶ The Taskforce Report noted that:

In a highly competitive environment where there is increasing demand for workers with similar skills, action is needed at industry, organisational and local levels to address the factors influencing attraction and retention of the workforce.¹⁷

The Royal Commission will investigate the factors that impact on the recruitment, retention and turnover of staff in more detail in the next phase of its work.

Educating and training the aged care workforce

Much of the evidence to the Royal Commission indicates that, despite their best efforts, aged care workers and professionals too often have limited training and insufficient knowledge to do their jobs as well as they potentially might do. Workers are not trained in how to care for older people with the complex conditions that abound in aged care, such as the myriad forms of dementia or conditions which affect their physical and cognitive functioning. There is also a shortage of staff who are qualified and experienced in providing good palliative care.¹⁸

Some witnesses at hearings spoke of the need to improve professional and vocational training and education in order to equip workers with the knowledge and skills to provide good aged care. At the first Adelaide Hearing, Mr Sean Rooney, the Chief Executive Officer of Leading Aged Services Australia, stated that an aged care training framework should:

include nationally consistent training in partnership with the sector and an aged care capability framework to underpin role design and skills acquisition in the aged care sector (covering nursing, allied health, management, care and other support staff). Subsidies for traineeships for aged care workers should be developed across a number of key aged care sector roles and skills (e.g. dementia care). The capability framework should be suitably linked to the [Aged Care] Quality Standards Framework. Any solution should engage outside of the aged care sector, including working with universities, to re-focus current nursing education to provide specific aged care nursing streams which include a focus on ageing well.¹⁹

Ms Melissa Coad, a representative from United Voice, the union which represents many personal carer workers in the sector, told us that there should be a mandatory minimum qualification to work in aged care that is transferable and recognised across the sector. Ms Coad also called for continuous professional development in areas such as dementia,

16 Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia's Aged Care Workforce Strategy*, 2018, p 5.

17 Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia's Aged Care Workforce Strategy*, 2018, p 54.

18 Exhibit 5-33, Perth, Statement of Joshua Cohen, 29 May 2019, WIT.0179.0001.0001 at 0017 [96]; Exhibit 5-39, Perth Hearing, Statement of Dr Elizabeth Reymond, 30 May 2019, WIT.0187.0001.0001 at 0016 [72].

19 Exhibit 1-46, Adelaide Hearing 1, Statement of Sean Thomas Rooney, 31 January 2019, WIT.0013.0001.0001 at 0015 [128]; Transcript, Dr Jane Fischer, Perth Hearing, 27 June 2019 at T2717.20-2768.40.

palliative care and mental health to allow workers to deliver better care and to provide them with career pathways.²⁰

At the second Adelaide Hearing, a panel of four personal care workers from home care services spoke about the impact that a lack of mandatory minimum qualifications and inadequate on the job training had on their effectiveness.²¹ Ms Rosemary Dale, a personal care worker, expressed concern that there are not enough workers who hold a Certificate III qualification relevant to aged care, and that this places additional pressure on those who are qualified.²²

Ms Heather Jackson described how the quality of on-the-job training for personal care workers has eroded during her 24 years of working in the aged care sector. Her training has moved from face-to-face sessions involving practical scenario-based lessons to an online-based training system which she described as being more of a ‘tick and a flick’ approach.²³ This worrying insight was reprised at many community forums. Ms Jackson also called for more employer supported Certificate III training, saying:

Funding for further education in this sector is terrible. On our pay, people can’t afford to pay for any additional qualification out of their own pay. There should be more employer supported on-the-job training, a 12 month apprenticeship for example...I understand this is more costly for the providers but I truly believe that if there was more training offered like that then people would be more likely to stay longer working in the industry.²⁴

At the Sydney Hearing, the Royal Commission heard evidence that the quality and safety of care for people with dementia in aged care, and particularly in residential aged care, frequently falls well short of the standard that the community has the right to expect.²⁵ Inadequate knowledge is exacerbated by poor workplace design and working conditions which limit the time available for providing care.²⁶ As a result, physical or chemical restraints are used far too often to manage dementia symptoms, causing great distress to older people and their relatives.

20 Exhibit 1-52, Adelaide Hearing 1, Statement of Melissa Coad, 06 February 2019, WIT.0018.0001.0009 at 0009 [54] – [55].

21 Transcript, Sally Warren, Rosemary Dale, Heather Jackson, Anna Hansen, 19 March 2019 at T804.25–T832.30.

22 Exhibit 2-29, Adelaide Hearing 2, Statement of Rosemary Dale, 06 March 2019, WIT.0079.0001.0001 at 0003 [22].

23 Transcript, Heather Jackson, 19 March 2019 at T813.25–30.

24 Exhibit 2-27, Adelaide Hearing 2, Statement of Heather Jackson, 07 March 2019, WIT.0080.0001.0001 at 0005 [36].

25 Exhibit 3-8, Sydney Hearing, Statement of Lillian Reeves, 26 April 2019, WIT.0141.0001.0001 at 0002-0003 [23] – [24]; Exhibit 3-9, Hearing, Statement of Michelle Lauren McCulla, 23 April 2019, WIT.0097.0001.0001; Exhibit 3-6, Sydney Hearing, Statement of Eresha Dilum Dassanayake, 01 May 2019, WIT.0109.0001.0001; Exhibit 3-20, Sydney Hearing, Statement of DM, 17 April 2019, WIT.0099.0001.0001.

26 Exhibit 3-57, Sydney Hearing, Statement of Elizabeth [full name known to the Royal Commission], 14 May 2019, WIT.0152.0001.0001 at 0006 [23] – [26]; Exhibit 3-28, Sydney Hearing, Statement of Kathryn Nobes, 29 Apr 2019, WIT.0143.0001.0001 at 0001-0002 [9]; Exhibit 3-68, Sydney Hearing, Statement of Associate Professor Stephen Robert Macfarlane, 24 April 2019, WIT.0125.0001.0001 at 0016, 0017, 0018-0019 [72] [77] [85] – [89]; Exhibit 3-49, Sydney Hearing, Statement of Professor Elizabeth Ruby Anne Beattie, 30 April 2019, WIT.0119.0001.0001 at 0017-0019 [59] – [65].

A number of witnesses said that limited training in dementia, particularly about how to manage its behavioural and psychological symptoms, contributes to substandard care.²⁷

Ms Jennifer Lawrence of Brightwater Care Group said that while specialised training is important, so too is selecting people of good character with personal attributes such as patience, empathy and creative problem solving:

Having the right staff in residential aged care is critical to quality and safety. A recruitment process that identifies staff that are well suited to the industry and are skilled, or have the ability to be trained, is essential. Investment in training, values and culture to ensure a consistent approach is critical...well-trained and compassionate staff that are suited to work in an environment that supports clients with dementia is important. Staff trained in manual handling, maintaining dignity, identifying triggers and symptoms for behaviours and de-escalation techniques are particularly important...the key to supporting all clients from all backgrounds is to have continuity of staffing.²⁸

Ms Merle Mitchell AM, who lives in a residential care home, expressed similar views:

What sets good staff members apart is compassion. Compassion needs to be included as a criteria in the selection of staff. A number of staff at the facility lack this and don't seem to want to be working in aged care...Training for staff needs to include communication, compassion, grief and loss, respect and dignity alongside the day to day care requirements of supporting and caring for older people.²⁹

Several witnesses at the Sydney Hearing expressed support for an increased level of mandatory and continuing training in dementia, which is an essential skill and a core knowledge requirement for aged care workers.³⁰ Personal care worker Ms Kathryn Nobes said that:

In my opinion, staff working with dementia residents need more training. It is very helpful to understand that this is a disease of the brain, that there can be over 100 diseases that may cause neurological dysfunction. This will lead to a more tolerant attitude, to know that this is not a choice but a behaviour caused by this disease. I think we also need more training on how to de-escalate a potentially dangerous situation—sometimes it can be as simple as diverting someone with a cup of tea. This may also include training on how stay safe and not be hurt physically, for example how to get out of holds without hurting the resident.³¹

27 Exhibit 3-52, Sydney Hearing, Statement of Associate Professor Lynette Goldberg, 04 May 2019, WIT.0120.0001.0001 at 0009 [38]; Exhibit 3-49, Sydney Hearing, Statement of Professor Elizabeth Ruby Anne Beattie, 30 April 2019, WIT.0119.0001.0001 at 0017-0019 [59] – [65]; Exhibit 3-48, Sydney Hearing, Statement of Professor Constance Dimity Pond, 06 May 2019, WIT.0118.0001.0001 at 0005 [14] – [15].

28 Exhibit 3-46, Sydney Hearing, Statement of Jennifer Lawrence, 01 May 2019, WIT.0123.0001 .0001 at 0002-0003 [2].

29 Exhibit 3-1, Sydney Hearing, Statement of Merle Valma Mitchell AM, 27 April 2019, WIT.0107.0001.0001 at 0005 [54] – [57].

30 Exhibit 3-49, Sydney Hearing, Statement of Professor Elizabeth Ruby Anne Beattie, 30 April 2019, WIT.0119.0001.0001 at 0018-0019 [59] – [65]; Exhibit 3-48, Sydney Hearing, Statement of Professor Constance Dimity Pond, 06 May 2019, WIT.0118.0001.0001 at 0005 [14] – [15]; Exhibit 3-59, Sydney Hearing, Statement of Susan Marie Walton, 11 May 2019, WIT.0153.0001.0001 at 0010-0011 [40] – [44]; Exhibit 3-57, Sydney Hearing, Statement of Elizabeth [full name known to the Royal Commission], 14 May 2019, WIT.0152.0001.0001 at 0006 [23] – [26].

31 Exhibit 3-28, Sydney Hearing, Statement of Kathryn Jill Nobes, 29 April 2019, WIT.0143.0001.0001 at 0008 [49].

Professor Henry Brodaty AO from the University of NSW raised concerns that hospital-based nursing staff are not skilled in communicating with people with dementia, which exacerbates the stress and behaviour management challenges that can be associated with the condition.³² He also said:

In my view, current education is clearly not sufficient for staff caring for people living with dementia. Improvement can be by requiring basic qualifications depending on level of work and by on-the-job training. We found mini-tutorials that are case based at handovers work well and do not disrupt work flow. These could be led by a nurse champion who has had extra training...Changes should definitely be made to the curricula for doctors, nurses and personal carers to improve the care provided to people living with dementia in residential aged care. It's often a competition for space in curricula.³³

At the Cairns Hearing, medical experts and health professionals also described inadequate training in a number of areas relevant to aged care. One witness, Ms Sandy Green, a nurse practitioner (an advanced registered nurse who is trained to assess patients' needs, order and interpret some diagnostic tests, diagnose medical conditions, and in some circumstances prescribe medication), said that undergraduate nursing courses do not equip graduates with the skills to work in aged care:

I believe that basic nursing assessment skills are lacking in both nurses and care workers in aged care. Having registered nurses come out of university without the experience, knowledge and skill set for aged care is prevalent across all of the aged care facilities to whom I provide services.³⁴

Other witnesses at our hearings described specific skill and knowledge gaps in several aspects of clinical and functional health, including wound care,³⁵ continence³⁶ and nutrition.³⁷ Dr Joan Ostaszkiwicz, a Research Fellow at Deakin University in the Centre for Quality and Patient Safety Research, explained that undergraduate nurses were not adequately educated about continence nor adequately skilled to care for people with incontinence.³⁸

32 Transcript, Professor Henry Brodaty, 17 May 2019 at T1911.25–30.

33 Exhibit 3-80, Sydney Hearing, Statement of Professor Henry Brodaty, 16 May 2019, WIT.0116.0001.0001 at 0013 [66] – [67].

34 Exhibit 6-55, Darwin and Cairns Hearing, Statement of Sandy Marie Green, 25 June 2019, WIT.0191.0001.0001 at 0007 [43].

35 Transcript, Associate Professor Sussman and Hayley Ryan, Darwin Hearing, 11 July 2019 at T3339.15–40.

36 Exhibit 6-24, Darwin and Cairns Hearing, Statement of Professor Michael John Murray as amended, 01 July 2019, WIT.0273.0001.0001 at 0007 [9].

37 Exhibit 6-48, Darwin and Cairns Hearing, Statement of Robert Hunt and Sharon Lawrence on behalf of the Dietitians Association of Australia, 20 June 2019, WIT.0205.0001.0001 at 0016 [80].

38 Exhibit 6-25, Darwin and Cairns Hearing, Statement of Joan Ostaszkiwicz, 05 June 2019, WIT.0222.0001.0001 at 0007-0008 [31] – [34].

Dr Drew Dwyer, a consultant nursing gerontologist, characterised the current capability gap in the field of gerontology among registered nurses:

The education of gerontic nursing is well established in other OECD (Organisation for Economic Cooperation and Development) countries and yet not a focus of nursing specialty in Australia. Nursing the older client and particularly the geriatric client requires an expert in-depth knowledge of geriatric sciences, clinical leadership and decision making. RN's (Registered Nurses) are the perfect healthcare practitioner to be educated and specialised into the role.³⁹

At the Cairns Hearing, cook and media personality Ms Maggie Beer AM spoke about the Maggie Beer Foundation, set up to provide training and education to chefs and cooks who work in the aged care sector. She highlighted the importance of relevant training for people in aged care other than direct carers. She stated that relatively minor reforms, such as increased training in nutrition and special diets for chefs, would make a significant impact on the quality of food offered to aged care residents:

The roles of cooks and chefs in aged care is extremely demanding and highly responsible...in the busy world of aged care they often take on responsibility for menu design, staff, procurement, budget and for kitchen and dining room management. They are expected to have knowledge of the special needs of older people, their nutrition and special diets, the psychology of their social interaction...Yet many of the cooks and chefs currently in aged care have no formal training in cooking, let alone hospitality and are expected to learn on the job.⁴⁰

Training and education for the aged care workforce was also a key topic at the roundtable discussion on workforce. Participants raised concerns about whether the aged care sector and education and training sectors have worked together effectively to delineate a framework for education and training for aged care workers, including core curriculum and minimum standards. Participants also identified problems with the quality assurance of vocational training providers, suggesting that some deliver training packages as a mere commodity rather than a critical means of supporting labour force capability in the care of vulnerable older people.

Roundtable discussion participants suggested there was a need for the aged care sector to assume responsibility for the training and education of its own workforce. We understand that work is under way to repackage the current Certificate III in Individual Support into a Certificate III in Ageing Support.⁴¹ From the evidence to date at the Royal Commission, it is apparent that a qualification like this, which is designed for personal care workers, should equip them with the skills to care for older people at home and the increasingly frail people who enter residential care. It should also train them to manage the behavioural

39 Exhibit 6-57, Darwin and Cairns Hearing, Statement of Drew Darren Dwyer, 24 May 2019, WIT.0192.0001.0001 at 0005 [4-A-iii].

40 Exhibit 6-46, Darwin and Cairns Hearing, Statement of Maggie Beer, 21 June 2019, WIT.0202.0001.0005 at 0005 [23].

41 SkillsIQ is the Skills Service Organisation that supports the Aged Services Industry Committee's development of the Certificate III Ageing Support training package. For information about the status of this work, see the SkillsIQ site: <https://www.skillsiq.com.au/TrainingPackages/CHCCommunityServicesTrainingPackage>.

and psychological symptoms of dementia and other common aged related conditions such as cardiovascular disease, arthritis, frailty and osteopenia, macular degeneration, and hearing loss. Personal care workers also need training in how to assist older people to retain as much independence as possible.

However, if the aged care sector is to attract and retain high quality employees effectively, it must not only provide high quality training and development opportunities but also address the very low enablement level of its workers. 'Enablement' refers to workers' sense of empowerment to be able to do their jobs well.⁴²

According to research conducted for the Aged Care Workforce Strategy Taskforce in 2018, only 53 per cent of aged care worker participants reported favourable enablement levels, well below industry benchmarks.⁴³ This is largely driven by dissatisfaction with learning and development opportunities.⁴⁴

Improving aged care workers' engagement requires an education and training framework that supports their career development and progression and which enables them to deliver professional care at all stages of their careers.

The Royal Commission's further inquiries will explore the reforms needed in the aged care, vocational education and training, and higher education sectors to provide aged care workers with the skills and knowledge to deliver person-centred and specialised care.⁴⁵ Reforms are needed in training and professional development frameworks for all aged care occupational groups, including in undergraduate and postgraduate courses for medical practitioners, nurses and allied health professionals to broaden their knowledge and capability to support those in aged care.

42 Enablement is defined as having the right people in the right roles in an enabling work environment. It is typically driven by factors relating to performance management; authority and empowerment; resources; training; collaboration; and work structures and process Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia's Aged Care Workforce Strategy*, 2018, p 56.

43 This was an Employee Engagement Survey conducted in 2018 by Korn Ferry Hay Group for the Aged Care Workforce Strategy Taskforce. The results were benchmarked against global and national benchmarks in health care, Australian businesses and high performing organisations. Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia's Aged Care Workforce Strategy*, 2018, pp 55–59.

44 Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia's Aged Care Workforce Strategy*, 2018, pp 55–59. In addition to these findings, only 51 per cent of aged care worker participants reported favourable levels of engagement, which was largely driven by dissatisfaction with immediate leadership and management.

45 While there are varied definitions, generally, person-centred care is a philosophy of care that respects, and responds to, the preferences, needs and values of people receiving care and those who care for them. The concept of person-centred care was explored during the Perth Hearing in June 2019.

Selecting the best workforce

The Royal Commission has heard evidence of misconduct by individual workers who have provided poor quality care, with serious consequences for the people in their care.⁴⁶ This evidence raises the question whether adequate safeguards exist to ensure that people working in aged care not only have the relevant knowledge and skills but are people of good character, integrity and compassion.

At the Adelaide Hearing, we heard that registered health care professionals must meet a range of registration standards to practise, including a requirement for minimum accredited education and training prerequisites and continuing professional development. In contrast, there are no minimum qualifications to work as a personal care worker, with no mandatory pre-employment screening other than a police check.⁴⁷ Ms Coad from United Voice expressed support for a registration scheme that features enhanced pre-employment screening, mandated minimum entry qualifications, and ongoing education and training. However, she suggested that any minimum qualification-based accreditation scheme for personal care workers should be free or subsidised, given the low pay rates in the sector.⁴⁸

In evidence provided about the mistreatment of her husband Mr Bob Spriggs at the Oakden Older Persons Mental Health facility, Mrs Barbara Spriggs called for improved safeguards for people receiving care services:

Processes need to be put into place to screen out those unsuitable for the work. Aged care workers need to be registered and highly trained, with a clear set of qualifications required for registration...if an aged care worker does something wrong, this should be documented in a national database. Future employers should be able to see that there is a mark against their name in the system.⁴⁹

Similarly, in evidence presented at the Darwin Hearing about the care of her mother, Ms Lisa Backhouse called for improved worker regulation:

The workforce must be professionalised to improve standards and quality of care, and yes, that means regulation and appropriate funding and remuneration. It means developing proper career pathways to attract and retain the best employees. It is expensive and going to become more so as the baby boomers enter the system, but change must come and it must come quickly.⁵⁰

46 For example: Exhibit 6-20, Darwin and Cairns Hearing, Statement of Lisa Maree Backhouse, 03 July 2019 WIT.0221.0001.0009 at 0005 [27] – [28]; Exhibit 5-9, Perth Hearing, Statement of Noleen Joy Hausler, 29 May 2019 WIT.1124.0001.0001 at 0010-0012 [79] – [111].

47 Part 6 of the Accountability Principles 2014 made under section 96-1 of the *Aged Care Act 1997* (Cth).

48 Exhibit 1-52, Adelaide Hearing 1, Statement of Melissa Coad, 06 February 2019, WIT.0018.0001.0009 at 0009 [54] – [58].

49 Exhibit 1-1, Adelaide Hearing 1, Statement of Barbara Elizabeth Spriggs, 08 February 2019, WIT.0025.0001.0001 at 0004 [27] – [30].

50 Exhibit 6-20, Darwin and Cairns Hearing, Statement of Lisa Maree Backhouse, 03 July 2019, WIT.0221.0001.0009 at 0009 [50] – [51].

Options identified by the roundtable discussion participants for further consideration by the Royal Commission included strengthened pre-employment screening measures for improved safeguarding of care recipients, and a broader registration or employment standards scheme for currently unregistered employees. Participants identified the potential for a scheme that features accredited training requirements and career progression to lift the professional standards and status of all aged care workers. However, some participants expressed concern that the blunt implementation of a scheme with minimum mandatory qualifications could impact workforce supply in the short to medium term. Some also noted that any scheme would need to be suitable for workers entering the sector from overseas, including under any special immigration arrangements that aim to increase workforce supply for the aged care sector.

Building on the insights from the roundtable discussion and the evidence we have heard, the Royal Commission will explore developmental, preventative and corrective measures to ensure the quality and suitability of aged care workers who are not subject to the registration scheme in place for health professionals. This includes considering screening and registration measures used in other sectors, such as the disability sector. In making recommendations, we will take into account all the suggestions and proposals that have been put to us.

Remuneration and career pathways

The 2016 Aged Care Workforce Census and Survey indicated that an intrinsic interest in caring for older people is a common motivator for many people working in aged care. However, many workers still see the aged care sector as a career stepping stone or potential pathway to a nursing career in the acute health sector.⁵¹ Given the low pay and limited career opportunities available, it is not surprising that staff leave the sector because of dissatisfaction with remuneration, income insecurity, and excessive and stressful work demands.⁵²

Aged care workers are consistently less well remunerated than their counterparts in related sectors. Similarly, nurses employed in aged care have less attractive conditions and fewer career opportunities compared with those in other sectors. The 2017 review into the 2011 changes to the *Aged Care Act 1997* (Cth), conducted by Mr David Tune AO PSM, identified that nurses earn up to 10% less than their counterparts in the acute health sector.⁵³ Analysis conducted for the 2018 Aged Care Workforce Strategy Taskforce identified that nurses and personal care workers earn up to 15% less than their counterparts in all other sectors.⁵⁴ The Taskforce proposed that the sector develop a strategy to support the

51 Department of Health, *2016 National Aged Care Workforce Census and Survey - The Aged Care Workforce*, 2017, pp 136–139.

52 Department of Health, *2016 National Aged Care Workforce Census and Survey - The Aged Care Workforce*, 2017, pp 140–141.

53 D Tune, *Legislated Review of Aged Care 2017*, 2017, p 180. The 2017 Legislated Review of Aged Care estimated that level 1 Registered Nurses in aged care earn around \$160 a week less than their counterparts in acute health care. Year 5 Enrolled Nurses in aged care earn around \$103 less than their counterparts in acute health care.

54 Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia's Aged Care Workforce Strategy*, 2018, pp 91–92.

transition of personal care workers and nurses to pay rates that better reflect their value and contribution to delivering care outcomes.⁵⁵ In many ways, the wages and conditions in the aged care sector are a mirror which reflects the community's attitudes towards older people and ageing. The Royal Commission will consider these matters further in its Final Report.

Participants at the workforce roundtable discussion suggested there was a need for redefined job classifications, known as 'job families', and career pathways in aged care. Several participants also suggested that a greater definition of aged care career paths will support the delivery of more holistic models of care as well as attracting people to the sector. Existing structures and job roles within aged care organisations do not provide visible or sufficient career development or progression pathways. For nurses, there is an established career pathway through enrolled nursing to registered nursing, together with then moving to nurse practitioner and specialist roles. In contrast, career pathways for allied health workers and personal carers are limited or ill-defined. This issue was examined in depth by the 2018 Aged Care Workforce Strategy Taskforce, which identified a new aged care job family structure.⁵⁶ It also proposed that the sector standardise its job families, job design, job grades, job definitions, success profiles and career pathways. The Royal Commission is examining what the sector is doing to respond to the Taskforce's proposal on how to improve career options and paths for its workers.

Staffing levels and continuity

We have also received extensive evidence showing that aged care workers often experience excessive work demands and time pressure to deliver care.⁵⁷ The evidence suggests that the adequacy and consistency of staffing is an underlying cause of these pressures and a barrier to the capacity of workers to deliver person-centred care.⁵⁸

Witnesses have given evidence of the impact of inadequate staff on people in aged care. Basic standards are often not met.⁵⁹ For care workers, inadequate staffing levels mean that they are overworked, rushed and generally under pressure.

55 Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia's Aged Care Workforce Strategy*, 2018, p 95.

56 Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia's Aged Care Workforce Strategy*, 2018, pp 38–39.

57 Department of Health, *2016 National Aged Care Workforce Census and Survey - The Aged Care Workforce*, 2017, pp 152–153; Transcript, Sally Warren, Rosemary Dale, Heather Jackson, Anna Hansen, 19 March 2019, T817.5 – T824.40; Exhibit 3-28, Sydney Hearing, Statement of Kathryn Jill Nobes, 29 April 2019, WIT.0143.0001.0001 at 0004 [23] [50].

58 Exhibit 1-60, Adelaide Hearing 1, Statement of Gerard John Hayes, 01 February 2019, WIT.0019.0001.0001 at 0005 [23] – [29]; Exhibit 1-52, Adelaide Hearing 1, Statement of Melissa Coad, 06 February 2019, WIT.0018.0001.0001 at 0008 [50] – [52]; Exhibit 1-3, Adelaide Hearing 1, Statement of Ian Yates, 31 January 2019, WIT.0006.0001.0001 at 0008 [28].

59 Exhibit 6-20, Darwin Hearing, Statement of Lisa Maree Backhouse, 3 July 2019, WIT.0221.0001.0001 at 0003 [15]; Exhibit 6-52, Cairns Hearing, Statement of Lisa Jayne Jones, 2 July 2019, WIT.0275.0001 at 0002 [8]; Exhibit 5-33, Perth Hearing, Statement of Joshua Cohen, 29 May 2019, WIT.0179.0001.0001 at 0017 [96]; Transcript, Emma Murphy, Perth Hearing, 26 June 2019 at T2533.28-30.

This has serious implications for the health and safety of workers.⁶⁰

The question of how to ensure adequate staffing levels in residential care settings has emerged as a contested issue. During the second Adelaide Hearing, we received evidence from the Australian Nursing and Midwifery Federation that the Aged Care Act, the former Accreditation Standards and the current Aged Care Quality Standards are not explicit enough about what constitutes adequate staffing arrangements.⁶¹ This means that there is no guarantee that a nurse will be on duty at all times. A number of witnesses have argued forcefully for the introduction of mandated staffing levels and skill mix to guarantee a minimum level of care.⁶² Other witnesses have raised concerns about the possible risks of staff ratios, including that of themselves ratios do not guarantee quality, or suggested alternative means to ensure adequate staffing levels would be more effective.⁶³ Our Final Report will give close consideration to options to ensure staffing levels, and the mix of staffing, are sufficient to ensure quality and safe care.

Several witnesses have also talked about the importance of continuity of staffing to deliver quality care. According to Mr Chris Mamarelis, the Chief Executive Officer of the Whiddon Group:

Transient staff, casual workforce: that's a challenge because you are looking for consistency of staffing and when you're seeing staff turnover and high levels of casuals come in, that can be challenging...And if you're talking about consistency of staffing to enhance relationship-based care, we need to find other ways to deliver that as well.⁶⁴

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- 60 SafeWork Australia, 'Psychosocial Safety Climate and Better Productivity in Australian Workplaces: Costs, Productivity, Presenteeism, Absenteeism', 2016. Psychosocial Safety Climate (PSC) refers to an organisational climate for employee psychological health, wellbeing, and safety. It is determined by organisational policies, practices, and procedures for the protection of worker psychological health and safety. See MF Dollard & AB Bakker, 'Psychosocial Safety Climate as a precursor to conducive work environments, psychological health problems, and employee engagement', *Journal of Occupational and Organizational Psychology*, 2010, Vol 83, pp 579–599.
- 61 *Aged Care Act 1997* (Cth) Section 54(1)(b); Aged Care Quality and Safety Commission, Accreditation Standards (Standards 1.3 and 1.6) and Aged Care Quality Standards (Standard 7)
- 62 Exhibit 1-16, Adelaide Hearing 1, Statement of Annie Butler, 1 February 2019, WIT.0020.0001.0001 at 0004-0005 [29] – [32]; Exhibit 1-64, Adelaide Hearing 1, Royal Commission letter to Professor Pollaers inviting a response dated 14 February 2019, and ACW.9999.0002.0001, Response of Professor John Pollaers, 20 February 2019, ACW.9999.0001.0001 at 0018 [5]; Transcript, FA, 17 July 2019, T3780.35; Transcript, Noleen Hausler, 24 June 2019 at T2259.5; Transcript, Elizabeth [full name known to the Commission], 15 May 2019, T1718.45; Transcript, Susan Walton, 15 May 2019 at T1716.5.
- 63 Exhibit 5-40, Perth Hearing, Statement of Lisa Jane Trigg, 04 June 2019, WIT.0156.0001.0023 at 0022 [129] – [132]; Exhibit 6-5, Darwin and Cairns Hearing, Statement of Donna Ah Chee concurred in by Dr Boffa, 04 July 2019, WIT.0265.0001.0001 at 0010 [41a]; Transcript, Associate Professor Stephen MacFarlane, Sydney Hearing, 15 May 2019 at T1766.35–37.
- 64 Transcript, Chris Mamarelis, Perth Hearing, 25 June 2019 at T2433.5–10.

At the second Adelaide Hearing, Mr Josef Rack described the impact of a lack of continuity of staffing from his home care provider:

...I had countless different people appear at my door. I did not know who to expect... I was sent a new worker every two or three visits...The trouble with having different people come to my house is that I need to explain where everything is, like the power points and laundry items...and what goes where. After I have finished explaining, half the allocated time is gone.⁶⁵

At future hearings, we will consider the issues that are relevant to achieving continuity of care, including different care models, as well as the governance structures and practices and the culture of providers.

The Royal Commission has heard in evidence that staffing is a critical element in ensuring the quality and safety of those in care. Services must have the right number of staff with the right skill mix, with compassion and empathy combined with knowledge of aged care and the illnesses and conditions of those in care. These are critical factors in delivering high quality and safe care to some of the most vulnerable people in our community.

Conclusion

The quality of care that people receive from aged care services depends very much on the quality of the paid carers and their working conditions. Workforce issues are relevant to every aspect of our inquiry. It is clear that most people working in aged care are doing their best, and that many of them are doing so in difficult circumstances.

Throughout the remainder of the Royal Commission, we will continue to examine closely workforce issues, including the issues explored in this chapter: attraction and retention; education and training; choosing the right staff; remuneration and careers; continuity of care; and staffing levels and staff mix. These workforce issues, among others, will be critical to the recommendations in our Final Report for comprehensive reform of the aged care system.

⁶⁵ Exhibit 2-15, Adelaide Hearing 2, Statement of Josef Rack, 04 March 2019, WIT.0068.0001.0001 at 0002 [10].

10. Falling through the Gaps: Younger People in Residential Aged Care

The first night I was there, I went back to my room after having my tea and closed the door. I dropped my head in my hands and started crying...When you're locked in a facility and unable to get access to the community, your life stops. You gradually disappear from other people's lives and are forgotten about.¹

Introduction

One of the Royal Commission's terms of reference requires that we inquire into 'how best to deliver aged care services to...people with disabilities residing in aged care facilities, including younger people'.² Such an inquiry first begs a different question: should younger people be in residential aged care in the first place? Having regard to that and other evidence before the Royal Commission, the answer to this question must, in the vast majority of circumstances, be 'no'.

The Royal Commission has heard harrowing evidence about the plight of younger people in residential aged care. This chapter examines the issue of younger people living in residential aged care, their experiences, and the policy framework that enables it.

Who are the younger people in residential aged care?

Almost 6000 people under the age of 65 years live in residential aged care in Australia.³ That number has been relatively unchanged for more than a decade, despite previous efforts to reduce it. The Australian Government accepts that '[t]he situation of younger people in residential aged care is a grave and persistent problem'.⁴

In their evidence to the Royal Commission, Australian Government officials acknowledged that it is inappropriate for younger people to live in aged care settings.⁵ In written submissions to the Royal Commission, the Government acknowledged that '[s]uch living

1 Exhibit 9-18, Melbourne Hearing 1, Statement of James Nutt, WIT.1237.0001.0001 at 0002 [19] and 0003 [27].

2 *Letters Patent*, 6 December 2018, as amended on 13 September 2019, subparagraph (b)(i).

3 This figure does not include Aboriginal and Torres Strait Islander people under 65 years of age receiving National Aboriginal and Torres Strait Islander Flexible Aged Care Program services.

4 Submissions of the Commonwealth – Melbourne Hearing 1, 25 September 2019, RCD.0012.0031.0001 at 0002 [3].

5 For example: Transcript, Michael Lye, Melbourne Hearing 1, 10 September 2019 at T4938.32–34.

arrangements are singularly inappropriate for young people who wish to live on their own terms, in their own dwellings, and with independence in the community'.⁶

Despite this acknowledgement, over the 2017–18 financial year, a total of 2187 younger people entered residential aged care.⁷ That figure equates to 42 younger people, on average, entering residential aged care every week.

There is a lack of clarity about who the younger people in residential aged care are.⁸ There is uncertainty about their needs and their reasons for admission. In 2015, a Senate Committee recommended that the Australian Government compile a database of all young people under the age of 65 years living in residential aged care facilities.⁹ It was envisaged that this database would be provided in a regularly updated form to the National Disability Insurance Agency and to State and Territory Governments so they would understand the group and be better able to offer alternative care and accommodation, suited to their needs. The database was to include the following information for each younger person in residential aged care: name, age, age on entry, diagnosis, length of time spent in the aged care system, and the factors needing to be addressed for the person to move out of residential aged care. In its response to the Senate Committee's report, the Australian Government 'noted', but did not accept, this recommendation.¹⁰

The failure to develop a proper understanding of the circumstances and needs of younger people in residential aged care, together with the continued entry of younger people into residential aged care at undiminished rates, indicates a lack of sufficient interest by the Government in the plight of these people and a level of complacency about the capacity of existing policy settings to solve the problem.

We do know that the population of younger people in residential aged care is not uniform. The Royal Commission has heard evidence that there are four broad categories into which most younger people in residential aged care fall:

- people with a disability—according to data from the National Disability Insurance Agency, around 3700 people under the age of 65 in residential aged care are active scheme participants with an approved plan¹¹
- people who have palliative and end of life care needs

6 Submissions of the Commonwealth – Melbourne Hearing 1, 25 September 2019, RCD.0012.0031.0001 at 0002 [4].

7 Summer Foundation, *Younger People in Residential Aged Care: True Stories, Practical Solutions*, 2019, p 13.

8 See Submissions of the Commonwealth – Melbourne Hearing 1, 25 September 2019, RCD.0012.0031.0001 at 0003 [5].

9 Senate Community Affairs References Committee, *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*, June 2015, p xiii.

10 Transcript, Dr Nicholas Hartland, Melbourne Hearing 1, 9 September 2019 at T4880.10-4881.21; Exhibit 9-1, Melbourne Hearing 1, General Tender Bundle, Tab 115, Australian Government response to the Senate Community Affairs References Committee report, RCD.9999.0186.0001 at 0004–0005.

11 Exhibit 9-1, Melbourne Hearing 1, General Tender Bundle, Tab 146, National Disability Insurance Agency's Response to NTG-0354, CTH.0001.8000.0001 at 0016 [42].

- people with age-related conditions, such as early onset dementia
- people who are assessed as having an early need for aged care services, such as people who have experienced homelessness and Aboriginal and Torres Strait Islander people.¹²

There is little information about the precise nature and size of each of these groups. It is possible that many of these people are or will be eligible for support under the National Disability Insurance Scheme. It is nonetheless likely that there is a sizeable minority not eligible for that support. This ineligibility is concerning and suggests that solutions across multiple systems are required.

Of the sizeable minority of younger people in residential aged care who are ineligible to receive National Disability Insurance Scheme supports, many are likely to be in the category of people who have palliative and end of life care needs. This is of great concern to the Royal Commission. According to a recent report from the Australian Institute of Health and Welfare, over the five-year period from 2009–10 to 2013–14 cancer was the primary condition diagnosed (that is, the condition with the greatest clinical impact) in 12.5% of all admissions of younger people into residential aged care.¹³ In the report, the Australian Institute of Health and Welfare noted that the proportion of younger people who died within their first year in residential aged care was 26.5%.¹⁴ This suggests that aged care is being used as an end of life care option in many cases.

Such a situation was the subject of evidence by Mrs Jessica Dodds about her husband, Tony. She told the Royal Commission:

More often than not, by the time that the registered nurse came with the care worker to administer Tony's pain relief, she would comment 'sorry it took so long but I am the only registered nurse on for this floor of the facility tonight'. The aged care facility was a three storey facility and there would have been easily 50 or more residents residing on each floor. I was horrified to think that if there were other people needing nursing care, there weren't enough staff to assist with their care in a timely manner. Three nights before Tony died, I asked him if he was in pain as I usually did on arrival after work when checking if he was feeling comfortable. He asked me 'can you drive home, pick up the pain meds and drive back and give them to me because that would be quicker than asking the nurses here'. For me to drive home and back as he requested is a 40-minute round trip.¹⁵

12 *Aged Care Act 1997* (Cth); *Allocation Amendment (People with Special Needs) Principles 2012* (Cth).

13 Australian Institute of Health and Wellbeing, *Pathways of younger people entering permanent residential aged care*, 2019, p 9, <https://www.aihw.gov.au/getmedia/c43debe7-cc79-401e-b028-6d0859d9d802/aihw-age-89.pdf.aspx?inline=true>, viewed 30 August 2019.

14 Australian Institute of Health and Wellbeing, *Pathways of younger people entering permanent residential aged care*, 2019, p 15–17, <https://www.aihw.gov.au/getmedia/c43debe7-cc79-401e-b028-6d0859d9d802/aihw-age-89.pdf.aspx?inline=true>, viewed 30 August 2019.

15 Exhibit 9-5, Melbourne Hearing 1, Statement of Jessica Dodds, WIT.1239.0001.0001 at 0017 [109]–[110].

The Royal Commission has also received evidence about specialist services provided to younger people with an early need for aged care services, such as people who have experienced homelessness and Aboriginal and Torres Strait Islander people. An example is Wintringham Specialist Aged Care. Mr Brian Lipmann, Chief Executive Officer at Wintringham, gave evidence that the residents there, predominantly those with experience of homelessness and a number of whom are under 65 years of age, are:

such a different client group which, clearly, the Aged Care Act was never intended for.¹⁶

Why are younger people admitted to residential aged care?

The presence of younger people in residential aged care is a symptom of the failures of other systems, and too often residential aged care is offered as a default response.

The Summer Foundation's aim is 'to resolve the issue of young people living in nursing homes'.¹⁷ Its Chief Executive Officer, Luke Bo'sher, told the Royal Commission that one common precipitating factor which drives younger people into residential aged care, and prevents them from leaving, is a lack of alternative services.¹⁸ This includes:

- limited access to rehabilitation through the health system¹⁹
- insufficient accessible and affordable housing options²⁰
- a lack of palliative care options²¹

The late Mr Michael Burge's experience demonstrated the rehabilitation service gap. His wife, Ms Kate Roche, described how this left her with no choice but to place Mr Burge into residential aged care:

There should have been other options available to us so that he could have been properly cared for in a specialised rehabilitation facility, or at home with adequate supports...Instead, I was forced to place him in residential aged care.²²

16 Transcript, Brian Lipmann, Perth Hearing, 26 June 2019 at T2457.39–41.

17 See <https://www.summerfoundation.org.au/about-us/>.

18 Exhibit 9-20, Melbourne Hearing 1, Statement of Luke Bo'sher, WIT.0373.0001.0001 at 0007 [38].

19 Exhibit 9-19, Melbourne Hearing 1, Statement of Dr Bronwyn Morkham, WIT.0372.0001.0001 at 0030 [142]–[143].

20 Exhibit 9-19, Melbourne Hearing 1, Statement of Dr Bronwyn Morkham, WIT.0372.0001.0001 at 0059 [297]; Exhibit 9-21, Melbourne Hearing 1, Statement of Shane Jamieson, WIT.0371.0001.0001 at 0017 [91].

21 Exhibit 9-20, Melbourne Hearing 1, Statement of Luke Bo'sher, WIT.0373.0001.0001 at 0035 [186]; Exhibit 9-21, Melbourne Hearing 1, Statement of Shane Jamieson, WIT.0371.0001.0001 at 0017 [92].

22 Exhibit 9-4, Melbourne Hearing 1, Statement of Catherine Eileen Roche, WIT.1238.0001.0001 at 0011 [91]– [92].

Hospital discharge arrangements, and the pressure that State public hospitals are under to clear beds, also contribute to the referral of younger people from hospital into the aged care system.

Ms Lisa Corcoran illustrated what this meant for her:

I didn't get a choice about moving into residential aged care. I didn't get a choice about which aged care facility I would go to. I didn't even get to look at where I would be living before I went there. Nobody talked to my brother so that he could have an opportunity to look at other places. The staff just bundled up all my clothing and moved me—they didn't even tell me where I was going.²³

Under section 6(1) of the *Approval of Care Recipients Principles 2014* (Cth), a person is eligible to receive residential aged care only if they meet the following criteria:

- they are assessed as having a condition of 'frailty or disability' that requires continuing personal care
- they are incapable of living in the community without support
- for a person who is not an aged person, there must be no other care facilities or care services more appropriate to meet the person's needs.²⁴

It is the role of an Aged Care Assessment Team to assess whether or not a person meets these criteria and is therefore eligible to receive aged care services. Evidence before the Royal Commission suggests that there is little or no monitoring of compliance by Aged Care Assessment Teams with their obligations to assess, in particular, the last of the above criteria. The Australian Department of Health does not have an audit process for the teams' decisions, and there are no 'third party audits'.²⁵ Given the importance of the outcome of an Aged Care Assessment Team assessment, this is unacceptable.

Ms Kym Peake, the Secretary of Victoria's Department of Health and Human Services, acknowledged that aged care may well be the more likely destination when an Aged Care Assessment Team²⁶ assessment is being undertaken:

So obviously they do have requirements under the guidelines...that residential aged care should sort of be the last resort. They're not quite the words but all other alternative options should be examined. But I don't think they have the specialist expertise to understand what those range of options should be.²⁷

23 Exhibit 9-3, Melbourne Hearing 1, Statement of Lisa Corcoran, WIT.1240.0001.0001 at 0002 [18].

24 The term 'aged person' is not defined in the *Aged Care Act 1997* (Cth) or any of the Principles made pursuant to that Act.

25 Transcript, Dr Nicholas Hartland, Melbourne Hearing 1, 9 September 2019 at T4926.18–20.

26 Save for in Victoria, this terminology is used throughout Australia. In Victoria, the term 'Aged Care Assessment Service' (ACAS) is used.

27 Transcript, Kym Peake, Melbourne Hearing 1, 13 September at T5243.7–18.

A person may be admitted to residential aged care following approval from an Aged Care Assessment Team. Often, the Royal Commission heard, a sense of urgency prompts assessment for and placement into residential aged care. This urgency reflects a lack of suitable accommodation or care following a hospital stay or some other crisis, often exacerbated by a lack of thorough and early discharge planning. As Mr Shane Jamieson of Youngcare put it, ‘because there is a lack of options out there, that’s when people end up going into aged care.’²⁸

Mr Michael Lye, Deputy Secretary of the Australian Department of Social Services, also recognised the pressure on hospitals and Aged Care Assessment Teams to expedite the discharge of people from hospital. He told the Royal Commission that:

Look, there is no doubt that—that hospital officials involved in the discharge process or the ACAT [Aged Care Assessment Team] process, they’re under huge pressure to free up available beds in hospitals.²⁹

Following approval by an Aged Care Assessment Team, the pathway into residential aged care is clear and defined and, it would seem, virtually inevitable.

‘Cell 14’³⁰

At the age of 48, Mr Neale Radley had a diving accident while on a houseboat with friends. He suffered a spinal injury that left him quadriplegic. Before the accident, he had been active and independent, spending time outdoors and travelling across Australia as a truck driver.

Mr Radley’s life in a country town in Victoria changed dramatically after the accident. After a long stint in hospital and rehabilitation facilities, Mr Radley needed somewhere to live long term. His parents were in their 80s and had their own care needs.

Ultimately, Mr Radley made what he describes as ‘one the most difficult decisions of my life’ to enter residential aged care. The nearest facility to his home and family that would accept Mr Radley was 150 kilometres away. At the time he gave evidence, he had lived in the facility for four years.

Life for Mr Radley is lived almost exclusively inside the aged care facility. His care needs are different to those of the other residents, and his health has suffered as a result.

28 Transcript, Shane Jamieson, Melbourne Hearing 1, 13 September 2019 at T5192.23.

29 Transcript, Michael Lye, Melbourne Hearing 1, 10 September 2019 at T4974.7–9.

30 Based on the evidence of Neale Radley: Exhibit 9-8, Melbourne 1 Hearing, Statement of Neale Marcum Radley, 3 September 2019, WIT.1251.0001.0001; Transcript, Neale Radley, Melbourne 1 Hearing, 10 September 2019 at T4966.27–4971.17

Mr Radley's emotional wellbeing has also suffered. A social person prior to his accident, Mr Radley's social life is limited to brief visits by friends and family, phone calls from his dad and a fortnightly peer support group in Bendigo. If time permits after an appointment, he can sometimes go around the lake in Bendigo.

Being surrounded by the deaths of other residents has added to Mr Radley's sense of loneliness and isolation.

Approval for the National Disability Insurance Scheme in 2016 meant that Mr Radley could access additional therapy services. However, because he lives in a rural location, he needs to use much of that entitlement on the travel required to get to appointments.

Mr Radley has aspirations to leave the aged care facility and instead to live in a home near his family and friends, with support and surrounded by people his own age. An approval for Specialist Disability Accommodation took six to eight months to be approved. At the time he gave evidence, it had been six months since the application's approval.

Mr Radley has no sense of when a place will become available. In the meantime, he continues to live in the room he has nicknamed 'Cell 14'.

Why is aged care inappropriate for younger people?

Aged care, by its very nature, is designed for older people. Older people have different wants, needs and aspirations to those who may be one, two or even three generations younger. They have usually had the chance to live a long and fulfilling life in the community, prior to entering residential aged care in old age.

Ms Kirby Littley's strokes occurred at just 28 years of age following surgery for a brain tumour.³¹ At the time she was working as a teacher. Mr James Nutt was still a teenager at the time of his accident. He entered residential aged care at 21 years of age.³² He had just started his career in defence. Neither Ms Littley nor Mr Nutt belonged in residential aged care.

The Royal Commission heard multiple accounts from younger people who have been, or remain, in residential aged care. They spoke of the social isolation, neglect, loss of function, sense of hopelessness and grief associated with their time in aged care. Their words are the best way to convey just how inappropriate residential aged care

31 Exhibit 9-11, Melbourne Hearing 1, Statement of Kirby Littley, WIT.1241.0001.0001 at 0001 [5] and [8]; and 0002 [21].

32 Transcript, James Nutt, Melbourne Hearing 1, 11 September 2019 at T5155.24–30 and T5156.39–47.

can be for a younger person. Ms Lisa Corcoran expressed her feelings about living in residential aged care most clearly:

My number one goal is to get the fuck out of the nursing home. My number two goal is to hug my children.³³

I hate it in the facility and I want to leave. Up until recently, every day I felt like killing myself. I can't move, so I can't do this—I would have if I could.³⁴

Ms Roche described the isolation her husband, Mr Burge, experienced. Mr Burge was decades younger than the majority of residents:

Because the vast majority of the patients were old and, I would think, you know, maybe 50 per cent of them had dementia, a lot of the social activities were geared towards that. So you know, playing bingo, bringing all the patients in and having, kind of, Second World War singsongs was not particularly appealing to a 56 year old man...what it meant was Michael became more and more isolated. And by that, he would just remain in his room day in, day out.³⁵

Mr Neale Radley spoke of the social and physical isolation of living in residential aged care as a younger person, and the constant reminder of the different stages of life of younger and older residents:

Being in a place where people are constantly dying isn't the right place for young people. I feel isolated and alone.³⁶

I don't have the freedom to get out. I feel like a prisoner. The outside doors are kept locked. When my bedroom door is shut I can't open it on my own, I have to ask someone to let me out, and then let me back in.³⁷

Part of Mr James Nutt's compelling description of his first night in residential aged care is detailed at the start of this chapter.

Social isolation and frustration are only part of the difficulties faced by younger people living in aged care. There are also issues with the quality and range of care available to people with complex care needs. Ms Roche told us about her experience in engaging allied health services for her husband:

I engaged a speech therapist quite early because, you know, they clearly told me that there wouldn't be speech therapy as part of the package, and that was fine. I also engaged a physiotherapist privately because my thought pattern was, I'll get one session out of the nursing home and then maybe I can fund two

33 Transcript, Lisa Corcoran, Melbourne Hearing 1, 9 September 2019 at T4821.39–44.

34 Exhibit 9-3, Melbourne Hearing 1, Statement of Lisa Corcoran, WIT.1240.0001.0001 at 0001 [4].

35 Transcript, Catherine Roche, Melbourne Hearing 1, 9 September 2019 at T4838.23–29.

36 Exhibit 9-8, Melbourne Hearing 1, Statement of Neale Radley, WIT.1251.0001.0001 at 0004 [26].

37 Exhibit 9-8, Melbourne Hearing 1, Statement of Neale Radley, WIT.1251.0001.0001 at 0004 [31].

or three other sessions a week. So that we would be able to maintain Michael's tone—muscle tone and condition, so that we could keep going with his mobility and his walking.³⁸

Mr Radley detailed the personal impact of not having access to carers with the requisite skills to meet his care needs:

The facility doesn't have the right people with experience caring for someone like me. If something happens to me that requires medical attention then I am taken by ambulance to Bendigo. I have nearly died three times on the way to Bendigo during an emergency.³⁹

A human rights issue

The Royal Commission is concerned that many younger people in residential aged care may not enjoy all their rights under the United Nations Convention on the Rights of Persons with Disabilities. Australia was one of the original signatories to the Convention on 30 March 2007. It ratified the Convention on 17 July 2008 and acceded to the Optional Protocol on 21 August 2009. Article 19 of the Convention recognises:

the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) People with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) People with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

There are real concerns about the extent to which younger people living in residential aged care are enjoying this right. The Australian Disability Discrimination Commissioner, Dr Ben Gauntlett, stated that the placement of younger people in residential aged care is inappropriate from a human rights perspective, particularly insofar as younger people with

38 Transcript, Catherine Roche, Melbourne Hearing 1, 9 September 2019 at T4839.30–35.

39 Exhibit 9-8, Melbourne Hearing 1, Statement of Neale Radley, WIT.1252.0001.0001 at 0003 [20].

disabilities are compelled to live in inappropriate institutional settings in residential aged care.⁴⁰ Ms Vicki Rundle, acting Chief Executive Officer of the National Disability Insurance Agency, also acknowledged the risk that this group of Australians may not be afforded their rights under the Convention.⁴¹

Dr Gauntlett also gave evidence about the importance of independent advocacy for people currently living in, or at risk of entering, residential aged care.⁴²

The importance of care and accommodation

The care needs of many younger people in residential aged care are significant. These needs are often coupled with the need for accommodation, which allows for that care to be delivered and for the person to live with maximum independence. Where possible, modifications to existing homes may be made, but this is not always feasible.

In order to provide real choices for younger people in or at risk of entering residential aged care, alternative options for both accommodation and care are critical. There is, however, a substantial shortfall in Specialist Disability Accommodation. Governments have known this shortfall for a considerable time. In 2011, the Productivity Commission estimated that there was only existing Specialist Disability Accommodation for 15,700 people but that, by the time of full implementation of the National Disability Insurance Scheme, around 28,000 (6%) scheme participants would require Specialist Disability Accommodation.⁴³ Even taking into account Specialist Disability Accommodation, which is currently under development and for which construction has not yet been completed, it is still estimated that there will be a shortfall of over 9000 places.⁴⁴ There is also an acknowledged lack of market confidence in Specialist Disability Accommodation in rural and remote areas.⁴⁵ This results in unequal access to specialist accommodation, even for those who are entitled to it.

We heard that the Australian Government has not updated the work that the Productivity Commission prepared in 2011 on the availability of Specialist Disability Accommodation and does not have projections of the supply and demand for Specialist Disability Accommodation into the future.⁴⁶

40 Transcript, Dr Ben Gauntlett, Melbourne Hearing 1, 11 September 2019 at T5147.1–14 and T5150.34–38.

41 Transcript, Vicki Rundle, Melbourne Hearing 1, 11 September 2019 at T5041.12–5042.15.

42 Transcript, Dr Ben Gauntlett, Melbourne Hearing 1, 11 September 2019 at T5151.6–36.

43 Exhibit 9-1, Melbourne Hearing 1, General Tender Bundle: Tab 146, NDIA's Response to NTG-0354, CTH.0001.8000.0001 at 0009 [17].

44 Exhibit 9-1, Melbourne Hearing 1, General Tender Bundle, Tab 37, Summer Foundation and Social Ventures Australia, *Specialist Disability Accommodation: Supply in Australia*, 2019, RCD.9999.0178.0029 at 0053.

45 Transcript, Vicki Rundle, Melbourne Hearing 1, 11 September 2019 at T5073.45–5074.2.

46 Transcript, Scott McNaughton, Melbourne Hearing 1, 10 September 2019 at T5015.31–5016.11; Transcript, Vicki Rundle, Melbourne Hearing 1, 11 September 2019 at T5064.46–5065.1.

The Royal Commission heard that the lack of Specialist Disability Accommodation is not due to a lack of available funds for investment. Mr Bo'sher from the Summer Foundation stated that the presence of capital funding must, however, be accompanied by confidence in modelling that will ensure any new building will in fact be occupied:

there is hundreds and hundreds of millions of dollars that those superannuation funds would commit tomorrow if they were confident that the housing was going to be occupied by a person with disability. But right now they don't have that confidence.⁴⁷

Market confidence is further hindered by the Australian Government's failure to prepare projections of the need for Specialist Disability Accommodation.

The Royal Commission heard that the market alone is unlikely to provide sufficient Specialist Disability Accommodation to meet the expected levels and kinds of demand within a reasonable timeframe. In some rural and remote areas, the market may never provide suitable supply.⁴⁸ Ms Peake gave the following view on the reliance of a market response to resolve the issue:

We do not assume that the best models of care and accommodation will simply emerge from a market responding to individual care plans and funding packages.⁴⁹

This prompts consideration of alternative approaches to the current market-driven model, which could include, for example, engagement with social housing providers.

Another concerning piece of evidence before the Royal Commission was that just 66 of the more than 4700 people in residential aged care with a National Disability Insurance Scheme plan have been approved for Specialist Disability Accommodation in their plan.⁵⁰ Even allowing for the overdue introduction in late March 2019 of changes to the National Disability Insurance Scheme rules for Specialist Disability Accommodation, which now permit inclusion of Specialist Disability Accommodation in a person's plan without first having to identify a particular 'appropriate dwelling', that figure is still, some six months later, disturbingly low.⁵¹

With the lag time associated with property development, the Royal Commission was surprised to hear that there is an additional waiting period due to National Disability Insurance Scheme eligibility and assessment processes, which has been reported to take up to six months.⁵² In contrast, the Royal Commission heard that an Aged Care

47 Transcript, Luke Bo'sher, Melbourne Hearing 1, 13 September 2019 at T5209.12–15.

48 Transcript, Luke Bo'sher, Melbourne Hearing 1, 13 September 2019 at T5209.12–34.

49 Exhibit 9-22, Melbourne Hearing 1, Statement of Kym Lee-Anne Peake, WIT.0420.0001.0001 at 0015 [93].

50 Transcript, Vicki Rundle, Melbourne Hearing 1, 11 September 2019 at T5055.37–5056.9.

51 Exhibit 9-1, Melbourne Hearing 1, General Tender Bundle, Tab 32, *National Disability Insurance Scheme (Specialist Disability Accommodation) Rules 2016*, RCD.9999.0177.0042 at 0060–0062. See also Submissions of the Commonwealth – Melbourne Hearing 1, 25 September 2019, RCD.0012.0031.0001 at 0008[24] – 0009 [29].

52 Transcript, Luke Bo'sher, Melbourne Hearing 1, 13 September 2019 at T5195.18–30.

Assessment Team approval for residential aged care can be processed in a matter of days.⁵³ Mr Radley described his ongoing journey towards living in Specialist Disability Accommodation:

In March 2019 I was approved for [Specialist Disability Accommodation]. It took roughly 6-8 months if not longer for my application to be approved after submitting it. My NDIA [National Disability Insurance Agency] support coordinator did so much work to make sure the application had everything it needed, including an assessment by my OT [occupational therapist]. I received an acknowledgement after we submitted the application but I didn't hear anything after that. I just had to wait. It felt like I was climbing a mountain.⁵⁴

Adequate support for younger people with complex health care needs has been a significant challenge. It is apparent that there has been a disconnect between the Commonwealth and State and Territory Governments about funding for disability-related health care supports, such as disability-related nursing care. At best, there has been a lack of clarity over which government would fund these supports. At worst, it seems that some people have been denied these supports while the various Commonwealth, State and Territory Governments have debated who bore responsibility for funding them. Mr Lye described the recent agreement between the Commonwealth and State and Territory Governments that the National Disability Insurance Scheme would fund such clinical supports. He acknowledged that, without this agreement, the Commonwealth and the States and Territories could not assure access to the care needed, and the agreement reflected:

that it was very important that we not let people fall through the gaps... an intent not to leave people stranded.⁵⁵

It is unclear how many people were required to enter a residential aged care home prematurely or unnecessarily due to these gaps. The Royal Commission will continue to examine the issue of policy and service interfaces between State, Territory and Commonwealth Government programs and will hold a future hearing dedicated to this issue. Of particular interest is the role that a lack of access to community-based slow stream rehabilitation (that is, long-term, low intensity rehabilitation for people who can continue to show functional improvement over many years)⁵⁶ and to palliative care has had on admissions of younger people into aged care.

53 Transcript, Luke Bo'sher, Melbourne Hearing 1, 13 September 2019 at T5195.18–30.

54 Exhibit 9-8, Melbourne Hearing 1, Statement of Neale Radley, WIT.1251.0001.0001 at [33].

55 Transcript, Michael Lye, Melbourne Hearing 1, 10 September 2019 at T4955.6–13.

56 Transcript, Dr Nicholas Hartland, Melbourne Hearing 1, 10 September 2019 at T4933.30–42.

The Action Plan

The Royal Commission heard evidence about the Australian Government's Younger People in Residential Aged Care Action Plan, requested by the then Minister for Families and Social Services, the Honorable Paul Fletcher, in the month following the announcement of the Royal Commission. The Action Plan, released in March 2019, has the following goals:

- supporting those already living in aged care aged under 45 to find alternative, age appropriate housing and supports by 2022, if this is their goal;
- supporting those already living in aged care aged under 65 to find alternative, age appropriate housing and supports by 2025, if this is their goal; and
- halving the number of younger people aged under 65 years entering aged care by 2025.⁵⁷

The Action Plan has significant gaps and the Australian Government has had a 'preference' not to engage with the States and Territories.⁵⁸ In addition, the Royal Commission heard that the Action Plan does not include any milestone targets or projections.⁵⁹ It is focused on younger people who are eligible for the National Disability Insurance Scheme and it has designated other younger people who are in residential aged care or at risk of entering residential aged care as 'out of scope'.⁶⁰ The States and Territories were not consulted on the design of the Action Plan.⁶¹ The States and Territories are not represented on the Project Board for the Action Plan and are not members of the Stakeholder Reference Group.⁶² Ms Peake described that lack of consultation as 'a missed opportunity'.⁶³

The Action Plan also lacks ambition, with modest targets that still allow the admission of unacceptably large numbers of younger people into residential aged care well into the future. In his evidence, Dr Gauntlett said that it was the Australian Human Rights Commission's recommendation that the targets of the Action Plan be revised so that:

By 2025, we should have no [younger] people with disabilities in Australia living in old aged care institutions.⁶⁴

57 Exhibit 9-1, Melbourne Hearing 1, General Tender Bundle, Tab 9, Younger People in Residential Aged Care Action Plan, 2019, CTH.0001.5000.1931 at 1931.

58 Transcript, Michael Lye, Melbourne Hearing 1, 10 September 2019 at T4975.19–4976.34.

59 Transcript, Peter Broadhead, Melbourne Hearing 1, 10 September 2019 at T5014.31–28.

60 Transcript, Christopher Carlisle, Melbourne Hearing 1, 10 September 2019 at T5024.19–25.

61 Submissions of the Commonwealth – Melbourne Hearing 1, 25 September 2019, RCD.0012.0031.0001 at 0003 [8].

62 Submissions of the Commonwealth – Melbourne Hearing 1, 25 September 2019, RCD.0012.0031.0001 at 0004 [9b].

63 Transcript, Kym Peake, Melbourne Hearing 1, 13 September 2019 at T5232.43–5233.37. ,

64 Transcript, Dr Ben Gauntlett, Melbourne Hearing 1, 11 September 2019 at T5152.44–45.

This position was supported by others, with Dr Morkham adding that the Australian Government should act decisively:

We think the targets are not good enough. We want to see no younger person enter residential aged care by 2022.⁶⁵

The Royal Commission does not consider that the Action Plan in its current form is likely to achieve even its limited targets and should not be relied on as a solution to the policy failures that have consigned so many younger people to a life lived in residential aged care. While a slight reduction in the number of younger people in residential aged care has been identified in recent quarters, this trend preceded the release of the Action Plan.⁶⁶

What are the alternatives?

The Royal Commission heard evidence about the 2006–11 Younger People in Residential Aged Care Initiative, which applied significant resources to the issue but had a modest impact on the total number of younger people in residential aged care.⁶⁷ Since the completion of the Initiative, there has been little in the way of deliberate and coordinated efforts to reduce the number of younger people in residential aged care.

Mr Lye acknowledged the need for ‘fresh thinking’ when considering how to reduce the number of younger people entering residential aged care.⁶⁸ He conceded that to change the inertia that continues to see dozens of younger people entering residential aged care each week, a cultural shift is required:

I think that the reality is that unless we have cultural change to divert people from coming into aged care...and also available accommodation and supports... then that's a practical impediment.⁶⁹

The Royal Commission heard evidence from three State compensable insurance schemes. These schemes only very rarely place younger people in residential aged care. Victoria's Transport Accident Commission scheme has just 13 of around 2500 active scheme participants under 65 years of age in residential aged care.⁷⁰ South Australia's Lifetime Support Authority has one out of just over 200 participants under 65 years of age in residential aged care (and that participant was in the aged care facility prior to being accepted into the scheme).⁷¹ New South Wales' Lifetime Care and Support Scheme (managed by icare) has just two of approximately 1470 participants in residential aged care.⁷²

65 Transcript, Dr Bronwyn Morkham, Melbourne Hearing 1, 13 September 2019 at T5184.44–45.

66 Transcript, Peter Broadhead, Melbourne Hearing 1, 10 September 2019 at T5011.20–5012.21.

67 Transcript, Michael Lye, Melbourne Hearing 1, 10 September 2019 at T4946.25–33. See also Submissions of the Commonwealth – Melbourne Hearing 1, 25 September 2019, RCD.0012.0031.0001 at 0006 [16].

68 Transcript, Michael Lye, Melbourne Hearing 1, 10 September 2019 at T4981.26–30.

69 Transcript, Michael Lye, Melbourne Hearing 1, 10 September 2019 at T4973.21–24.

70 Transcript, Liz Cairns, Melbourne Hearing 1, 11 September 2019 at T5134.36–47.

71 Transcript, Tamara Tomic, Melbourne Hearing 1, 11 September 2019 at T5136.21.

72 Transcript, Suzanne Lulham, Melbourne Hearing 1, 11 September 2019 at T5135.40.

We note there are fundamental differences between these compensable insurance schemes and the National Disability Insurance Scheme, and that these differences include, for example, the way in which scheme funds are generated and allocated and the scope of coverage. However, they have in common the provision of reasonable and necessary supports for those with significant and lifelong disability. There are lessons to be learned by the National Disability Insurance Scheme from their practices and procedures.

The critical factors that mean residential aged care admission is rare in these compensable schemes include early and active engagement with hospital and rehabilitation services and a strong policy framework and culture that prioritises alternative care and accommodation. These schemes also have a focus on extended rehabilitation that enhances prospects of successful community living and reducing lifetime care needs.⁷³

The importance of early, collaborative hospital discharge planning was highlighted by compensable scheme witnesses as an important way to reduce the likelihood of a younger person's admission into residential aged care.⁷⁴ This was often enhanced by the role of a dedicated key worker or 'systems wrangler'.⁷⁵ These people, often in conjunction with committed family members, work tirelessly to navigate between health, aged care, palliative care and disability systems.

Some witnesses who reflected on their exit from aged care into supported accommodation described feeling lucky to have had such dedicated family members or others advocating on their behalf. Others spoke of being found 'purely by chance' in residential aged care and guided to alternative options by dedicated independent advocates.⁷⁶ It is not known how many younger people remain 'lost' in aged care.

We heard from people with access to their full entitlement under the National Disability Insurance Scheme, including appropriate accommodation and care, whose life had improved dramatically since leaving residential aged care. Mr Nutt and Ms Kirby Littlely were two such examples. They spoke of the suitability of their accommodation and access to support delivered by carers whom they had chosen. For these young people, life has become more independent, positive and enriching. However, their stories also highlight the inequity and the opportunities being foregone by those thousands of other younger Australians in residential aged care who are not able to access sufficient support to live in the community. Luck should not determine the future of younger people in residential aged care.

It is clear that reducing the number of younger people in residential aged care requires a coordinated, collaborative response. It also requires a focus on the drivers of admission to aged care, as well as a firm commitment to ensure that those currently in aged care can leave.

73 Transcript, Suzanne Lulham, Melbourne Hearing 1, 11 September 2019 at T5139.15–23.

74 Transcript, Liz Cairns, Melbourne Hearing 1, 11 September 2019 at T5131.33–44; Transcript, Tamara Tomic, Melbourne Hearing 1, 11 September 2019 at T5133.5–10.

75 Transcript, Shane Jamieson, Melbourne Hearing 1, 13 September 2019 at T5188.20–40.

76 Transcript, James Nutt, Melbourne Hearing 1, 11 September 2019 at T5167.3.

Priorities for action

The Royal Commission appreciates that some critical parts of the solution will take time, including full rollout of the National Disability Insurance Scheme and the large scale building program to meet the shortfall in Specialist Disability Accommodation. However, there is much that can be done in the meantime to understand better and respond to the drivers of admission to aged care for younger people and to ensure that younger people with disabilities in residential aged care receive their full National Disability Insurance Scheme entitlements.

More detailed findings and recommendations and long-term reform strategies will appear in the Royal Commission's Final Report, and we will give careful consideration to the role of specialist aged care services for vulnerable groups that we know are working well. In the meantime, it is critical that immediate actions are taken to address what can only be described as a national embarrassment by stopping the flow of younger people into aged care.

Improve data collection

There remains a lack of data about the needs and circumstances of the 6000 or so younger people in residential aged care. This must be resolved immediately.

The Royal Commission will continue to seek data from relevant agencies to monitor the number of younger people in residential aged care and their characteristics.

For those not covered by the National Disability Insurance Scheme, more detailed information is required to enable a considered plan for more appropriate care options.

With better data, more ambitious and specific targets can be established. For example, the Younger People in Residential Aged Care Action Plan is silent on the issue of those requiring end of life care and others who may not be eligible for the National Disability Insurance Scheme. This is a significant omission that must be rectified.

Another practical application of improved data use would be the consolidation and public dissemination of information Specialist Disability Accommodation, both existing and under construction. It is unacceptable that there may be accommodation available that is not being used, while younger people enter or remain in residential aged care. Ready access to this information by care planners and advocates has the potential to reduce the time that a younger person may spend in residential aged care, or avoid it altogether.

Avoid new admissions to residential aged care from hospital

A number of steps can be taken to close what has been described as the ‘pipeline straight into residential aged care’ from hospital.⁷⁷

There is a need for improved discharge planning supported by information exchange between hospital and ongoing care providers, more streamlined National Disability Insurance Scheme and Specialist Disability Accommodation eligibility assessments and the creation of support plans that prioritise the avoidance of aged care entry. The approach must be based on a cultural presumption that, in the vast majority of cases, residential aged care is not an appropriate option for a younger person.

As noted above, it is an Aged Care Assessment Team assessment that approves a younger person for residential aged care. Therefore, avoiding referral of a younger person to an Aged Care Assessment Team must be the goal. As one member of the Action Plan Project Board suggested:

If this system was working as well as we’d like some years from now, then people wouldn’t be referred to the ACAT in the first place. So that really is—you know, in the case of shaking up that path, that’s the desirable outcome.⁷⁸

In the event that an Aged Care Assessment Team assessment is undertaken, strict compliance with the obligation to review alternative care and accommodation options is critical, particularly for those eligible for support under the National Disability Insurance Scheme. Audit of Aged Care Assessment Team assessments and targeted training for assessors and those referring people to Aged Care Assessment Teams will also assist.

Interim accommodation options for those requiring Specialist Disability Accommodation, with services aimed at improving functional capacity, will further reduce the likelihood of temporary admission to residential aged care. The lack of dedicated rehabilitation and functional restoration in aged care may subsequently reduce a person’s ability to transition to community accommodation. The Australian Department of Health acknowledged that ‘[r]esidential aged care services are intended to serve the needs of older people and are not equipped to support the functional improvement of younger people with disability or to meet their social and developmental needs.’⁷⁹ The absence of such support can result in functional decline as well as the sense of social and physical isolation described by witnesses whose evidence is set out above. Mr Lye noted the importance of avoiding or minimising the time a younger person is in residential aged care:

So, for example, what we do know is that...the successful exits are in part people who have spent a relatively short period of time in aged care.⁸⁰

77 Transcript, Dr Bronwyn Morkham, Melbourne Hearing 1, 13 September 2019 at T5193.44.

78 Transcript, Peter Broadhead, Melbourne Hearing 1, 10 September 2019 at T5004.33–36.

79 Exhibit 9-1, Melbourne Hearing 1, General Tender Bundle, Tab 1, Department of Health’s Response to NTG-0355, CTH.0001.1000.9493 at 9495 [12]; Transcript, Dr Nick Hartland, Melbourne Hearing 1, 9 September 2019 at T4866.28–32.

80 Transcript, Michael Lye, Melbourne Hearing 1, 10 September 2019 at T4951.28–30.

Independent and individualised advocacy

The exit from residential aged care for those younger people wishing to leave takes too long and is too difficult. It relies on a combination of tenacity, luck and being in the right place at the right time, as was the case with Mr Nutt.⁸¹ It is similarly opaque for those younger people at risk of entering residential care, who must traverse multiple systems if they are to receive the care they need and want, at a time when they are especially vulnerable or ill.

In order to offer real choice for those currently in residential aged care, resources will be required to support them. Accommodation and ongoing care are significant pieces of the puzzle. A committed and independent advocate and access to support that prepares someone to live in the community are also required.

The appointment of independent ‘system wranglers’ to assist with planning and coordinating care was discussed at length during the hearing on younger people in residential aged care.⁸² This is particularly important for those without a dedicated and informed family to advocate on their behalf. Dr Gauntlett made the point that substantial obstacles inhibit the ability of younger people at risk of entering the aged care system from effectively advocating on their own behalf.⁸³

Don’t wait for the market

For Specialist Disability Accommodation, the market response has been slow and incomplete. That market response is likely to create inequities across the country. There is no evidence to suggest that this will change in the short term and the current level of market response is far too slow to meet the massive shortfall of specialist accommodation. This requires alternative approaches to increase the supply of Specialist Disability Accommodation.

Government must actively engage with the prospective Specialist Disability Accommodation market, as well as considering alternative providers of this type of service. This may require active participation in the market as has been the case for compensable insurers,⁸⁴ or direct investment in additional social housing or Specialist Disability Accommodation particularly in thin markets. Building market confidence by formulating accurate supply and demand projections may also stimulate activity to assist with reducing the shortfall of suitable accommodation.

81 Transcript, James Nutt, Melbourne Hearing 1, 11 September 2019 at T5167.3.

82 Transcript, Dr Brownyn Morkham, Melbourne Hearing 1, 13 September 2019 at T5189.9–T5190.3 and T5192.8–37; Transcript, Luke Bo’sher, Melbourne Hearing 1, 13 September 2019 at T5190.8–T5192.4; Transcript, Kym Peake, Melbourne Hearing 1, 13 September 2019 at T5241.32–40; Transcript, Catherine Roche, Melbourne Hearing 1, 9 September 2019 at T4843.30–39.

83 Transcript, Dr Ben Gauntlett, Melbourne Hearing 1, 11 September 2019 at T5151.6–31.

84 Transcript, Liz Cairns, Melbourne Hearing 1, 11 September 2019 at T5135.15–24.

Provide the care that is needed

Many people are admitted to, or remain in, residential aged care because of a lack of suitable care and supports. Facilitating access to the care that is needed, at the time it is needed, is critical. It requires a shared will and commitment across State and Territory and Commonwealth Governments.

There is an urgent need to improve the availability of palliative care for younger people nearing the end of their lives. A younger person does not deserve to live their final days in a place that is not suited to their end of life needs.

There is also a fundamental need for many younger people, particularly those recovering from brain or spinal injury, and those with progressive illness or disease, to have access to long-term rehabilitation in order to maximise functional capacity. This is true for many older people as well. Improved access to rehabilitation will afford people the greatest opportunity to live their most independent life.

It is also critical that those younger people currently in residential aged care are not further disadvantaged. Evidence before the Royal Commission is that the cost of providing care to a younger person in residential aged care is lower than what would be provided in the community.⁸⁵ Younger people in residential aged care may be receiving less care and support than they would otherwise receive in the community. This group must be given access to equivalent levels of care that they would receive in the community, not merely the level of care that is available under the Aged Care Funding Instrument.

Other groups who fall through the gaps

For younger people not eligible for the National Disability Insurance Scheme, careful consideration must be given to the provision of suitable care and accommodation options. Aged care as it is currently conceived is not appropriate for most of these people, for many of the same reasons as it is unsuitable for younger people with disabilities. It is entirely inadequate that these groups have been overlooked in the Younger People in Residential Aged Care Action Plan and there has been no effort to find out who they are or what their needs are. The Royal Commission will be considering appropriate solutions for these important groups of people in future hearings.

85 Transcript, Michael Lye, Melbourne Hearing 1, 10 September 2019 at T4972.39–4973.8.

Conclusion

The Royal Commission heard from an Australian Department of Health representative that younger people in aged care is a ‘somewhat intractable problem’.⁸⁶ Now that the National Disability Insurance Scheme exists, the Royal Commission does not accept that the problem is intractable, only that there has been a lack of will and effort to address the issues that have left younger people to be accommodated in aged care.

We heard that the ambitions of younger people in residential aged care are relatively simple. As Mr Radley put it:

I want to live in the community and be close to my family.⁸⁷

Residential aged care is not suitable for younger people. They have different aspirations, preferences and needs to older residents. For those younger people who find themselves in residential aged care, many aspire to leave and look forward to their independence. The experience of those who have managed to exit aged care is telling. Consider the transformation in the life of Mr James Nutt, who was able to leave residential aged care after spending most of his twenties in that environment. He agreed that, in Specialist Disability Accommodation, near his family and with appropriate care, he was ‘living the dream’.⁸⁸

The Australian Government’s Younger People in Residential Aged Care Action Plan does not do enough, soon enough. The Royal Commission agrees with Dr Morkham and Dr Gauntlett that, subject to very limited exceptions, by 2022 no younger people should be entering residential aged care, and by 2025 no younger people should be living in residential aged care, except for those who choose to be there.

In developing a response to the issue of younger people in residential aged care in our Final Report, the Royal Commission will also consider the role of specialist services, noting the evidence we have received about their importance for particularly vulnerable populations.

The rhetoric and buck-passing that has perpetuated the admission of younger people into residential aged care, particularly those who are admitted from hospital with a disability or with palliative care needs, has been going on far too long. Australia now finds itself with a human rights issue that is costing people their independence, dignity and wellbeing.

Action must be swift. It must be thorough. And it must be considered. But most of all, it must be fair and compassionate. In the words of Mr Mario Amato:

younger people shouldn’t be in aged care facilities.⁸⁹

⁸⁶ Transcript, Dr Nicholas Hartland, Melbourne Hearing 1, 9 September 2019 at T4867.3.

⁸⁷ Exhibit 9-8, Melbourne Hearing 1, Statement of Neale Radley, WIT.1251.0001.0001 at 0004 [30].

⁸⁸ Transcript, James Nutt, Melbourne Hearing 1, 11 September 2019 at T5171.26–34.

⁸⁹ Transcript, Mario Amato, Melbourne Hearing 1, 11 September 2019 at T5120.4. See also Exhibit 9-13, Melbourne Hearing 1, Statement of Mario Amato, 29 August 2019, WIT.1244.0001.0001 at 0008 [65].

Conclusion

Where to Next?

Conclusion: Where to Next?

The Royal Commission has heard harrowing evidence of the experiences of people caught in an aged care system that too often fails to provide appropriate standards of care or to treat older people, and their families and friends with dignity and respect.

While we have heard a number of examples of specific providers failing to meet existing standards, the problems in aged care are not just about a series of individual failures. The flaws of the aged care system as a whole are at the heart of this story. As you have read in this Interim Report, the systemic problems with the aged care system include that it:

- is designed around transactions, not relationships or care
- minimises the voices of people receiving care and their loved ones
- is hard to navigate and does not provide the information people need to make informed choices about their care
- relies on a regulatory model that does not provide transparency or an incentive to improve
- has a workforce that is under pressure, under-appreciated and lacks key skills.

All of these problems need to be resolved.

Australia's aged care system has not kept pace with the expectations of care that can be provided in a modern, wealthy and compassionate society.

The Australian aged care system is failing and needs fundamental reform. The Royal Commission will recommend steps to achieve this transformation in our Final Report.

We are under no illusion about the scale of the task before us. The aged care system is complex, and it does not operate in isolation.

The Royal Commission is planning a detailed program of hearings and other engagement activities with care recipients and their families and supports, those providing and supporting care and the officials responsible for the aged care system.

Our final recommendations will draw on the knowledge and experience of experts, advocates, providers and policymakers, which will be critical to the substantial reforms that will be required.

Most of all, however, we will continue to benefit from the insights of older people and their friends and family. Their voices are fundamental to our ability to design a system that puts older people at the centre of aged care services.

Over the next 12 months, we will build on the valuable evidence we have heard as well as our research currently in train, to delineate why Australia's aged care system is in such a parlous state.

We will also build on the evidence we have heard, to describe more fully the excellent care that can be delivered to older people. Some providers are already delivering high quality care, despite the obstacles inherent in the system. Our further work will be informed by the lessons they have learned, and taught to us.

Our work over the next 12 months will inform comprehensive recommendations for substantive reform of the existing aged care system in our Final Report.

Hearings

Our hearings for the remainder of 2019 will focus on:

- provision of aged care in regional areas: this will be a focus of our Mudgee Hearing commencing 4 November 2019
- aged care operations of selected approved providers—this will be a focus of our Hobart Hearing commencing 11 November 2019
- access and interface issues between aged care and health services: this will be a focus of our Canberra Hearing commencing 9 December 2019.

In 2020, we will continue our thematic examination of issues within our Terms of Reference, with a particular focus on how to design a future aged care system that puts older people first. Some of the issues we expect to explore in future hearings include:

- the funding of aged care and the impact it has on how care is delivered
- integration and transition between different parts of the aged care system, including home, residential and respite care
- governance and accountability in aged care
- how to identify and encourage innovation and improvement in aged care
- models for the delivery aged care
- system architecture and design to support a good quality of life for people using aged care services
- how best to deliver aged care in a sustainable way.

As with our previous hearings, witnesses may include experts, advocates, service providers and policymakers. Evidence of the direct experience of older people and their family and friends will continue to be a priority for our hearings.

We will also conduct a number of hearings focused on the operation, governance and leadership of certain approved providers, with a particular focus on which factors affect the quality and safety of care. While these case studies will examine the practices of particular providers and the care outcomes they achieve, we expect that they will also enhance our understanding of the practical operation of the aged care system, including design, funding and regulation.

Engagement

We will continue our extensive engagement program over the coming months. We anticipate holding a number of additional community forums in the first half of 2020 in a range of metropolitan and regional locations. We will publicise these through the website, the Royal Commission mailing list and in local media. Further issues to be explored at roundtable discussions include options for future design of the aged care system and implementation challenges arising from comprehensive reforms to aged care.

Submissions

We will continue to accept submissions until 30 April 2020. The Royal Commission considers every submission we receive. Each submission helps to inform our inquiry and our Final Report. We encourage members of the community to make their submissions as soon as possible. The earlier that we receive submissions, the more opportunity there is for those submissions to influence our approach to hearings and research.

Submissions can be made:

by using our web form at

<https://agedcare.royalcommission.gov.au/submissions/Pages/default.aspx>

by email to ACRCenquiries@royalcommission.gov.au

- by writing to GPO Box 1151 Adelaide SA 5001
- by telephoning 1800 960 711
(between 8:00am-6:30pm ACST Monday-Friday
except on public holidays. Interpreter service available).

Research

Understanding the needs and expectations of older Australians is by no means a simple endeavour. Our recommendations for comprehensive reform of the aged care system will need to be underpinned by a thorough understanding of the complexities of the system, and the many factors that will affect the system into the future. From the beginning, we have recognised the importance of a comprehensive research agenda to inform our inquiry.

Our data and research team is conducting and commissioning work in a number of important areas, including:

- community attitudes to ageing and aged care
- the quality of life, satisfaction with care and extent of sub-standard care in both home care and residential care
- understanding the cost of care and how much it costs to deliver an acceptable standard of care
- the accessibility of aged care services in rural and remote areas
- the extent of differences in the care experiences of people with low income or wealth
- understanding the aged care systems in other countries
- innovative models of care, including internationally
- financial analysis of the state of the aged care industry and its different segments
- modelling the economic and budgetary implications of various scenarios and structural options for aged care.

