Royal Commission into Aged Care Quality and Safety

Final Report: Care, Dignity and Respect

Volume 3A

The new system

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ISBN: 978-1-921091-69-8 (print)
ISBN: 978-1-921091-70-4 (online)

Table of Contents

Introduction to Volume 3

In this volume, we set out our vision for the future of aged care in Australia. We make recommendations, the implementation of which will result in an aged care system that is capable of delivering high quality and safe aged care.

The structure of this volume

Many of the recommendations and observations that we make in this volume are joint. However, there are instances where we make differing observations and recommendations which are contained, in some cases, in separate chapters on the same topic.

This volume is divided as follows.

Chapter 1, *Foundations of the New Aged Care System:* sets out the foundations that are to underpin the aged care system that we envisage.

Chapter 2, *Governance of the New Aged Care System:* details the governance arrangements that are crucial to our proposed reform of the aged care system.

Chapter 3, *Quality and Safety:* outlines the manner in which high quality and safe care should be embedded within the new aged care system**.**

Chapter 4, *Program Design:* sets out the programs through which high quality and safe aged care are to be delivered.

Chapter 5, *Informal Carers and Volunteers:* outlines the manner in which the future aged care program should ensure that people who provide informal care and support to older people should themselves be supported.

Chapter 6, *Aged Care Accommodation:* describes what is required to ensure that people's accommodation can cater, where possible, to their changing needs, including having regard to features of accessibility and dementia-friendly design.

Chapter 7, *Aged Care for Aboriginal and Torres Strait Islander People:* sets out our blueprint for aged care for Aboriginal and Torres Strait Islander people.

Chapter 8, *Aged Care in Regional, Rural and Remote Australia:* details what is needed to ensure that people living in regional, rural and remote areas have better access to aged care.

Chapter 9, *Better Access to Health Care:* describes how health care is to be better provided to older people engaging with the new aged care system.

Chapter 10, *Aged Care for Older People with Disability:* details what is necessary to ensure that older people with disability have equivalent access to the care and support available under the National Disability Insurance Scheme as people aged 65 years or under.

Chapter 11, *Younger People in Residential Aged Care:* details the importance of ensuring that younger people in need of care have the support that they need so that they are not forced to live in residential aged care.

Chapter 12, *The Aged Care Workforce:* sets out what is needed to ensure that the aged care workforce is able to deliver safe and high quality aged care.

Chapter 13, *Provider Governance:* outlines improvements that will strengthen the integrity of the aged care system and focus approved providers on their core task of delivering safe and high quality aged care.

Chapter 14, *Quality Regulation and Advocacy:* contains a number of recommendations to improve the regulation and oversight of aged care quality.

Chapter 15, *Research and Development and Aged Care Data* | Commissioner Pagone: outlines the importance of research and development and of data to understanding how the aged care system works now and should be working into the future.

Chapter 16, *Data, Research, Innovation and Technology* | Commissioner Briggs: outlines how data and research will help to inform and evaluate the delivery of aged care, and recommends the adoption of improved models of care and new technologies to better position aged care in the future.

Overview | Funding and Financing the New Aged Care System | Commissioner Pagone

Chapter 17, *Funding the Aged Care System* | Commissioner Pagone: outlines reform to the funding of aged care to address both short-term threats to continuity of suitable aged care and the need for stable funding in the longer term that will deliver high quality care into the future.

Chapter 18, *Capital Financing for Residential Aged Care* | Commissioner Pagone: outlines a changed approach to capital financing for residential aged care.

Chapter 19, *Prudential Regulation and Financial Oversight* | Commissioner Pagone: explains the elements of a new prudential regulation and financial oversight framework, guiding principles for its refinement over time, certain statutory duties directly binding on providers, enhanced regulatory powers, and measures to improve regulatory capability.

Chapter 20, *Financing the New Aged Care System* | Commissioner Pagone: considers the available options for sustainable public financing of the aged care system's recurrent operating costs into the future.

Overview | Funding and Financing the New Aged Care System | Commissioner Briggs

Chapter 21, *Funding the Aged Care System* | Commissioner Briggs: outlines the ways in which funding arrangements should be improved to ensure the economic sustainability of the aged care system as a whole.

Chapter 22, *Personal Contributions and Means Testing* | Commissioner Briggs: sets out an approach to the system of contributions and means testing in aged care as a consequence of the recommended entitlement to aged care.

Chapter 23, *Capital Financing for Residential Aged Care* | Commissioner Briggs: outlines a changed approach to capital financing for residential aged care, including phasing out Refundable Accommodation Deposits.

Chapter 24, *Financial Oversight and Prudential Regulation* | Commissioner Briggs: outlines the elements of a new financial oversight and prudential aged care regulation framework, guiding principles for its refinement over time, certain statutory duties directly binding on providers, enhanced regulatory powers, and measures to improve regulatory capability.

Chapter 25, *Financing the New Aged Care System* | Commissioner Briggs: considers the need for an aged care improvement levy as an investment to improve the quality and safety of aged care.

Chapter 26, *Oversight, Implementation and Monitoring:* details the need for oversight and monitoring of the implementation of our recommendations.

Institutional arrangements

In Chapter 2, we each make recommendations about the governance of the new aged care system directed to the establishment of the institutions that we consider will improve the system.

We differ on the institutional form that certain aspects of these governance arrangements should take in the new system.

The model that Commissioner Pagone prefers—the Independent Commission model—involves greater independence from the Australian Government of the institutions that he proposes should govern the system. Commissioner Pagone believes the time has come for rebuilding the aged care system, rather than renovating a system that has proven not to be sufficiently effective. Commissioner Pagone believes rebuilding the aged care system is best achieved by establishing a new independent Commission—the Australian Aged Care Commission—the only objective of which is the effective governance of aged care in Australia. Commissioner Pagone proposes that this newly created body should perform the roles of System Governor, Quality Regulator and Prudential Regulator. Aged care pricing should be carried out by a new body—the Australian Aged Care Pricing Authority.

The model that Commissioner Briggs prefers—the Government Leadership model—supports greater independence in certain areas such as standard-setting, quality regulation and pricing, but maintains a strong Australian Government system leadership and stewardship role. Commissioner Briggs believes that reforming the existing institutions will deliver aged care reform quicker and more effectively, and that the Government is a necessary and important part of the transformation process. Commissioner Briggs proposes that a reformed Department of Health and Aged Care should perform the roles of System Governor and Prudential Regulator. Quality regulation should be the responsibility of a reconstituted Quality Regulator body, the Aged Care Safety and Quality Authority. Aged care pricing will be added to the responsibilities of the Independent Hospital and Pricing Authority, renamed as the Independent Hospital and Aged Care Pricing Authority.

To assist with readability, throughout the text of this volume, unless otherwise specified, we use the shorthand terms ‘System Governor’, ‘Quality Regulator’, ‘Prudential Regulator’ and ‘Pricing Authority’ which have the meanings as set out in the following table:

Term	Independent Commission model	Government Leadership model
System Governor	Australian Aged Care Commission	Australian Department of Health and Aged Care
Quality Regulator	Australian Aged Care Commission	Aged Care Safety and Quality Authority
Prudential Regulator	Australian Aged Care Commission	Australian Department of Health and Aged Care
Pricing Authority	Australian Aged Care Pricing Authority	Independent Hospital and Aged Care Pricing Authority

1. Foundations of the New Aged Care System

1.1 Introduction

The Australian aged care system requires fundamental reform. It requires a change in direction from the approach embodied in the existing legislation. In this chapter, we explain what the new direction should be.

Much has been said during our inquiry about the need to 'place people at the centre' of all aspects of aged care. To achieve this, we are convinced that a new Act is needed. The *Aged Care Act 1997* (Cth) focuses on service providers and the allocation to them of rationed subsidies to fund certain services for limited numbers of people. The new Act must focus on the safety, health and wellbeing of older people and put their needs and preferences first. It should provide an entitlement to the support and care each individual needs, and deliver care to prevent and delay the impairment of their capacity, due to age-related infirmity, to live independently. In 2013, Australia adopted a systems entitlement to support people with disability, but has not yet done so for those receiving aged care.

Framing the reform agenda as one based on entitlement is essential. There has been vigorous support for a rights-based approach in response to Counsel Assisting's final submissions.[1] Approaching reform in this way will embed the interests of people who need or receive aged care in all key aspects of the new system. It will guide policy development and refinements to program administration, and will govern and inform regulatory approaches, workforce development initiatives, and the approaches to be taken by approved providers to their own internal governance, organisational culture and care delivery.[2]

Aged care is much more than the sum of tasks that meet an older person's biomedical and basic daily living needs. The system of aged care that we propose will support people to live well into old age. People receiving aged care must be encouraged and supported to continue to enjoy the rights of social participation which are available to members of society generally. People receiving aged care should retain control over the planning and delivery of the care that they receive. Older people have their own desires and goals for a meaningful life and for their pursuit of happiness. The aged care system should support older people to achieve these goals.

The care and support to be provided in the new system should enable older people to continue to find hope, enjoyment and meaning, as far as possible, at all stages of their life and regardless of poor health or physical or cognitive impairment. Older people who experience ill health or injury should be supported to learn or relearn the skills that they need to function in everyday life. The aged care system must focus on supporting them

to re-establish or maintain living skills and to restore or maintain their connections within their communities. As a matter of principle, aged care must focus on older people being supported to live their lives in dignity, wherever they choose to do so.

In this chapter, we first identify important themes in the evidence about community expectations of the aged care system, and then make several recommendations proposing the foundational provisions of a new Act that will meet those expectations.

As we describe in Recommendation 1, a new declaration of purposes is required, focused squarely on the rights and interests of those who need aged care. We identify the rights to be promoted under the new Act (Recommendation 2) and the key considerations and the guiding principles for the administration of the new Act (Recommendation 3).

The Australian Government, in its response to Counsel Assisting's submissions, has told us that it:

> considers that the future aged care system should be underpinned by a number of key principles, in particular: older Australians receiving care must be at the centre of the system; families and carers must be supported to access the information and supports they need; care and services must be safe and of high quality; and the system must be sustainable into the future.[3]

We agree—and the system of entitlements under the new Act should extend not only to people receiving aged care, but also to those seeking it. They should also extend to family members and friends who undertake significant carer-related responsibilities—people we refer to as 'informal carers'. The inclusion of entitlements for informal carers in the new Act is consistent with the principles expressed in the *Carer Recognition Act 2010* (Cth). However, unlike the Carer Recognition Act, the new Act should provide means of enforcing those entitlements.

We go on to make a longer-term reform proposal (Recommendation 4) for the development of an integrated, long-term care strategy for older people in Australia, to be prepared through intergovernmental cooperation at the highest levels.

1.2 Common themes and desired outcomes

Each individual has their own ideas about how they want to age and what they want from aged care. However, over the course of our inquiry we have identified clear common themes in what the community expects from the aged care system. It is clear to us that people want to be treated with dignity and respect; to have control and choice about how they live their lives; to have and maintain relationships; to have quality of life which enables them to live the best life they can; and to maintain connections to their communities. It is clear that people wish to age in their own homes.

1.2.1 Dignity and respect

We have heard repeatedly about the importance of dignity and respect in aged care. Each person, regardless of their age or level of frailty, wants to be valued as a person and as an individual. Dignity is about how we would like our parents, grandparents, children and ourselves to be treated when we are old and frail; it is about mutual respect and trust and feeling valued. Ideally, treating people with dignity is about doing things with them, not doing things to them. Dignity and respect for the intrinsic worth of every person should mean that individuals are not to be perceived or treated merely as instruments or objects of the will of others.[4]

A team from Caring Futures Institute at Flinders University and led by Professor Julie Ratcliffe found, in a study conducted on our behalf, that being 'treated with respect and dignity' was the most important characteristic for people to rate the quality of a provider as satisfactory.[5] A 2018 study, conducted by COTA Australia, of over 700 older people and family carers in the community reached the same conclusion. When describing what 'quality' meant to them, participants in the COTA Australia study highlighted the need for 'quality' to involve aged care staff supporting them with dignity and respect, and the need for aged care staff to be trained to understand fully the importance of respect and dignity as fundamental elements of care delivery. Family members also stressed the value of respect for each older person, including understanding the person's past, their preferences and their identity.[6]

The overwhelming majority of respondents in the Flinders University study also considered all other aspects of care to be 'important' or 'very important'. However, older people being treated with respect and dignity was among the highest (94%) along with aged care staff having the skills and training needed to provide appropriate care and support (94%), and older people feeling safe and comfortable receiving aged care services whether in a nursing home or in their own home (94%).[7]

Being treated with dignity or indignity can have a profound impact on a person's life. The way that care is delivered influences whether an older person feels respected, and is likely to have the greatest effect on a person's sense of dignity.[8]

There are simple ways in which dignity can be afforded, such as a care worker clearly introducing themselves, seeking permission to enter a person's private space, or gently tapping the person on the shoulder and explaining what they are there to do. Mrs Patti Houston, a personal care worker, described 'looking at a person as a whole, not just that they need to be in a room, they need to be washed and cleaned. We need to be actually [fulfilling] their needs as human beings'.[9]

This approach is no less important when the person receiving care has a cognitive impairment. At all times care should be respectful, engaging and kind. Indeed, it is precisely when a person in need of care has a severe cognitive impairment or some other vulnerability that it is most critical to stress the rights of that person. As the preamble to the Universal Declaration of Human Rights reminds us, 'all members of the human family' have 'inherent dignity' as well as 'equal and inalienable rights'; and the 'peoples of the United Nations' reaffirmed their faith in that Declaration 'in the dignity and worth of

the human person'.[10] That dignity and worth—something Professor Tom Kitwood called 'personhood'—can be placed at risk by the actions of others where the person is living with cognitive impairment, but must be upheld in spite of any level of cognitive decline.[11]

Recognising that every person is a unique individual with their own values, preferences, beliefs and experiences, and getting to know the person as well as possible, is central to dignity. Even when a person is severely cognitively impaired or has very little ability to communicate, they can still share a moment of connection that gives life a quality that is very meaningful.[12] Mr Barrie Anderson spoke movingly about Grace, his wife, and her experience of living with dementia in the palliative care stage. He told us that there were always moments of connection—'Eureka moments', he called them—to be sought and found.[13] He said that when people asked him how to care for his wife, he replied:

> It's a fairly simple message, actually, to walk in Grace's shoes, to recognise that she's had a rich past, that there's a present and that she has an evolving future.[14]

Knowing those that they are caring for well helps carers to understand how someone would like to be cared for and what is important to them. Of course, this takes time and an environment in which care staff are not 'run off their feet'—a point that is relevant to the recommendations that we make later in this report about the aged care workforce, staffing levels and funding. Knowing the person well also allows care to be given in a way that reinforces that person's sense of self and maintains their dignity.[15]

1.2.2 Self-determination

Self-determination is having autonomy, control and choice over your own life. It is closely connected with dignity. Choice and control, and involvement in decision-making, promotes dignity.[16] It is hard to maintain dignity when there is an inability to be involved in decisions about your own life.[17] However, being able to make decisions and choices has been shown to improve quality of life and health outcomes, and may help maintain cognitive function.[18] Having a sense of control can make the transition to old age easier.[19]

Connected to self-determination is the concept of 'dignity of risk', where older people have the freedom to choose how to live their lives. Professor Joseph Ibrahim, the Head of Health Law and Ageing Research at Monash University, described the concept this way:

> It's all to do with the person who is making their choice. So dignity of risk is, 'I get to take risks with my life, because, by taking risks with my life I feel alive, I have my autonomy, and I learn'.[20]

The right to take risks that align with personal goals and values is an important part of life. People have different risk appetites, so risk will mean something different to each person. Some people have a high-risk appetite, while others want to be largely protected from all risks.[21] It is important to older people that they set the boundaries about what is acceptable and important to them, and that this is reflected in the aged care system.

A diagnosis of dementia or cognitive impairment does not mean that a person is incapable of making decisions. However, it may mean that an older person requires support to help them understand information, make decisions, and communicate those decisions. Dr Craig Sinclair, from the Centre of Excellence in Population Ageing Research, said that across a spectrum of decision-making abilities, tailored support can help a person exercise their capacity, even as their cognition might be declining.[22] Research from La Trobe University found that people with dementia appreciated when support was 'subtle' and helped them to make their own decisions. But when carers took over and people's role in decision-making was reduced or removed, it left them feeling excluded.[23] The authors concluded that:

> Being and remaining central to decisions that affected them was a way to affirm: I am a person! I am still here![24]

Mrs Rosemary Milkins PSM told us of the 'very fine balance' between carers helping people 'to do something' and 'supporting them do things for themselves'.[25] One day she arrived at her mother's house to find a 'big red box' on the table containing all her mother's medication. Mrs Milkins assumed a nurse had decided that 'she would put the tablets in the box so that my mother could no longer take them herself'.[26] She described her mother's reaction:

> My mother was furious. Every fibre of her body was outraged. Because what it showed to her, this symbolic red box was, you are a fool now, you are daffy, you can't work it out for yourself, you're stupid, so we're taking it away from you, your toys and we're putting you in the naughty corner. I was outraged because it meant how the hell was my mother supposed to take her tablets then? Who would give them to her if she could not give them to herself? And that would mean nurses would have to come every morning to do it and if she was given something that was three times a day, how were they going to do that? When in fact she was just confused for a moment. So it's that simple. You can actually take away someone's skill to do something that quickly.[27]

Supported decision-making is an approach that emphasises the ability of people to make their own decisions with the right support.[28] It is based on the premise that everyone has the right to make their own decisions, and they should be supported to do so. The principles underlying this approach are empowerment, choice and control. There are many ways to achieve supported decision-making, but the best approach will depend on the particular needs of the older person. It can include spending time to determine a person's preferences and wishes, and helping a person communicate their decision to others.[29] Most importantly, it is what the older person wants. Supported decision-making is very different to substituted decision-making, where a person steps in to make a decision on another person's behalf.

In 2014, in its *Equality, Capacity and Disability in Commonwealth Laws* report, the Australian Law Reform Commission proposed a set of National Decision-Making Principles to guide the drafting of relevant Australian and State and Territory laws. The decision-making principles are:

- 'All adults have an equal right to make decisions that affect their lives and to have those decisions respected.'
- 'Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.'
- 'The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.'
- 'Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.'[30]

The Australian Law Reform Commission recommended aged care laws and legal frameworks be amended to be consistent with these decision-making principles. It reiterated this recommendation in its more recent report, *Elder Abuse—A National Inquiry*.[31] We support the recommendations of the Australian Law Reform Commission.

In our view, there will be limited circumstances where it will not be possible to give effect to supported decision-making in some way. However, in the event that it is not possible to ascertain the preferences of an older person, we support the Australian Law Reform Commission's recommendation that decision-making must 'give effect to what the person would likely want, based on all the information available, including by consulting with family members, carers and other significant people in their life'.[32] Further, the Carer Recognition Act requires that informal carers 'should be considered as partners with other care providers in the provision of care'. [33]

1.2.3 Quality of life

Quality of life should be the constant and predominant aim of the aged care system.[34] The desire for a good quality of life may change in content but does not diminish with age. Whether a person is young, old, active or frail, there is an inherent desire to live a quality life.

Quality of life extends beyond physical health to social and emotional fulfilment. We believe that even when a person is very frail or unwell, they generally have the desire and capacity to improve or maintain their physical, social and emotional wellbeing. This not only helps preserve the dignity of the person, but in some cases it can help prevent deterioration.

Ms Eileen Kramer, at 105 and a half years of age, was the oldest witness to give evidence to us. Ms Kramer had a successful career overseas and in Australia in modern dance and

the arts. She continues to contribute to the arts. Ms Kramer said that she did not want 'to be involved' in talking about age. But she continued:

> But now that I am involved, I see it's important and I'm quite enjoying it. So long as I'm not expected to behave old. I don't feel old. I don't want to behave old. But I realise that the spirit has a house to live in and that house is our body, so we have to look after that. And that's what aged care is about, in a way. We have to look after that house so that our spirit can enjoy life.[35]

Aged care focused on quality of life should not be afraid to aim to deliver fun and joy. Mr Bryan Lipmann, the Chief Executive Officer of Wintringham—a provider of aged care for people who are experiencing homelessness or at risk of homelessness—explained that when thinking about how to deliver aged care, the staff at Wintringham ask themselves how they would like to be treated when they are old and frail:

> The second part of the answer to that is joy. Our clients say that joy comes from talking and laughing with those around them; from feeling that another person is finding genuine pleasure and comfort in their company. Finding a way to give our clients that feeling is a challenging, but fundamental part of our care workers' role, and facilitating and supporting that is an essential part of our management team's role.[36]

There should be every opportunity for older people to enjoy a satisfying life in later age. Opportunities need to be available for people to realise this capacity. Older people are entitled to receive aged care services that enable them to continue living their lives, rather than creating a sense that quality of life is no longer achievable.

1.2.4 Relationships

People are highly sociable beings who need contact with others and caring or loving relationships. Throughout this Royal Commission, we have heard about the importance of quality relationships to older people and to the quality of their care. We have also heard that older people want to spend more time with others. Their wishes are heightened in the environment many older people find themselves in, where siblings, partners and friends may have died, leaving them increasingly alone.

Caring, by its very nature, depends upon relationships and interactions between people. That is how the terms 'care' and 'caring' are commonly understood. Caring relationships that leave older people feeling heard and seen, respected and cared for are central to maintaining dignity. It is essential in aged care to build respectful and reciprocal relationships that are based on trust between everyone involved in caring for older people. These relationships include those between the older person, their loved ones, aged care providers, those working in aged care, and the wider community.

Investing sufficient time and ensuring that carers provide support consistently are key to building genuine relationships between older people receiving care and the people providing aged care services. Without time and consistency, it is very difficult for the older person receiving care and the person giving care to get to know each other well and to build the level of trust needed to ensure that the older person's needs are met as those needs change.

Building relationships helps those providing care learn and know about a person's history, goals, values and preferences, including what is important to them, how they react to certain scenarios, and how they like to spend their time. These insights can then be used to inform how care is provided to that person. A witness, EA, told us about the steps taken by a support worker to develop a genuine relationship with her partner, EB. EB has Younger Onset Alzheimer's disease:

> They asked me about EB's work and social history, her interests and what she needed, what she liked to do. I told them about her love of animals and gardening and that she was not a TV watcher and that instead she liked the outdoors and working. I told them about how she needed to feel useful and busy and that she was not really a group person and engaged more willingly in one-to-one conversations. So when EB wanted to walk around rather than sit, the staff let her do that and asked her to help with tasks, such as hanging out the washing or setting the table or wiping the dishes.[37]

A culture of care that prioritises relationships has to be the 'core business' of any organisation involved in the delivery of aged care. The corporate strategy and budget priorities determined by the board, the chief executive officer and the executive group must aim to achieve this kind of culture of care.[38] The absence of the right culture flowing down from the top of an organisation will necessarily impede even the most motivated of care staff to prioritise relationships.[39] Mr Jason Burton, Head of Dementia Practice and Innovation at Alzheimer's WA, explained that:

> the majority of people working in aged care…are very caring, compassionate, inspirational, passionate people who want to do the best for their clients, and they're looking for care environments that will allow them to do that.[40]

1.2.5 Care at home

It has been made plain throughout our inquiry that older people who need care want to receive it in their own homes. We commissioned a survey to help us understand what people think of ageing and aged care. The responses suggested that the preference to remain at home increases as people reach their 70s and 80s.[41]

Ageing at home can be central to a person's sense of identity and independence.[42] For many people, home is a place of familiarity, comfort and privacy, providing meaning and security in situations where major life changes need to be confronted.[43] At home, older people have more control over their routines and more opportunity to continue performing roles that are important to their sense of identity.[44] Remaining at home is also important in keeping people socially connected.

There is a need to increase the availability of accessible social housing throughout Australia, so that an increased number of older people, including people experiencing homelessness and those at risk of homelessness, can age and receive aged care services at home. Unsuitable and insecure housing poses greater risks of falls, injury and immobility, as well as the prospect of unanticipated or early entry into residential aged care.[45]

1.2.6 Connection to the community

Part of the task of supporting people to live well in their old age at home involves keeping people socially connected. People who are actively engaged in the community have reduced rates of mortality, use fewer health services and have a better quality of life.[46]

The broader community has a role in supporting older people. Checking on someone to see how they are, helping them by mowing the lawn, taking them shopping or running errands, or simply sharing a cup of tea with them, can make all the difference for an older person.

When a person needs to move into residential aged care, it is essential that the new residence should feel like their home. The ambience, the sounds and the smells can make the place feel warm, welcoming and joyous. Residential aged care should be an appealing place to visit but the sad reality is that there is not always space in a person's room even to spend time comfortably with visitors.

Social connection also benefits members of the community who hear the stories, wisdom and lessons of history from older people. Aged care can and should provide an opportunity for people of different ages to connect. We agree with researchers and writers Lisa Fenn and Ian Holland, who put it this way:

> Residential aged care is a repository of community memory, encapsulating the social history of the last seventy, eighty, one hundred years. This vast collection of narrative creates a picture of the world not long past and the people who breathed life into its form.[47]

People should not feel cut off from life as they knew it before they moved into residential care. Whether people are receiving aged care in their homes or in residential care, they are still members of our community and it is important that they remain engaged, valued and socially connected.

1.3 A new Act and purpose

To achieve the fundamental reforms that we envisage so that older people's needs and wellbeing come first, a new Act is required.

The current aged care legislation is, and reads like, a scheme to ration the funding of limited subsidies which are made available by the Australian Government from time to time, accompanied by the imposition of responsibilities on approved providers to meet certain minimum quality and safety standards and consumer rights. The very definition of 'aged care' in the Aged Care Act is based on the particular forms and programs of services that are funded by the Australian Government rather than on any objective criteria of need.[48]

The Aged Care Act should be replaced if for no other reason than the constraints imposed by its structure. Neither its content nor its structure are compatible with the aged care system that we recommend, namely an aged care system based upon the necessary entitlements to lead a quality life in old age.

Purpose of the aged care system

The purpose of the aged care system must be to ensure that older people have an entitlement to high quality aged care and support and that they must receive it. Such care and support must be safe and timely and must assist older people to live an active, self-determined and meaningful life in a safe and caring environment that allows for dignified living in old age.

This purpose should be the touchstone for the administration of the new system. The purpose and the guiding principles should be embedded and evident in every part of the system, from overarching aged care policy development through to on-the-ground aged care service delivery.

If aged care is to meet community expectations as articulated in the purpose, a new Act is required. The current Aged Care Act does not sufficiently recognise older people who are seeking or receiving aged care. Section 3-4 and Chapter 4 of the Aged Care Act create a framework for the imposition of certain kinds of 'responsibilities' on approved providers in relation to the care they provide, but there is no provision protecting or ensuring a person's access to aged care if they need it but are not receiving it.

The general approach taken to the detail of those responsibilities in the delegated legislation and subordinate instruments made under the Aged Care Act is to treat the person receiving aged care as a 'consumer' of services. This evokes concepts akin to consumer protection rights rather than substantive rights as individuals, irrespective of a consumer bargain.[49] The 'consumer' protections approach depends on there being a reasonably well-functioning market in which the 'consumer' may make informed choices between service providers in effective competition with each other. As we explain in more detail later in our chapter on governance of the new aged care system, we do not think that this is realistic.

We consider that the aged care market lacks the key characteristics that are essential to achieve the beneficial outcomes for 'consumers' that would be expected from a properly functioning market. In particular, the idea of giving consumers choice and control depends on people having easy access to meaningful information about aged care services, and the ability to act on this knowledge. Despite the increasing rhetoric of 'consumers' and 'choice' within aged care, the notion that most people have substantial control over their own care is largely an illusion. 'Consumer-directed care' may be a noble policy aim but in reality choice and control are constrained in significant ways.

The Aged Care Act should be replaced with legislation that articulates the purpose of the new aged care system from the perspective of enforceable rights and entitlements.

It must protect and promote the rights of the people who need care as the central tenet and rationale of the system of aged care, and provide for the key elements and processes of the system from that starting point. Those early, foundational provisions will provide useful guidance to inform the design and operation of all key elements and processes in the system. They will guide the interpretation of all aspects of the new Act and will help to resolve any uncertainty or ambiguity in its provisions.[50]

Recommendation 1: A new Act

1. The *Aged Care Act 1997* (Cth) should be replaced with a new Act to come into force by no later than 1 July 2023.
2. The new Act should define aged care as:
    a. support and care for people to maintain their independence as they age, including support and care to ameliorate age-related deterioration in their social, mental and physical capacities to function independently
    b. supports, including respite for informal carers of people receiving aged care.
3. The objects of the new Act should be to:
    a. provide a system of aged care based on a universal right to high quality, safe and timely support and care to:
        i. assist older people to live an active, self-determined and meaningful life, and
        ii. ensure older people receive high quality care in a safe and caring environment for dignified living in old age
    b. protect and advance the rights of older people receiving aged care to be free from mistreatment and neglect, and harm from poor quality or unsafe care, and to continue to enjoy rights of social participation accessible to members of society generally
    c. enable people entitled to aged care to exercise choice and control in the planning and delivery of their care
    d. ensure equity of access to aged care
    e. provide advocacy and complaint mechanisms for people receiving aged care
    f. provide for regular and independent review of the aged care system
    g. promote innovation in aged care based on research
    h. promote positive community attitudes to enhance social and economic participation by people receiving aged care.
4. Unless indicated otherwise, the new Act should incorporate provisions giving effect to amendments to the *Aged Care Act 1997* (Cth) and the *Aged Care Quality and Safety Commission Act 2018* (Cth) (as well as to delegated legislation made under those Acts) the subject of other recommendations.

In Commissioner Pagone's view, it will be important for the new Act to identify the key institutional arrangements which he considers will be necessary to secure the successful attainment of the Act's purposes. They are: the Australian Aged Care Commission, a new independent body with system management, governance and regulatory responsibilities; the Australian Aged Care Pricing Authority, an independent pricing body to determine prices and funding levels necessary to support the provision of high quality and safe care; and an Inspector-General of Aged Care to provide oversight.

Our views differ on the most appropriate institutional arrangements for governance and management of the new aged care system. We each set out our views on those matters in detail in our chapter on governance of the new aged care system.

1.3.1 A rights foundation for high quality aged care

As outlined at the start of this chapter, we propose that the new system for aged care should be based squarely on the protection and promotion of the rights of the people who require support and care. This should be based on the application of objective criterion of need arising from ageing-related effects on older people's capacity for independent living. Before we turn to the rationale for this purpose, something must be said about the limitations of the current legislation and of the existing 'Charter of Aged Care Rights'.

Charter of Aged Care Rights

The Charter of Aged Care Rights is contained in a schedule of the *User Rights Principles 2014* (Cth), a piece of delegated legislation made by the Minister under the Aged Care Act.[51] The Aged Care Act requires that an approved provider must not act in a way that is inconsistent with any of the rights and responsibilities of care recipients listed in the User Rights Principles.[52] There are 14 rights listed in the Charter of Aged Care Rights. These rights apply when a person is provided with residential care, home care and short-term restorative care.[53]

The Charter of Aged Care Rights has obvious shortcomings. It does not recognise the rights of people who need care but who are not receiving it. Informal carers, who are so important to the sustainability of the system of aged care, are not recognised. Despite these shortcomings, each of the 14 rights is important and worth retaining in either statutory or delegated legislative form in the new system. It is clear that some of them are fundamentally important and deserve statutory protection, such as the rights to:

(1) safe and high quality care and services;

(2) be treated with dignity and respect;

(3) have my identity, culture and diversity valued and supported;

(4) live without abuse and neglect.[54]

However, because the Charter of Aged Care Rights is not enshrined in the Aged Care Act or any other Act, the list of rights in it, and any other aspects of the subordinate legislation to which it is scheduled, may be amended by the Minister from time to time. The Charter itself has been amended six times in five years, with the most recent amendments coming into effect on 1 July 2019.[55] That, no doubt, may be thought to give flexibility to add to or amend the rights and their description, but it lessens their weight in the legal structure created by the Act. Although expressed as a charter of rights, the Charter sits below, and is subordinate to, the provisions of the Aged Care Act. It does not govern or even inform the approach to interpreting other aspects of the aged care system administered under the Act.

It is also unhelpfully symbolic that the Charter is found in a schedule to a subordinate instrument that was made under the Aged Care Act.[56] This is a place one would expect to find operational detail rather than a measure for the protection of enforceable rights.

1.3.2 Rights

As we have made clear, in our view the new Act must enshrine the rights of older people who are seeking or receiving aged care. This will leave no doubt about the importance placed on these rights. Any rights-based approach must guarantee universal access to the supports and services that an older person is assessed as needing. The proposed rights of older people seeking or receiving care, as set out in Recommendations 2 and 3, are each elements of a core human right derived from Article 12(1) of the *International Covenant on Economic, Social and Cultural Rights*, which Australia ratified in 1972:

> the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.[57]

The *International Covenant on Economic, Social and Cultural Rights* provides that governments must use 'all appropriate means' to work towards the stated ends, 'particularly the adoption of legislative measures'.[58] We intend that the list of rights set out in Recommendation 2 may be invoked by individuals seeking protection from neglect, and its effects, by providers or governments in the implementation of the new system. The prescription of these rights recognises Article 12 of the Covenant and opens avenues for its enforcement.[59]

Recommendation 2: Rights of older people receiving aged care

The new Act should specify a list of rights of people seeking and receiving aged care, and should declare that the purposes of the Act include the purpose of securing those rights and that the rights may be taken into account in interpreting the Act and any instrument made under the Act. The list of such rights should be:

a. for people seeking aged care:
    i. the right to equitable access to care services
    ii. the right to exercise choice between available services
b. for people receiving aged care
    i. the right to freedom from degrading or inhumane treatment, or any form of abuse
    ii. the right to liberty, freedom of movement, and freedom from restraint
    iii. the right of autonomy, the right to the presumption of legal capacity, and in particular the right to make decisions about their care and the quality of their lives and the right to social participation
    iv. the right to fair, equitable and non-discriminatory treatment in receiving care
    v. the right to voice opinions and make complaints
c. for people receiving end-of-life care, the right to fair, equitable and non-discriminatory access to palliative and end-of-life care
d. for people providing informal care, the right to reasonable access to supports in accordance with needs and to enable reasonable enjoyment of the right to social participation.

International obligations to older people are implicit in most core human rights treaties. In addition to the key foundational document for modern human rights, the 1948 Universal Declaration of Human Rights, four further instruments stand out in significance in the context of aged care:

- the *International Covenant on Civil and Political Rights*[60]
- the *International Covenant on Economic, Social and Cultural Rights*[61]
- the *Convention on the Elimination of All Forms of Discrimination against Women*[62]
- the *Convention on the Rights of Persons with Disabilities*.[63]

Explicit references to older people in binding international human rights instruments are scarce.[64] However, there is a growing call for an international convention pertaining to the human rights of older people.[65]

The 1991 *United Nations Principles for Older Persons* encourages governments to incorporate a number of principles into their national programs whenever possible. There are 18 principles in total. They relate to independence, participation, care, self-fulfilment and dignity.[66] The themes are instructive and are similar to our proposed guiding principles.

More recently, a United Nations action plan, called the *2002 Madrid International Plan of Action on Ageing*, commits fully to the rights of older people, including empowering them to participate fully and effectively in the economic, political, and social lives of their societies.[67]

In 2012, the United Nations Office of the High Commissioner on Human Rights raised 'serious concerns about the realisation of older people's rights in long term care settings'.[68] The High Commissioner noted that:

> There are areas related to the experience of older persons which are all but completely overlooked by the human rights system, such as the rights issues arising in the delivery of home, institutional or residential care services, or the rights engaged at the end of life and access to palliative care.[69]

While there is no international consensus on a common set of human rights and principles that should underpin aged care, we have identified those which we think are necessary elements of a human rights-based aged care system, best adapted to the Australian context.

In recent years, Australian Government policy has been to make aged care more 'consumer-directed'. That might accord a measure of freedom of choice to some people and in some circumstances. However, in our view it will never be enough. People need to be placed at the centre of the system in a manner that meets community expectations and ensures their dignified and respectful care. We consider that a rights-based approach which permeates all aspects of aged care is far more likely to ensure that older people are treated with humanity, dignity and respect.

Typically, rights are supported by a related enforceable duty. With the exception of the right to freedom from restraint, we do not propose that each of the rights we list in Recommendation 2 should be separately and directly enforceable in the courts. Rather, they should be seen as aspects of a general duty to provide high quality care imposed by the new Act on approved providers. We refer in detail to the enforceable general duty we recommend for inclusion in the new Act in Chapter 3: Quality and Safety and Chapter 14: Quality Regulation and Advocacy, later in this volume.

1.3.3 Principles for the aged care system

Principles or core values underpin most areas of government activity. The Royal Commission has provided us with an opportunity to refocus the foundational principles of the aged care system in the new Act. We have identified two paramount principles for the administration of the new Act:

- to ensure the safety, health and wellbeing of people receiving aged care
- to put older people first so that their preferences and needs drive the delivery of care.

These paramount principles are mandatory and provide high level guidance to all the participants in the aged care system about what is important and what they need to have regard to as they go about their day-to-day business. We are also conscious that more guidance is needed for these principles to be embedded in the culture and practice of aged care and, accordingly, we recommend a number of subsidiary principles in Recommendation 3.

Recommendation 3: Key principles

The new Act should:

a. provide that the paramount considerations in the administration of the Act should be:
   i. ensuring the safety, health and wellbeing of people receiving aged care
   ii. putting older people first so that their preferences and needs drive the delivery of care
b. specify the following principles that should also guide the administration of the Act:
   i. older people should have certainty that they will receive timely high quality support and care in accordance with assessed need
   ii. informal carers of older people should have certainty that they will receive timely and high quality supports in accordance with assessed need
   iii. older people should be supported to exercise choice about their own lives and make decisions to the fullest extent possible, including being able to take risks and be involved in the planning and delivery of their care
   iv. older people should be treated as individuals and be provided with support and care in a way that promotes their dignity and respects them as equal citizens
   v. older people are entitled to pursue (and to be supported in pursuing) physical, social, emotional and intellectual development and to be active and engaged members of the community, regardless of their age or level of physical or cognitive capability

vi. the relationships that older people have with significant people in their lives should be acknowledged, respected and fostered

vii. to the fullest extent possible, older people should receive support and care in the location they choose or, where that is not possible, in the setting most appropriate to their circumstances and preferences

viii. older people are entitled to receive support and care that acknowledges the aged care setting is their home and enables them to live in security, safety and comfort with their privacy respected

ix. older people should have equal access to support and care irrespective of their location or personal circumstances or preferences

x. care should be provided in an environment which protects older people from risks to their health

xi. care and supports should, as far as possible, emphasise restoration and rehabilitation, with the aim of maintaining or improving older people's physical and cognitive capabilities and supporting their self-determination

xii. Aboriginal and Torres Strait Islander people are entitled to receive support and care that is culturally safe and recognises the importance of their personal connection to community and Country

xiii. the system should support the availability and accessibility of aged care for all older people, including people of diverse backgrounds and needs and vulnerable people

xiv. the aged care system should be transparent and provide public access to meaningful and readily understandable information about aged care

xv. government entities, providers, health care professionals and aged care workers operating in the aged care system should be open, honest and answerable to older people and the wider community for their decisions and actions

xvi. innovation, continuous improvement and contemporary best practice in aged care are to be promoted

xvii. older people should be supported to give feedback and make complaints free from reprisal or adverse impacts

xviii. people receiving aged care should respect the rights and needs of other people living and working within their environment, and respect the general interests of the community in which they live; the rights and freedoms of people receiving aged care should be only limited by the need to respect the rights of other members of their community

xix. the Australian Government will fund the aged care system at the level necessary to deliver high quality and safe aged care and ensure the aged care system's sustainability, resilience and endurance.

We consider that these guiding principles should be used to signal to those working within the system how they should conduct themselves, including the ethical constraints on their actions. The principles will also provide a level of surety to the older people using aged care that their interests will be protected, their needs responded to appropriately, and their circumstances recognised in a fair and respectful way.

On a day-to day-basis, it can be difficult to remember all that is required, so Commissioner Briggs has developed the following simple working guide to the principles, with which Commissioner Pagone agrees. This should help everyone working in aged care to keep at the centre of their thoughts that the aged care system should put older people first and that it should be equitable, effective, ambitious, accountable and sustainable. These are expanded upon in the annexure to this chapter.

Working guide to the principles for the aged care system

1. **Putting older people first**: The preferences and needs of older people drive aged care.

   Older people should genuinely be at the centre of their care. They should be part of the conversations about their care and their needs and preferences should be respected and reflected in their care. Care services should enable older people to live the life they want to live and to be all they can be.

   Care services should respect the privacy and dignity of each older person, and be delivered with kindness and compassion. Time and effort should be put into building relationships with older people and ensuring that they remain a core part of our community.

2. **Equitable**: Older people have fair and equal access to high quality aged care.

   Older people should have a fair and equal opportunity to receive high quality aged care, regardless of gender, race, ethnicity, sexual preference, where they live, religion, income, socioeconomic status, and linguistic and other circumstances.

3. **Effective**: High quality aged care that delivers the best possible outcomes for older people.

   Aged care services will be effective if they deliver on the promise of their purpose—to assist older people to live a self-determined and meaningful life, and ensure they receive high quality care in a safe and caring environment for dignified living in old age. For many, this will involve enabling them to improve their health and wellbeing; for others, it will enable them to be all that they can be as their health and capabilities decline.

   Care will be integrated between health and aged care services so that it meets each individual's needs across the care continuum. It will be flexible, responsive and timely. It will be informed by sound evidence and research-based practice and professional knowledge.

4. **Ambitious**: The aged care system is the very best it can be.

   The system should be ambitious for older people and walk alongside them so that they can live the best life possible.

   Ambition is also about striving for the very best aged care system possible. It is about excellence. It is about going well beyond the minimum regulatory requirements, by adopting best practice and innovating to improve future practice.

5. **Accountable**: The aged care system is open, honest and answerable to older people and the wider community for its decisions, actions and consequences.

   Older people, their carers and families have every right to honest, comprehensive and accessible information about aged care services. Those who provide services and the Australian Government should be accountable to the Australian people for the claims they make about the services and for the quality of those services. They should act ethically, with integrity and with honesty.

   Government should hold aged care providers and its agencies to account. It should provide information to the public that reports accurately and honestly about the quality of aged care and the state of aged care services.

6. **Sustainable**: The aged care system is resilient, adequately funded and enduring.

   A sustainable system is one that has what it needs to develop and renew itself. A sustainable aged care system is able to adapt, respond quickly to change and evolve in line with community expectations about the reliability and quality of care. It has sufficient resources to deliver on its high quality care purpose now and into the future. It is enduring.

1.4 Supporting people to age well

The experience of ageing is different for everyone. Some people are fit and healthy well into their 80s, while others may experience cognitive decline or frailty well before then. Their experience is influenced as much by social expectations as by the biological process of ageing. Certain conditions, such as hearing difficulties, pain and feelings of depression, can be put down to ‘old age’ by older people and by their doctors, when actually many of these conditions are preventable and reversible if treated early. There is much that can be done to help people have more active, healthy and engaged lifestyles as they age.

It is apparent to us that the aged care system is only one component of what is needed to support people to age well. There are other government strategies and policies that can complement formal aged care to help people live a long life in good health. These sorts of strategies include designing age-friendly communities that support people to stay in their own homes into later life, designing age-friendly city and town planning, and fostering more positive attitudes and beliefs about older people.

Beyond this, there are little everyday things that we can all do to enable older people to live their lives to the fullest extent possible, to be less isolated, and to be happier. We urge all Australians to talk to their older relative or friend or neighbour about what they can do for them. It might be as simple as taking them to the shops, helping by mowing their lawn or putting out their washing, having a coffee together, or watching a game on the TV.

Older people should be encouraged to think about what it is that would make them happy, and to have some goals or objectives for each day or week that give purpose to their lives. Many people will want to help their families or spend time with grandchildren. Often it is relationships with friends or siblings that will get people out of the house and doing things in the wider community. These relationships are to be cherished and fostered. Some older people have the capacity, and the inclination, to talk to a young person in trouble or who needs help finding their way. Older people have a lifetime of stories to tell, but they also want to hear the stories of others, including young people. Each older person has much to contribute.

Governments and society need to recognise that increased life expectancy provides opportunities that should be embraced and developed. Longer lifespans provide a valuable resource for society. Older people contribute to society in a number of ways, including as mentors, entrepreneurs, consumers, caregivers, volunteers and friends. Cross-generational engagement and programs have been, and should continue to be, established to link older people to their communities.

1.4.1 Integrated long-term support and care

There is a tendency to think and to speak of 'aged care' in isolation from related service types rather than considering it as part of a spectrum of supports and care that can assist people in their old age. In our view, a key reason for this is Australia's federal system and its associated division of governmental responsibilities between different jurisdictions. This has contributed to a complex patchwork of intergovernmental arrangements establishing different funding and administrative responsibilities. This includes the various tiers and types of health and allied health care, housing and homelessness assistance, retirement income supports and social welfare, and local community services supporting social inclusion and participation. These arrangements would be very difficult to unpick in isolation of each other, and no level of government has leadership responsibility for them all. Thus, we tend to think about and plan for each of these areas separately. The founders of our Constitution foresaw such fragmentation and problems in the context of interstate trade and commerce by providing for the existence of an Inter-State Commission.[70] Something of that kind would be desirable in the complex system for the provision of aged care and related services.

In a sense, this Royal Commission illustrates the point poignantly. Our Terms of Reference give us only limited authority to travel outside the boundaries of a set of activities funded by the Australian Government under various programs that are labelled as 'aged care'.

Yet this is quite arbitrary. Aged care is but one aspect of what an individual may need to ensure a dignified and meaningful life in old age, and what a cohesive community should have available to ensure older people are respected as they deserve.

In 2001, the Australian Department of Health and Ageing released a *National Strategy for an Ageing Australia*.[71] The National Strategy was designed to be the framework for the 'national response to the challenges and opportunities that an older Australia' would present.[72] In the 20 years since that strategy, there have been efforts to improve the health, wellbeing and social participation of older people across all levels of government.[73]

There are pioneering examples in Australia and elsewhere of efforts to deliver more integrated forms of support and care for older people.[74] However, there has been limited concerted national effort to coordinate this work.

In 2017, the World Health Organization launched a strategy called 'Integrated Care for Older People', known as ICOPE, which resonates strongly with many of the themes of our Terms of Reference and of this inquiry. In doing so, the World Health Organization highlighted the challenges posed by ageing demographics in countries across the world. The internationally-accepted term for support and care of older people is not 'aged care' but 'long-term care'.[75] Using this term, the World Health Organization explained the basics of integrated long-term care:

> WHO [the World Health Organization] defines long-term care as 'the activities undertaken by others to ensure that people with significant loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity'. These activities include social care, health care and the contribution of other sectors, such as transport – and all of these should be integrated to ensure optimal coordination and efficiency. Long-term care systems may include a range of paid and unpaid caregivers, so this needs to be considered in the implementation of the ICOPE approach.[76]

We commissioned a report from the National Ageing Research Institute on models of integrated care, health and housing.[77] The authors of that report explained that although 'integrated care' means different things to different people:

> Fundamentally, it refers to strategies aimed at overcoming fragmentation between different services and sectors as a way of improving the health and wellbeing of clients, client satisfaction with services, and the efficiency and long-term sustainability of health and aged care systems.[78]

The authors identified a number of different dimensions and approaches to integrated care. At the individual level, they said, a person-centred approach should be taken, and different models of integrated care might be appropriate for people depending on whether they have complex health needs, socioeconomic or cultural needs, or the need for moderate or low-level supports.[79] At the community level, they cautioned that integrated care 'works best when focused on health and wellbeing for a defined population, with governance and leadership at a local rather than system-wide level'. This is because each community 'requires an approach to integration that is responsive and adaptive to their demographic, geographic, socio-economic and cultural profile'.[80] Building on the work already done and on the World Health Organization's support for more integrated forms of support and care

for older people, we consider that there should, in time, be an integrated system for the long-term support and care of older people and their ongoing engagement with the rest of the community. Such a system needs to be sufficiently flexible to foster and support local models of integrated care for particular communities.

The potential for an integrated system of supports should be the focus of a new National Cabinet Reform Committee on Ageing and Older Australians, as set out in Recommendation 4. Placing this issue on the National Cabinet agenda will not only open the avenues needed for holistic attention to be given to the current patchwork of arrangements across housing, welfare, retirement income policy, health and aged care, but will elevate the status and enhance the rights of older people in the eyes of the community.

The Australian Government's role is clear—national leadership is required on these matters. State and Territory Governments also have a role to play in helping people age well. The service coverage offered by the States and Territories is critical to the success of any integrated system and they should be actively engaged in the process. The development of the national strategy and integrated long-term support and care for older people will require all levels of government and the community to look beyond individual programs and arrangements to focus on what older people want and need.

We propose a period of 10 years for the implementation of this integrated system of supports. After that, it should be comprehensively reviewed to inform development of the next strategy.

Recommendation 4: Integrated long-term support and care for older people

1. **The Australian Government should coordinate the development of an integrated system for the long-term support and care of older people providing for their needs for welfare support, community services directed at enhancing social participation, affordable and appropriate housing, high quality health care, and aged care. This should be achieved through a new National Cabinet Reform Committee on Ageing and Older Australians, to be established between the Australian and State and Territory Governments, and composed of the highest-ranking ministers whose primary responsibility is the care, health and wellbeing of older people.**
2. **Work on a strategy to develop the integrated system for the long-term support and care of older people should begin immediately. That work should:**
    a. **involve consultation with older people; and**
    b. **include measures to support the wellbeing of people receiving aged care by connecting and integrating aged care services with the broader community.**
3. **The strategy should provide for implementation of an integrated system for the long-term support and care of older people within a 10-year period.**

A key element of the strategy to support older people should be to encourage people as they age to take active steps to preserve and maintain their own health and wellbeing in later life. While the focus areas for the strategy should be identified and led by older people, we have identified the following areas of potential focus:

- supporting people to reach their full capacity so they are able to enjoy more healthy and meaningful years of life
- providing supportive and inclusive environments that promote dignity, independence and fulfilment despite any significant physical or cognitive incapacity
- establishing and enhancing mechanisms within the community that foster inclusion
- taking a proactive approach to preparing for older age—including engaging in healthy behaviours to promote health and function across the lifespan and adequately planning for future care needs
- supporting older people's ongoing engagement with the rest of the community and their choice to age at home.

In September 2020, in a hearing, the Hon. Paul Keating proposed that the Australian Government should establish an integrated system of supports for people aged over 80 or 85 years, catering to their housing, health, income and aged care needs. Their pension, superannuation assets and income could be 'tailored into' such a system.[81] In our view, this approach to a future integrated long-term care system should be evaluated by the new National Cabinet Reform Committee on Ageing and Older Australians.

The National Ageing Research Institute gave particular attention to the importance of secure housing, noting that Australia's aged care system 'assumes that aged care clients either have secure and appropriate housing or live in residential aged care' whereas housing insecurity is common and likely to become more so.[82] Estimates from Census data suggest that between 2006 and 2016, homelessness increased by 49% for people aged 55 years and over, with the greatest increase for all age cohorts being 59% for people aged 65 to 74 years.[83] Mr Lipmann expressed concern, based on his expertise on the needs of people experiencing homelessness, about the lack of connection between aged care and housing programs.[84] It is particularly clear that the proposed future strategy should involve Housing Ministers across all Australian Governments to provide for more integrated solutions to the housing and care needs of older people who are experiencing homelessness or at risk of homelessness.

An integrated system for the long-term support and care of older people and their ongoing engagement with the rest of the community will further support people as they age. This requires the involvement of all levels of government. It should be sufficiently flexible to permit diversity and choice in the forms in which long-term care should take. A strategy to develop this integrated system needs to be developed to support people to live well in their old age at home.

1.5 Conclusion

The challenges presented by forging a new aged care system for Australia extend beyond the Government to the entire Australian community. Only the community can bring to bear the desire and will for lasting change. It is a change that sees growing older as a normal part of life—as a stage of life that holds the potential for happiness and fulfilment. We are confident that the community supports fundamental change of this sort in aged care. That change should take as its foundation the new Act, with its purpose, outcomes and principles, and the universal rights that we propose.

1.6 Annexure: Policy principles

Principle	Individual	Provider	System
1. PUTTING OLDER PEOPLE FIRST: The preferences and needs of older people drive aged care.	Older people direct their own lives and the care they receive. Older people are supported to advocate for themselves. People receiving care are respected, and each is seen as an individual with an identity, a history and a future. Older people are not defined by any cognitive or physical impairment or by their age. Older people are supported to be active and engaged members of their community.	The views of older people influence how aged care services are delivered. Providers are able to support older people to make their own decisions. Providers are able to recognise the role and advice of appointed advocacy bodies. Care practices are dignified, compassionate, and culturally safe. Respectful relationships between all people involved in caring are the norm.	The views and needs of older people drive aged care policy over time. The aged care system reflects community expectations. Getting older is seen as a normal part of the lifespan that benefits from planning for the future.

Principle	Individual	Provider	System
2. EQUITABLE: Older people have fair and equal access to high quality aged care.	The aged care system is inclusive of all and recognises each person's unique wants and needs. Everyone has fair and equal access to high quality aged care—regardless of a person's gender, race, ethnicity, sexual preference, where they live, religion, income, socioeconomic status, and linguistic and other circumstances. People are able to equally access high quality aged care in their local area. There are no barriers to access aged care for people who do not have the capacity to pay. People contribute to the cost of their accommodation and living expenses according to their ability to pay.	Providers are able to ensure that services are suited to each older person's personal history and circumstances. Providers are able to provide services in a way that does not discriminate in access to, or the quality of, aged care services on the basis of a person's gender, race, ethnicity, sexual preference, where they live, religion, income, socioeconomic status, and linguistic and other circumstances.	The system responds to each individual older person's particular needs and ambitions. The system supports fair and equal access to high quality aged care—regardless of a person's gender, race, ethnicity, sexual preference, where they live, religion, income, socioeconomic status, and linguistic and other circumstances. There are no financial barriers to access aged care. People receiving aged care contribute to the cost of their accommodation and living expenses when they can afford to do so. The system initiates local and regional strategies to ensure coverage and equity of access.

Principle	Individual	Provider	System
3. EFFECTIVE: High quality aged care that delivers the best possible outcomes for older people.	People feel safe and secure in aged care. They have confidence that the aged care system works for them. Care is available when it is needed. Care is seamless and coordinated so that older people's needs are met as their conditions and circumstances change. Care is tailored to a person's particular needs and preferences as far as possible. Older people receive high quality clinical and personal care that is dignified, compassionate, and culturally safe.	Aged care services are able to respond to the diverse needs of people accessing care—it is not a 'one size fits all' approach. Care is informed by evidence and best practice guidelines. There are predetermined staffing levels and a skilled workforce supported to do good work. Providers are able to coordinate and link their services with other relevant services (e.g. with the health system).	The system provides people with the care they need, when they need it, and, where possible, in a setting they prefer. The system responds to the diversity of needs of people receiving care. The system supports best practice based on current evidence.

Principle	Individual	Provider	System
4. AMBITIOUS: The aged care system is the very best it can be.	Older people know that providers will be ambitious for them and support them to achieve their goals. People receiving care feel confident that providers will innovate and keep up with changes in best practice. Older people are confident that their experience of aged care will be acknowledged and properly responded to.	Older people are actively supported to give their views on improvements that could be made. There is a culture of continuous improvement and striving for excellence. Providers are supported to innovate and keep up with leading edge practices. Information from monitoring and evaluation is used to improve performance.	The performance of the aged care system is constantly monitored, evaluated and improved. The system incentivises and rewards innovation. The goal is excellence rather than compliance with minimum or core standards. It is possible to differentiate providers based on their performances. The views of older people about the system are actively sought out and listened to. There is support for a diversity of approaches to achieve future best practice in outcomes.

Principle	Individual	Provider	System
5. ACCOUNTABLE: The aged care system is open, honest and answerable to older people and the wider community for its decisions, actions and consequences.	Older people and their loved ones and advocates are able to hold providers to account for the quality of care they provide. Older people and their families are fair and respectful in their dealings with providers and their staff. Older people feel safe and supported to give feedback and make complaints. Older people receive timely feedback on the outcome of their feedback and complaints. Older people can easily and readily access meaningful data and information about aged care providers and aged care services.	Providers operate ethically and take responsibility for the quality of care they provide. Providers encourage and welcome scrutiny, feedback and complaints, and use this information to improve the quality of their services. There is a culture of continuous learning. Information about the operation and performance of providers is honestly provided, publicly available and open to scrutiny. People providing care have access to appropriate and effective mechanisms to assist them in dealing with challenging behaviours by people receiving care and/or their families and carers.	Roles and responsibilities within the system are clearly articulated and understood. The System Governor takes overall responsibility for the aged care system, and actively manages the system so that it achieves the best outcomes possible for older people. The public can understand the system and its purpose. Information and data on the system is publicly available, including information about the quality of care and the outcomes achieved by government agencies. The aged care system seeks out and stops poor performance.

Principle	Individual	Provider	System
6. SUSTAINABLE: The aged care system is resilient, adequately funded and enduring.	Older people have confidence that the aged care system has the capacity to meet their needs. Younger people have confidence that the aged care system will adapt to respond well to their needs.	Providers are able to withstand difficult circumstances and recover quickly without impacting the quality of care. Providers respond quickly to community expectations and evolve rapidly to deliver new and better services. Services are able to be provided consistently with the core purpose of aged care with minimum wasted expense and maximisation of available resources.	The aged care system is enduring and capable of adapting and growing over time. The aged care system is underpinned by a sound financial framework and has adequate resources to deliver high quality care. The aged care system is supported by policies and practices in other sectors, such as the healthcare sector and the higher education and VET sectors, the social services sector and the disability sector. The system is widely supported in the community and taxpayers are prepared to support it financially. The system is efficient in meeting its core purpose and operates with a minimum of administrative duplication and delay.

Endnotes

1 See, for example, Submission of Julie Gross McAdam, Response to Counsel Assisting's final submissions, 3 November 2020, RCD.0013.0002.0004 at Recommendation 1; Submission of William Norfolk, Response to Counsel Assisting's final submissions, 5 November 2020, RCD.0013.0005.0016 at Recommendation 1; Submission of Relationships Australia, Response to Counsel Assisting's final submissions, 10 November 2020 at Recommendation 1; Submission of Meaningful Ageing Australia, Response to Counsel Assisting's final submissions, 11 November 2020, RCD.0013.0009.0153 at Recommendation 1; Submission of Regis Healthcare, Response to Counsel Assisting's final submissions, 12 November 2020, RCD.0013.0011.0169 at Recommendation 1; Submission of the State of New South Wales, Response to Counsel Assisting's final submissions, 12 November 2020, RCD.0013.0014.0350 at Recommendation 1; Submission of the National Advisory Group for Aboriginal and Torres Strait Islander Aged Care, Response to Counsel Assisting's final submissions, 16 November 2020, RCD.0013.0018.0003 at Recommendation 1.

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2. Governance of the New Aged Care System

2.1 Introduction

In Volume 2, we report on aspects of the current system that contribute to substandard services. It would be wrong to blame those failures entirely on regulators and providers. There are problems embedded in the overall system, including in its governance. Older people do not receive high quality and safe aged care because existing system arrangements fail them.

Reform of the existing aged care system governance arrangements is crucial to the reform of the aged care system. We understand system governance to include guidance and direction, steering the system towards long-term policy outcomes, monitoring performance, addressing emerging issues and holding players in the system accountable for performance. In the context of aged care, these processes should apply to the delivery of high quality and safe aged care. These processes should not be allowed to stagnate. Instead, innovation and improvement must be encouraged and sustainability ensured.

The Australian aged care system has been under prolonged stress and has reached crisis point. This was illustrated by the tragic impact of the COVID-19 pandemic, which highlighted the weaknesses and shortcomings in the system, especially the lack of planning and the reactive nature of governance of the aged care system.

The aged care system includes a wide array of services defined and subsidised by the Australian Government, and delivered by approximately 3000 approved providers conducting thousands of 'services' or outlets throughout the country. We use the term 'aged care system' to describe all the entities, structures, people and processes contributing to how care to older people is provided, regulated and funded, and the policies that shape the content of that care.

The structure and functioning of the aged care system can only be understood and improved by taking into account the way it interacts with:

- the health care system
- the disability system
- the community
- all tiers of government.

Since 2012, save for the Home and Community Care programs in Victoria and Western Australia, the Australian Government has held policy and administrative responsibilities for aged care exclusive of the States and Territories.[1] Following the 2017 *Review of National Aged Care Regulatory Processes*, referred to as the Carnell-Paterson review, most responsibilities for quality and safety regulation were conferred on the independent Aged Care Quality and Safety Commission upon its establishment on 1 January 2019. The Australian Department of Health's remaining responsibilities for quality and safety regulation and for prudential regulatory compliance were divested to the Aged Care Quality and Safety Commission on 1 January 2020.[2] All other functions and responsibilities relating to management and governance of the aged care system remain with the Minister for Health and Aged Care, the Minister for Senior Australians and Aged Care Services and the Australian Department of Health.

The Minister and the Department—and their predecessor Ministers and Departments, over many years—have had the means available to provide effective leadership of the aged care system, but have proved unable to do so. The Australian Government has been the dominant funder of aged care services and has been described as the head of the 'supply chain'.[3] But it has not funded the system adequately. The Government has been in a position to create mechanisms for measuring performance of the aged care system and identifying areas for improvement. It has been responsible for the design of an effective regulatory system. It has failed to discharge these responsibilities.

Since assuming responsibility for all forms of in-home aged care from 2012, the Australian Government has failed to establish local system management to replace the role previously played by the State and Territory Governments. This has led to gaps in planning, development and management of services.[4] Waiting times for the assignment of Home Care Packages have been unacceptably long for several years. By 2018, the wait time was on average 22 months for higher-level packages.[5] Government announcements in relation to additional Home Care Packages have not kept pace with the demand reflected in the national waiting list.[6] For people entering the waitlist from 30 November 2020, the estimated waiting time was 3–6 months for those receiving a Level 1 package and still over 12 months for those approved for a higher-level package.[7]

Policy developments have intended to encourage competition between providers of aged care services in the expectation that competitive market forces would lead to innovation and improvements in quality and safety outcomes. The legislative and regulatory framework under the *Aged Care Act 1997* (Cth) uses language that reflects this approach, such as by describing people who need aged care as 'consumers' and emphasising the notion of consumer rights.[8]

Consistent with a market-based perspective, the Australian Government has not taken a proactive or even an active system governance role. Instead, it has tended to react to adverse developments, often belatedly. In short, there has been a vacuum in leadership of the entire aged care system and an unspoken assumption that market forces should generally be left to themselves, subject to quality regulation of the providers.

It is clear to us that a thorough systemic redesign is required to improve the aged care system.

Our task is to make recommendations for the future design and governance of an aged care system able to deliver, securely and predictably, high quality and safe care to older people. To achieve that, a commensurate financial commitment will be required from the Australian Government.

The success of our proposed reforms will depend on a coherent response by the Australian Government to all our recommendations. It is apparent from our inquiry into the aged care system that its character does not respond well, or predictably, to selective ad hoc or 'bolt on' reforms. This is one of the sources of its current defects and complexity.

2.2 Nature of governance required

The aged care system has many component parts and it is complex in its nature. Services are delivered through a range of mechanisms, and the providers and workers who deliver these services are diverse. The aged care system is affected and influenced by external factors, such as the quality of the education and training of its workforce and the availability of adequate sources of capital for investment. This complexity needs to be understood and managed effectively for the aged care system to be well governed and to deliver higher quality and safe aged care.

Although funded by the Australian Government, the aged care sector is in a large part a 'not-for-profit and for-profit service delivery system'.[9] Mr Michael Lye, Deputy Secretary for Ageing and Aged Care, Australian Department of Health, told us that residential aged care facilities have primary responsibility for the management of their services and they need to exercise judgment within their own legal responsibilities. He said the Australian Government cannot assume that responsibility.[10]

We acknowledge that there are particular challenges in designing and managing systems that are not private markets but depend heavily on government funding. The design and management of such 'quasi-markets' should be constantly refined.[11] However, this is not a reason for abdication of system governance responsibility by the Australian Government. Rather, it calls for a particular form of system governance that reflects the needs of the aged care system, which delivers intensely personal services. These needs are vastly different from the business-consumer style governance arrangements that exist in other sectors. The aged care System Governor needs to be proactive and adaptive, steering the system toward strategic objectives that are based on the health, safety and wellbeing of older people. It should not leave the system unattended and unwatched.

The System Governor must be able to set goals and evaluate the performance of each level of the system, and to correct and refine performance over time. The goals should be fixed but the ways of attaining them should be flexible. Regular review of performance should involve an iterative process of communication between those who deliver services, the institution that commissions them, and policymakers.[12] The regulator should also be involved in this process. Delivery methods should be refined and improved in light of standards, research, practical experience, funding levels and other realities.

The health care system must remain readily accessible and effective for people receiving aged care. Impediments to access to the various tiers and forms of health care that are available to the general community must be removed or at least lessened. Responsibilities for securing access to health care must be clarified.

Noting that 'Australia will not be able to afford to fund the social supports that are necessary to minimise risk for vulnerable older people in and of itself', Mr Robert Fitzgerald AM, NSW Ageing and Disability Commissioner, told us 'we have to reengage the community, as we have done through the COVID period, in being part of the solution'.[13]

Across all tiers of government, much would be gained from a more coherent and cooperative approach to advancing the interests of older people in areas including health, housing, welfare, industry innovation, workforce, education and training, community services and recreation.

We recommend that a strong and purposeful direction be set for the aged care system. We recommend that there be robust governance arrangements, including through independent examination of costs and prices, advisory mechanisms to ensure that older people have an effective voice, and high level review and evaluation.

We make recommendations directed to establishing institutions that we consider will improve the aged care system. Those institutions are:

- a strong system governor
- a focused quality and safety regulator
- an independent standard setting body
- an independent pricing authority
- an accountability and investigatory body
- a professional worker registration body
- an aged care data manager.

We differ, however, on the institutional form that certain aspects of these governance arrangements should take in the new system. The model that Commissioner Pagone prefers involves greater independence from the Australian Government of the institutions that he proposes should govern the system. In Recommendations 5 and 6, he recommends the establishment of two new fully independent agencies to lead and govern the aged care system, free from ministerial intervention. He also recommends the establishment of an Aged Care Advisory Council (Recommendation7). While Commissioner Briggs supports greater independence in certain areas, such as standard setting, quality regulation and pricing, she believes that reforming the existing institutions will deliver aged care reform quicker and more effectively. She considers the Australian Government to be a key part of the solution to aged care's systemic problems in Recommendations 8, 9, 10 and 11.

While the models that we propose are different, they have many similarities. These include a strong regional presence and active intervention in the marketplace to ensure the delivery of high quality and safe aged care. Together we recommend strong accountability through the establishment of an Inspector-General of Aged Care (Recommendation12).

We recognise that the design of Australian Government institutions is a matter for the Government. We therefore offer, in good faith, two models for the Government to consider, and the associated changes to institutional arrangements that will improve the governance of the aged care system.

We now outline our respective governance models in turn.

2.3 Independent Commission model | Commissioner Pagone

2.3.1 Overview of model

I recommend that the Australian Government implement governance arrangements for the aged care system that are independent of ministerial direction, and that involve an independent statutory body as System Governor, administrator and regulator. I suggest that this body be called the Australian Aged Care Commission. A specialist Australian Aged Care Commission can give undivided attention and focus to its task of being an effective System Governor of aged care.

Consistent with Australia's Westminster system of government and ministerial responsibility, however, there would continue to be a Minister responsible for aged care. The Minister would have responsibility for advising the Governor-General-in-Council—that is, with the advice of the Federal Executive Council being the Ministers meeting in Council—about appointments and removals of the board of the Australian Aged Care Commission, and powers of appointment or removal of other key officers. An Inspector-General of Aged Care would assist the Minister in the oversight of the system's governance, performance and fiscal demands. The Minister would be responsible for law reform and policy development and would be supported by their own Department. The Department head would be an ex officio member of the board of the Australian Aged Care Commission.

Funding arrangements for residential care have been volatile since at least 2012. Exposure of system governance to decision-making based directly on the Australian Government's fiscal position has contributed to that volatility. The focus of system governance should be on the continuity, quality and safety of aged care in the interests of people who need it. Yet the capacity for budgetary policy to affect system governance was present from the inception of the current residential aged care program. This was revealed by advice to government by the Australian Department of Health and Family Services and the Australian Department of Finance at the time. A Cabinet Memorandum from those Departments received by the Cabinet Office on 27 March 1997, relating to the integration of two

previously separate programs for residential care (in either hostels or nursing homes), is publicly available from the National Archives.[14] The memorandum identifies the 'billions' in savings that had been achieved to that time by 'capping service provision', the 'risks' to the government's budgetary position presented by the new program over the long term, and various mechanisms available to the government to control the costs of the system 'over the forward years'.[15]

The memorandum presented possible 'Options':

> Options that would be available, should Ministers decide at some point to consider further risk reduction measures, include enhancing the management controls on the number of high care or low care (nursing home or hostel) places, applying quotas to numbers of people at various care levels, an efficiency dividend or other adjustment to funding structures, various offsetting savings measures or changes to service provision benchmarks.[16]

The reference to an 'efficiency dividend' can be related to the method for calculation of annual indexation of funding levels adopted by the Australian Government in the years since 1997. However, all the options identified in this passage of the memorandum are of concern. The suggestion that there might be changes to 'service provision benchmarks' is particularly disturbing, as this goes beyond rationing and implies the possibility of reductions in quality levels to justify limitations in funding.

I see in the memorandum how decisions made by government, when working as it should, will be influenced by cost at the expense of health, care and wellbeing. The memorandum explained that 'capping or limiting' supply produced 'enormous savings' but 'necessarily results in higher average dependence and thus higher unit costs of care for those who get access to the system'.[17] In what was to be a new funding instrument, government was to have:

> total control over all of its parameters—the number of care classifications, the number of residents in each of them and the amount of funding that attached to each classification—and so total control of its theoretical cost.[18]

What Australians need for those in, and affected by, aged care is an independent champion for high quality and safe care rather than to have decisions made by the very people who must compromise between competing government and political priorities.

The independence of a Commission will enable it to put forceful arguments to secure what is needed to ensure that older people get the high quality care they need rather than needing to justify, and at times obscure, compromises between conflicting or competing demands.

The same cannot be achieved by requiring a Minister to make aged care a priority. It is instructive to look at the 1997–98 Annual Report of the Australian Department of Health and Family Services. Even then, its vision was expressed in terms that I have found to be lacking in the aged care system that has required this Royal Commission. Many of the recommendations that we make to improve the system were expressed in the 'vision and mission' of the Department at that time. Stating them again will not deliver them: a separate, focused and, crucially, independent champion has more chance of doing so.[19]

Internal structural changes within a department are also less likely to produce results than an independent Commission with the sole task of advancing the high quality care of older people. The Australian Department of Health and Family Services' 1997–98 Annual Report contains a useful central office management structure identifying the different units intended to advance the vision and mission at that time for the future. It already included many of the things that we identify as needing reform, such as 'Rural Coordination and Special Access', 'Program Development', 'Planning and Evaluation', 'Industry Development' and 'Strategic Development'. Aged and Community Care was one of the programs specifically within the Department, with the stated objective to 'enhance the quality of life of older Australians' through, among other things, 'the provision of a cohesive framework of high quality and cost-effective care services'. There was also a 'Portfolio Strategic Group' with individuals identified for such matters as strategic development and industry development. There is every reason to think that giving back to a department the tasks of system governor will result in the same general outcomes in aged care as we have had since the 1997–98 Annual Report.[20]

The impediment to better care is not with a lack of good intention or an absence of people with goodwill and public dedication. The impediment is in part structural—and part of that structural impediment can be removed by giving to an independent body the task of being the champion for those who are intended to receive high quality care.

It may be thought that the new aged care system for the long-term care of older people should simply become one of the core responsibilities of the Minister for Health and Aged Care, a senior member of Cabinet, as some might think has been achieved by the announcement on 18 December 2020 by the Prime Minister that aged care would be elevated to Cabinet.[21] In this context it should be recalled that all the debilitating savings measures and government responses to serial reports critical of the aged care system were all considered and formulated at Cabinet level. In effect, then, a senior Minister has run the system into its present state.

Fundamentally, aged care is not primarily a health issue. Health care is important, as for all Australians in all stages of life, but good health underwrites the wider dimensions of older people's lives: what gives meaning to life. Aged care must assist older people, to the highest degree practicable, to participate in social and economic activities and to enjoy an independent, fulfilling life in company with their loved ones, family and community. The care of older people should not be overwhelmed by the Australian Department of Health's priorities, bureaucracy and budgets.

The interests of older people lack a strong advocate whose only task is to promote their cause in government, to secure the benefits they need and to ensure that those benefits are delivered safely and equitably. The weight of evidence before me is that the current arrangements fail to meet Australians' expectations for a reliable, well-governed aged care system. The extent of the problems documented in this report is such that incidental changes to the way the system is structured and governed will not be sufficient to build a better, sustainable long-term care system. A fundamental redesign is required.

Regulation of the quality and safety of home care services is weak. Threshold requirements for the approval of providers are not rigorous, and months can pass before a quality review is performed upon a newly established home care service. Even then, regulatory visibility of in-home care is limited. The Aged Care Quality and Safety Commissioner has acknowledged the need for improvement of home care quality and safety regulation.[22]

In response to Counsel Assisting's proposal for the establishment of a new Australian Aged Care Commission, Mr Roger Beale AO, former Departmental Secretary of the Australian Department of Environment, Sport and Territories and Commissioner of the Public Service Board, and Dr Peter Freckleton, barrister, submitted:

> It would be disingenuous to suggest that this is an unprecedented or particularly radical move. We have long had other statutorily independent authorities dealing with citizens—for example the Australian Taxation Office…the Aged Care program, which has been administered by a department under the direct control of a Minister, has been demonstrated to have failed in meeting its responsibility to provide and regulate a humane, safe and efficient aged care system.
>
> …
>
> there are always costs in setting up new administrative arrangements—the key question is whether the benefits that come from having an independent administrative agency oversighted by experts with clear statutory obligations justifies those costs. Few would argue that current arrangements have worked well.[23]

Mr Beale and Dr Freckleton cautioned that 'policy issues must remain a matter for a department of state under the leadership of a Minister' and submitted further that 'co-locating policy responsibilities for health (including preventive health), disability and aged care in one Commonwealth department will reduce the scope for unjustified disjunctions between health, disability and aged care policies'.[24]

Mr Sean Rooney, Chief Executive Officer of Leading Age Services Australia, a national association for aged care providers, submitted that 'aged care providers overwhelmingly support the creation of an independent commission, though it will be important to ensure that the specific function and detailed institutional design is right'.[25]

I adopt the submission by Counsel Assisting that the primary responsibility for system governance should be conferred on a specialist statutory body that is independent from ministerial direction, subject to oversight by an Inspector-General of Aged Care.[26] I recommend that the key functions of system governance should be brought within the one organisation, leaving outside of that one body only the setting of subsidy levels and prices, the setting of regulatory standards for safe and high quality aged care, integration and

analysis of data, systemic oversight of the Australian Aged Care Commission itself, and high-level policy development and law reform, including continuing reform of the way aged care interacts with other human services. Quality outcomes, financial risk and program administration all require coherent monitoring and responses. The management of all these matters, and governance responsibility, should be placed in the hands of a statutory body with dedicated purposes and clear responsibilities confined to ensuring that high quality aged care reaches those who need it. That body should be independent from the short-term distractions that beset the government of the day.

My recommendation is similar in many respects to the model recommended by Professor Hjalmar Swerissen, Fellow at the Grattan Institute. He called for a 'national system governor', which he proposed should include the Aged Care Financing Authority and the Aged Care Quality and Safety Commission. Professor Swerissen would have the Australian Department of Health continue with the stewardship role by monitoring performance and providing policy advice to government.[27]

The formal establishment of the Australian Aged Care Commission under a new Act will take some time, probably about two years. In the meantime, the implementation of other relevant recommendations Commissioner Briggs and I are making should proceed under temporary administrative arrangements. In the period prior to the formal establishment of the Australian Aged Care Commission as an independent statutory body under the new Act, there should be an administrative unit to implement and direct implementation of the recommendations. Once the new Act is passed, its work will pass to the Australian Aged Care Commission.

One of the key tasks of the Inspector-General is that they monitor and report on progress of the implementation of our recommendations. For this reason, the Australian Government should prioritise the establishment of the office of the Inspector-General of Aged Care.

2.3.2 The Australian Aged Care Commission

Recommendation 5: Australian Aged Care Commission — **Commissioner Pagone**

1. **By 1 July 2023, the Australian Aged Care Commission should be established under the new Act as a corporate Commonwealth entity within the meaning of the *Public Governance, Performance and Accountability Act 2013* (Cth) and:**
   a. **be a body corporate, with perpetual succession;**
   b. **have a common seal;**
   c. **be able to acquire, hold and dispose of real and personal property; and**
   d. **be able to sue and be sued in its corporate name.**

2. The Australian Aged Care Commission:

    a. should be constituted by a board appointed to their respective roles by the Governor-General as full-time or part-time members, namely:

        i. a Presiding Commissioner, who must be appointed as a full-time member

        ii. a System Commissioner, who must be appointed as a full-time member

        iii. a Quality Commissioner, who must be appointed as a full-time member, and who acts as Presiding Commissioner in the absence of the Presiding Commissioner

        iv. a Complaints Commissioner

        v. a Workforce Development and Planning Commissioner

        vi. an Aboriginal and Torres Strait Islander Commissioner

        vii. the Secretary of the Department administered by the responsible Minister, who shall be an ex officio member of the board

        viii. two additional part-time members who are to be chosen for their integrity, eminence and public standing, each of whom must be independent of any current involvement in the aged care sector, and who should have experience and proven capacity in: aged care, clinical services, human services, legal services, or corporate governance; or in finance, accounting or general business

    b. shall appoint a Chief Executive Officer and staff, all of whom are to be employed or engaged by the Commission (whether under the provisions of the *Public Service Act 1999* (Cth) or otherwise).

3. The functions of the Australian Aged Care Commission should be:

    a. to maintain and operate a distributed network of offices, including regional offices, to deliver or manage the delivery of assessment and care finding services, administer the aged care program, and provide general assistance to the public

    b. to manage the system, including support and funding of local assessment and care finding teams and personnel, provision of information on services and providers, system data management, ensuring service availability for all aged care services to which people are assessed as eligible, commissioning and funding of providers to provide aged care services in all locations, analysis of information relating to financial risk presented by approved providers, providing assistance to providers to build capacity where appropriate, and managing the orderly exit of consistently poor-performing providers

c. the following particular functions:

   i. approval of service providers as providers eligible to receive subsidies for providing aged care

   ii. financial risk monitoring of providers, and prudential regulation of providers

   iii. approval of the scope of subsidised services approved providers may provide, and accreditation of the services provided

   iv. payment of subsidies to approved providers of aged care

   v. quality and safety regulation of approved providers and their services

   vi. ensuring that appropriate aged care services are widely available for Aboriginal and Torres Strait Islander people

   vii. workforce planning and development, including setting and refining requirements for minimum staffing levels and minimum qualifications for staff providing care, and (through a workforce planning division within or operated by the Australian Aged Care Commission) ongoing development of workforce capacity through requirements for training and professional development

   viii. consulting with the Australian Commission on Safety and Quality in Health and Aged Care (which is to be responsible under the new Act for review and setting of quality and safety standards and quality indicators) on reviews and revisions of the standards and indicators for the provision of safe and high quality aged care

   ix. management of complaints about providers, staff, assessors and care finders

d. system governance, including the responsibility of continuously monitoring the performance of the system, informing the responsible Minister and Department about new policy and reform proposals for improvement of the performance of the system, limited authority to make subordinate instruments about the details of arrangements for the administration of funding and service delivery, and the ability to raise and recommend amendments of legislation and delegated legislation to the responsible Minister and Department.

4. The responsibilities and functions of the Commissioners should be as follows:

    a. the Presiding Commissioner should:

        i. be the senior member of the Commission and chair of the board

        ii. be responsible for managing the performance of all of the Commission's functions, subject to the joint responsibility of other Commissioners for management of the performance of certain functions specified in subparagraphs b–e below

        iii. be responsible for governance and direction of the Chief Executive Officer as to the management of the administration of the Commission

        iv. be, for the purposes of the *Public Governance, Performance and Accountability Act 2013* (Cth), the accountable authority of the Commission

    b. the System Commissioner should be responsible for managing the performance of the Commission's functions of, and relating to, general management of the system, as described in paragraph 3.b

    c. the Quality Commissioner should be responsible for managing the performance of the Commission's functions of and relating to:

        i. the approval of the scope of subsidised services approved providers may provide, and accreditation of the services provided

        ii. the quality and safety regulation, prudential regulation and financial risk monitoring of approved providers and their services

    d. the Complaints Commissioner should be responsible for managing the performance of the Commission's functions of, and relating to, the management of complaints about providers, staff, assessors and care finders

    e. the Workforce Development and Planning Commissioner should be responsible for managing the performance of the Commission's functions of, and relating to, workforce planning and development

    f. the Aboriginal and Torres Strait Islander Commissioner should be responsible for managing the performance of the Commission's functions and relating to ensuring that appropriate aged care services are widely available for Aboriginal and Torres Strait Islander people

    and the Commissioners should have the powers to do all things necessary or convenient to be done for or in connection with the performance of their functions.

5. The Remuneration and allowances of the Commissioners should be determined by the Remuneration Tribunal.
6. The Chief Executive Officer should:
    a. be appointed by the Presiding Commissioner on the advice of the board of the Commission
    b. have their remuneration and entitlements determined by the Remuneration Tribunal
    c. in relation to matters not covered by the Act, hold office on the terms and conditions (if any) that are determined by the Presiding Commissioner on the advice of the board of the Commission
    d. be required to comply with any written direction by the Presiding Commissioner about the duties of the Chief Executive Officer
    e. for the purposes of the *Public Service Act 1999* (Cth), and together with the staff of the Australian Aged Care Commission, constitute a Statutory Agency of which the Chief Executive Officer is the 'Agency Head'.
7. The Commission should be independent of Ministerial direction, and there should be a requirement that any expectations or advice provided by the responsible Minister to the Australian Aged Care Commission should be made public.
8. The Commission should be required to:
    a. report quarterly to the Inspector-General of Aged Care and to the responsible Minister on the performance of its functions, and to publish these reports within one month of being provided to the responsible Minister subject to redaction of contents that are subject to public interest immunity
    b. lay before the Parliament and to publish an annual report on such aspects of the operation of the Act as the Australian Aged Care Commission considers relevant to ensure an accurate understanding of the operation of the Act, including:
        i. the extent to which providers are complying with their responsibilities under the Act
        ii. the amounts paid by people receiving residential care in connection with their care, including amounts paid for accommodation and daily living needs and amounts provided by way of accommodation deposits.

Composition

Under the Independent Commission model, the Australian Aged Care Commission should consist of a number of commissioners with assigned responsibilities identified in the legislation. The Commission should also have a chief executive and staff. One of the commissioners—the Presiding Commissioner—should be the chair of the board of the Commission. The other commissioners should also be on the board. The board should also include non-executive members with experience and proven capacity in aged care, clinical services, human services, legal services, or corporate governance; or in finance, accounting or general business. The Secretary of the Department responsible for aged care should be an ex officio member.

The board should meet regularly and its principal activity should be to provide governance to ensure the functions of the Commission are performed.

Accountability

At the heart of its duties, in my view, the Australian Aged Care Commission should be responsible to older people who need, or may need, aged care. Parliament ought to define its objectives in the new Act and hold the Australian Aged Care Commission accountable for its performance in meeting those objectives.

Some concern has been expressed about responsibility and accountability under the Australian Aged Care Commission model.[28]

A corporate Commonwealth entity is legally separate from the Commonwealth. While the Commission would enjoy a degree of independence from the policies and direction of the Australian Government, the Government and relevant Minister maintain ultimate accountability to the public. That is an appropriate balance given the importance of aged care to our community and the substantial investment of public funds in the sector.

As mentioned above, the Commission's scope of activities and accountabilities would be set by Parliament. The board would be accountable for providing optimal governance of the Commission. The Commission itself must comply with other legislative requirements, including the efficient, effective, economical and ethical use of public resources, and the duty to establish and maintain systems relating to risk and control. In addition, the Inspector-General will be expected to investigate, monitor and report on the administration and governance of the aged care system and report annually to Parliament.

Some submissions received in response to Counsel Assisting's final submissions took exception to the proposal that the Australian Aged Care Commission should have responsibility for complaints about any of its own processes—such as care-finding and assessment—and suggested that this complaint function should be the responsibility of a separate body.[29] There is a balance to be struck on this issue. As far as possible, there should be a highly visible avenue of complaints, not a fragmented set of complaint arrangements. It is also desirable that the Australian Aged Care Commission be alerted in the timeliest possible way to emerging issues concerning the network of care finders and assessors it supports. The allocation of responsibilities for complaints to a specific

commissioner will instil a healthy measure of objectivity into the process, because that commissioner will be expected to act as a champion for the integrity of the complaints process and to ensure that it is not influenced by system management concerns. Finally, and most importantly, the oversight role of the Inspector-General will extend to addressing complaints about any aspect of the performance by government institutions of their functions, as Commissioner Briggs and I explain below.

System management and regulatory functions

The Earle Haven Case Study is, I consider, an example of issues that arise when there are disconnects between the body exercising regulatory functions and the body exercising system management and governance functions.[30] System management and quality regulation should be directed to the same goals, namely, the protection and advancement of the interests, health and wellbeing of people who need and receive aged care. The same is true of oversight of financial risk, prudential regulation, the approval of providers, and complaints handling. Making fine distinctions and attempting to divide these functions into a 'system management' and 'regulatory' category is somewhat arbitrary. As the Earle Haven Case Study revealed, it can be counter-productive.

Whether the Australian Department of Health or the Aged Care Quality and Safety Commission, or both, should be responsible for the monitoring of providers' financial performance and risk profiling appears to remain a matter of debate between them.[31] That is understandable because the administration of the funding programs remains with the Department, while regulatory responsibility rests on the Aged Care Quality and Safety Commission and exercise of those functions rightly must remain independent of the Australian Government. The Australian Government submitted that the Aged Care Quality and Safety Commission 'has not been given a reasonable period of time to demonstrate fully the efficacy of the separate regulator model'.[32] In my view, the key point of importance about the separate regulator model is independence from the Government. Under the Australian Aged Care Commission model, the quality and safety regulatory function will remain separate from the Australian Government. Further, by virtue of the allocation of regulatory functions to particular commissioners within the Commission, there can be an appropriate degree of separate attention given to the need to attain regulatory objectives. The model should allow for regulatory aims to be considered independently from system management impacts, but ultimately executed in a manner that is coordinated with coherent system management measures.

The advantage in consolidating these functions in the hands of one organisation is that many of them are interrelated and should benefit from coordinated attention. Consolidation would limit the risks of delay in identifying emerging problems or inaction in addressing them. In particular, there are advantages in the consolidation of quality and safety monitoring and compliance, financial risk monitoring and prudential compliance, together with general system management functions. The latter include: approval and commissioning of providers; receiving and acting on feedback from providers about service delivery challenges and program improvements; funding administration; provider capacity-building; service coverage and market evaluation; special interventions in markets without a lot of competition, known as 'thin' markets, such as commissioning providers of last resort to ensure coverage; and managing orderly exits of poorly-performing providers who show no sign of improving.

I do not consider that there is any impediment to consolidation of quality regulation along with the other functions of the Australian Aged Care Commission. Provided that the body exercising regulatory functions is independent of executive government, any tension between the exercise of regulatory functions and the exercise of system management and funding functions under the same roof would be manageable. The benefits of consolidation outweigh the burden of managing any such tensions that may arise.

An alternative would be the continuation of the status quo, together with independent pricing and with clarification and strengthening of responsibilities. This model would be based on a department subject to ministerial direction retaining core system management responsibilities, and regulatory functions remaining in the hands of the Aged Care Quality and Safety Commission, exercised separately from the influence of the executive government. If the departmental model is retained, a broad role for a separate regulator must also remain. Conferral of far-reaching regulatory functions over privately owned entities to an agency under executive government direction would not be appropriate.[33] As already mentioned, there should also be a separation between regulatory responsibilities and policy responsibilities.

System governance and relevance to policy development

In addition to its system management and regulatory functions, I recommend that the Australian Aged Care Commission have primary responsibility for what I call system governance. This involves providing overall direction in steering the system toward the achievement of long-term policy outcomes, constantly monitoring the overall performance of the system for emerging issues, and proactively addressing such issues before they become problematic. I am conscious that the system governance role will involve active consideration of refinements to service arrangements, and this might in some sense be regarded as overlapping with the function of developing 'policy'. Commissioner Briggs and I were told that it is desirable for policy development to be separated from regulatory responsibilities. The Productivity Commission in 2011 and the Carnell-Paterson review in 2017 both recommended the separation of the quality regulator from the Australian Department of Health's policy and funding responsibilities.[34] The Australian Aged Care Commission model I envisage would respect this separation of responsibilities. Although the Commission would be expected to identify problems, and might suggest solutions, primary responsibility for development of policy options and adoption of reform proposals would rest with the responsible Minister, supported by the Department. This would include the important task of ongoing reform of the way aged care interacts with other human services, such as health care, housing and welfare.

Funding

I propose that the Australian Aged Care Commission's operating budget should be by way of special appropriation from the Consolidated Revenue Fund. While this would not necessarily insulate it from annual budget pressures, it would create a clearly identified, separate and dedicated stream of funding, and variations to the funding would be highly visible.

Ideally, the Australian Aged Care Commission should administer funding to providers, along with its other functions relating to the day-to-day management of the system and the aged care program. However, standard practice is that corporate Commonwealth entities are not funded directly via appropriation, but instead are funded by a non-corporate Commonwealth entity, usually the portfolio department, that draws down from the Consolidated Revenue Fund.[35] Although the Australian Aged Care Commission would be a corporate Commonwealth entity, there is a precedent for Parliament legislating for an exception. In 2015, Parliament provided the Commonwealth Superannuation Corporation with the legal power to access appropriations directly in the superannuation legislation.[36]

Regional presence

I note that Professor Swerissen proposed that regional agencies would provide support for assessment, care planning, service negotiation and service monitoring and be accountable to government for the quality and performance of aged care providers in their region.[37] Professor Kathy Eagar, Director of the Australian Health Services Research Institute at the University of Wollongong, submitted that there should be regional 'aged care planning and commissioning' agencies established under a new National Aged Care Authority.[38]

Associate Professor Gemma Carey, Research Director at the Centre for Social Impact, stated that that the role of 'local actors' in the National Disability Insurance Scheme is an essential part of the market stewardship strategy.[39] Mr Robert Bonner, Director of Operations and Strategy, Australian Nursing and Midwifery Federation (SA Branch), emphasised the importance of implementing the system management role at the regional level.[40] Mr Brian Corley, Chief Executive Officer, Community Options, urged consideration of a regional focus involving, as much as possible, local health authorities, local providers and local communities.[41]

Rather than establishing separately constituted regional agencies, I propose that the Australian Aged Care Commission should have a network of regional or local offices throughout Australia. To give impetus to decentralisation of its operations, I recommend that its headquarters should not be in Canberra. This regional presence will enable allocation and integration of resources according to the identified needs of the local population. The Australian Aged Care Commission should support community and provider engagement and relationship-building between all involved in the aged care system.

Independence from the sector

To promote independence from the sector, I consider that members of the governing board of the Australian Aged Care Commission must be independent of current involvement in the aged care sector, based on clearly defined criteria. Current employees of approved providers, advisors to the sector or representatives of peak bodies should not be eligible for appointment to the board. Another suggestion for assessing independence, which should be given consideration, involves exclusion of association with any organisation that derives a material component—say, more than 20%—of its revenue from aged care services.[42] The board should be given responsibility for the strategic direction of

the Australian Aged Care Commission, governance of the structures and processes the Commission adopts for the proper discharge of its functions, and for intervening if the performance of the Commission, and that of the aged care system as a whole, is below reasonable expectations.

Active intervention in the 'market'

In my view, the Australian Aged Care Commission should be prepared and equipped to intervene proactively in the aged care 'quasi-market', rather than leaving aged care service delivery solely to what in this sector is inaccurately equated with 'market forces'. The Australian Aged Care Commission should use its powers, including for approval of providers, for commissioning of providers, and for the funding of providers to address:

- an adequate coverage of services to meet the population needs for major city, rural, regional and remote Australia
- an adequately diverse mix and adequate number of providers to enable older people seeking services to exercise an informed choice, where possible, between available providers
- the capacity and capability of new and existing providers to foster better practice and innovation
- the continuity of service for older people.

My recommendation for an Australian Aged Care Commission aims to strike a balance between independence, ministerial responsibility and accountability. In my view, it is the most appropriate model for the dedicated, stable and transparent governance of such a vital national service as the aged care system.

2.3.3 The Australian Aged Care Pricing Authority

Recommendation 6: Australian Aged Care Pricing Authority

Commissioner Pagone

The Australian Government should establish an Aged Care Pricing Authority and confer on it all necessary functions for determining prices (inclusive of subsidies and user contributions) for specified aged care services so as to meet the reasonable and efficient costs of delivering those services. Its functions should include the function of identifying and recommending to the Australian Aged Care Commission the aged care services for which price cap determinations or other forms of economic regulation may be appropriate.

The function of determining the prices and subsidies for aged care services calls for highly specialised capabilities. It would be prudent for a body other than the one regulating approved providers, administering funding to them, and managing the performance of the system to be responsible for determining how much money should be available to them. The body responsible for the long-term performance of the system should not be able to 'write its own cheque'. I recommend that the pricing function be conferred on a separate body, the Aged Care Pricing Authority.

The introduction of independent pricing is critical to restore or to instil confidence and trust between the sector and government, and to instil confidence in the sustainability of the system in the wider community.

The Australian Government indicated its support for an Aged Care Pricing Authority 'on the express qualification that the function of the Aged Care Pricing Authority (ACPA) is advisory only, and that it does not have a power to determine pricing for aged care services'.[43]

The functions and purposes of the Aged Care Pricing Authority are outlined in greater detail in my Chapter 17, on funding the new aged care system. They should include:

- providing expert advice to the Australian Aged Care Commission on optimal forms for funding arrangements for particular types of aged care services and in particular market circumstances
- reviewing data and conducting studies relating to the costs of providing aged care services
- determining prices for particular aged care services based on estimates of the amounts (whether constituted by government subsidies or user payments or both) appropriate to the provision of high quality and safe aged care services
- evaluating, or assisting the Australian Aged Care Commission to evaluate, the extent of competition in particular areas and markets
- providing expert advice on appropriate forms of economic regulation, and implementation of such regulation, where necessary.

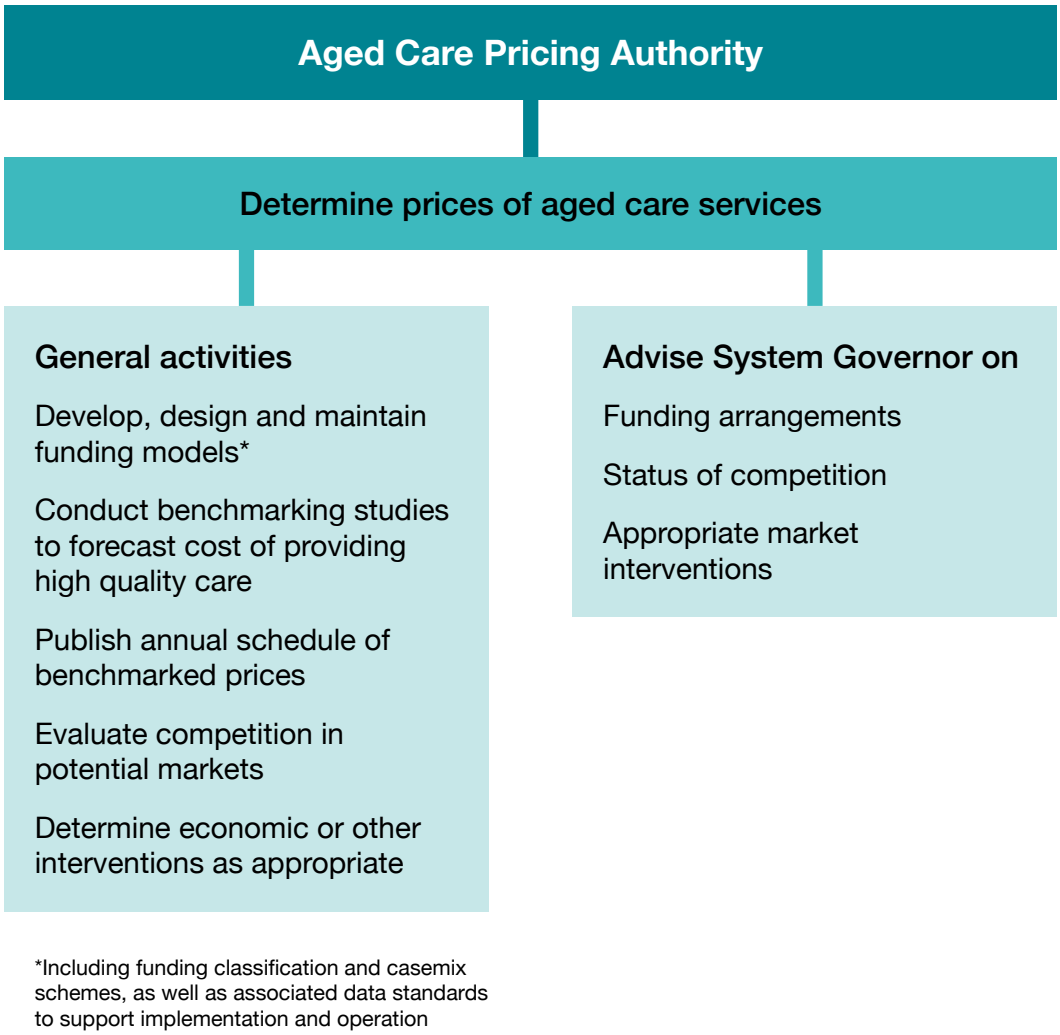
The Aged Care Pricing Authority should be required to report to the responsible Minister, and its reports should be made publicly available.[44]

There is already an existing independent statutory body with proven capabilities on which aged care pricing functions could be conferred—the Independent Hospitals Pricing Authority. Until the new pricing authority is operational, it may be appropriate for the Independent Hospitals Pricing Authority to provide capacity-building services under temporary administrative arrangements.

I do not consider the Independent Hospitals Pricing Authority, even if expanded with a focus on aged care, is the best model for aged care because there are very significant differences between hospital admissions and aged care. Broadly, hospital admissions are episodic whereas care for older people has a long-term focus. Hospital admissions concern clinical care but care for older people concerns both clinical care and quality of life.

The pricing body should be free to focus on the specific challenges of aged care without any budgetary or governance pressures to adopt similar methodological approaches to those adopted in hospital funding. I propose the conferral on the pricing body of broader economic regulatory functions specific to the aged care sector. If the body has a pre-existing core focus on hospital funding, that may impede the development of those capabilities or even create tensions or perceived conflicts in the exercise of that broader economic regulatory role.

Figure 1: Functions and purpose of the Aged Care Pricing Authority



*Including funding classification and casemix schemes, as well as associated data standards to support implementation and operation

2.3.4 Responsible Minister, Department, and new National Cabinet Health Reform Committee

The responsible Minister remains an important feature of the governance arrangements in the model I propose. Administrative arrangements adopted by the government of the day should allocate portfolio responsibility for aged care to a particular Minister, and that the Minister should continue to be supported by an Australian Government department.

While the Australian Aged Care Commission would be responsible for aged care programs and delivery, the Minister would continue to be responsible to Parliament for the Australian Government's aged care policies. The Minister would present to Cabinet any aged care policy proposals, recommend appointments by the Governor-General to the governing board of the Commission, and make appointments to the Advisory Council. The department responsible for supporting the Minister would be expected to work closely with the Australian Aged Care Commission in the development of aged care policy proposals.

The Minister and the department would also have primary responsibility for the provision of support and policy advice to the proposed National Cabinet Reform Committee in connection with the development of an integrated long-term care strategy for older people addressing needs across housing, welfare, health and community services (in addition to aged care). They would have a particular focus on achieving more smoothly functioning interactions between the health system and the aged care system via that Committee and also the Health National Cabinet Reform Committee.

2.3.5 Aged Care Advisory Council

An Aged Care Advisory Council should be established to provide advice to the System Governor.

Recommendation 7: Aged Care Advisory Council

Commissioner Pagone

1. **The Minister should appoint an Aged Care Advisory Council, to be constituted by such people of eminence, expertise and knowledge of aged care services as the Minister sees fit, drawn from all relevant aspects of the aged care system, including people receiving aged care, representatives of the aged care workforce, approved providers, health and allied health professionals, specialists in training and education, and independent experts.**
2. **The Advisory Council should be established with its own secretariat, funded by the Australian Government.**
3. **The Advisory Council's function should be to provide advice on aged care policy, service arrangements and any aspect of the performance of the aged care system, to the System Governor**
4. **The Advisory Council should convene itself regularly, and should have authority to provide advice to the System Governor on its own initiative.**
5. **The System Governor should have authority to convene the Advisory Council on reasonable notice, and may refer particular issues to it for advice.**

The Minister should appoint an advisory council to advise the System Governor, on policy matters concerning the performance of the aged care system and policy matters of importance from the perspectives of older people who need and use aged care services, the workforce, providers, educators, and professionals involved in the provision of aged care.

It is critical that this body include people receiving aged care. Many people and organisations making submissions in response to Counsel Assisting's final submissions made this point.[45] Mr Glenn Rees, Chair of Alzheimer's Disease International, put it to us like this: 'Empowering older people to speak for themselves is the priority'.[46]

2.3.6 Conclusion on Independent Commission model

The independent Australian Aged Care Commission model is a fundamental redesign. It recognises the shortcomings of the existing aged care system, and is a response that addresses them, based on my understanding of the complexity of the system and the need for active stewardship by a specialist System Governor.

The Australian Government submitted that it has been unable to cost the Australian Aged Care Commission model but that it would 'likely cost significantly more to operate than one based on the existing system'. By way of comparison, the Australian Government explained that in 2020–21, the National Disability Insurance Agency has estimated resourcing requirements of approximately $1.5 billion, whereas existing arrangements for aged care require resourcing of around $0.4 billion per annum.[47] The Australian Government submitted:

> the proposed new AACC [Australian Aged Care Commission] has the potential to provide new focus and leadership in aged care…However, the Royal Commission would need to provide clear evidence in its Final Report to support the contention that the costs and risks of establishing the AACC, and any potential delays in reform caused by the structural change, are outweighed by the benefits of the new structure.[48]

In my view, it will be a matter for the Australian Government, in its consideration of our Final Report, to decide whether the 'costs and risks…and any potential delays in reform caused by the structural change are outweighed by the benefits of the new structure'. As Professor Eagar submitted, the reforms required cannot be implemented if the current governance arrangements remain in place.[49] My view is that the governance of aged care should be independent, specialised and accountable to the Australian public through a single dedicated statutory agency. The best way to achieve systemic coherence and stability, coupled with agility and the capacity to respond to future need, is to entrust governance to an Australian Aged Care Commission. The Commission's sole focus would be on aged care. In this way, care for older people may be protected from the uncertainties of politics, lobbying and annual debate about budgetary allocations. The security and predictability of care are foundational to the wellbeing of older people. Other key elements in the governance arrangements include the Aged Care Pricing Authority, the supervisory role of the Inspector-General and the supervisory and policy roles of the Minister and

department. Along with the recommendations that Commissioner Briggs and I make concerning advocacy arrangements, these measures as a whole yield a solid institutional framework for the aged care system.

The proposition that a separate independent body should govern long-term care was simply and succinctly put by Mr Fitzgerald in his evidence to us:

> I think a separate agency, independent of the Department, would be appropriate…[50]

In arriving at this conclusion, Mr Fitzgerald was informed by his knowledge and experience as a former Royal Commissioner, a former Productivity Commissioner, and his current role as the NSW Ageing and Disability Commissioner. He has expertise in providing the Australian Government with advice on systemic economic and social issues affecting the welfare of Australians and knows the fine detail of protecting older people from exploitation and abuse.

A recommendation for a dedicated, separate and independent agency was recommended by the Productivity Commission in its 2011 report *Caring for Older Australians*.[51] It was rejected then by the Australian Government and the problems of aged care have deepened. The rationale for the rejection of the proposal—that similar outcomes could be achieved at lower cost by modifying the current arrangements—has not been vindicated. The recommendation ought to have been accepted in 2011 and I make it again now.

There are various examples of independent statutory agencies charged with the duty to govern sensitive and significant matters in the public interest. The Reserve Bank of Australia provides an attractive balance between dedicated expert governance and ministerial responsibility in a field of activity which, like the long-term care of Australians, needs security, predictability and reliability.

The Reserve Bank of Australia is our central bank with the power to set monetary, financial system and payments policies, and to deal with other financial matters. The Governor of the Bank frequently, formally and informally, consults with the Treasurer concerning monetary and banking policy. If there is an unresolvable difference of opinion between the Treasurer and the Governor of the Bank as to whether Reserve Bank policy is '*directed to the greatest advantage of the people of Australia'*, the Australian Government can set policy and direct its adoption by the Reserve Bank Board.[52] In such a case, the Treasurer explicitly takes responsibility for the policy. Under the *Reserve Bank Act 1959* (Cth), the Governor of the Bank and Secretary of the Department of the Treasury maintain close liaison and keep each other informed of matters of mutual interest.[53]

2.4 Government Leadership model | Commissioner Briggs

2.4.1 Overview of model

The aged care system requires fundamental and far-reaching reform. It is almost impossible to imagine how this very important reform to aged care services could distance the Australian Government from influence and direction over the aged care services it funds and delivers. In fact, over the past two years of our inquiry, I have heard from many older people and their representatives that they expect the Australian Government to step up and take greater responsibility for the delivery of safe and high quality aged care services.

Australian Governments of both political persuasions have been responsible for creation of the current system of aged care. For the foreseeable future, the Government will continue to be the funder, regulator and manager of the system as a whole. If anything, it will need to become a more active player in the aged care system than ever before as it implements our recommendations.

Strong Government leadership is necessary for the system of aged care to function effectively. The Prime Minister and his Cabinet have recognised the importance of reform in aged care and will be strongly committed to it. This has been demonstrated not only in the decision to establish this Royal Commission but also in successive Prime Ministerial statements since then, where the Prime Minister and other ministers have reiterated the Government's commitment to significant change and to providing new funding.

In the evidence we have heard and the research we have done, it is clear that Australians also expect the Australian Government to be a more determined and active steward of the aged care system, delivering its responsibilities effectively and with compassion. People have said consistently and clearly that they do not want a privatised system in which market forces determine the quality and safety of care—they expect the Government to take the lead role.

There is no doubt in my mind that the Australian Government should lead and drive the future aged care solution. It has a significant stake in the aged care system and its buy-in is essential to its ongoing funding commitment. My recommendations in this and other chapters on changes to governance and institutional arrangements reflect the Government's responsibility for aged care.

In our Westminster system of government, responsibility for deciding on national values, interests and priorities rests with the elected government, through its Cabinet processes. Decisions about aged care involve social values and preferences. These are matters for collective consideration by the Cabinet and Parliament, as representatives of the people. They are not matters for arms-length agencies independent of the Government to determine.

The Australian Government, working through a Minister and a responsible Department of State, can act in ways that no other body working in isolation can match. Large, dispersed systems like aged care need this cut-through government capability to motivate and direct change. Without it, I fear that little will happen.

In the words of Mr Rees:

> The causes of neglect are multiple… Replacing one bureaucratic structure with another will not solve the problem and increases the chance of delay in implementing change. After the agony of establishing a new body, many of the same people as before will be employed. I do not see the issue as a choice between DoHA [Department of Health and Ageing] and a Commission but rather of ensuring a system of checks and balances to secure accountability and transparency.
>
> …
>
> I suggest that a structure which has DoHA, an Inspector General, an Aged Care Pricing Agency, an enhanced Aged Care Quality and Safety Commission and the proposed Commission on Quality and Safety in Health and Ageing setting standards, AIHW [Australian Institute of Health and Welfare] and strengthened consumer advocacy would bring transparency, expertise and a consumer voice to the management of aged care. It would be quite a revolution but build on what is there. …A strong Minister and implementation unit in DoHA…with other expert agencies involved in monitoring, pricing regulation and standards setting is I suggest the best of all worlds.[54]

The Australian Government's submission in response to Counsel Assisting's final submissions reinforced my concerns:

> The establishment of a new AACC [Australian Aged Care Commission] would take some years, divert staff and financial resources to ensure its successful implementation, and potentially delay the process. It is relevant to look at the experience of the National Disability Insurance Agency (NDIA), where the formation of the organisation took longer than anticipated.[55]

It is especially important that the consumer representative organisations' submissions from COTA Australia and the Combined Pensioners and Superannuants Association are clear about their support for retention of the pre-eminent role of the Department and the separate quality regulator:

Aged care consumer movement organisations and advocates spent decades getting these functions set up independent of the managing Department and we cannot support them being put back again into the one body. It was dysfunctional before and it will be again.[56]

It is equally telling that provider groups appear to support the Australian Aged Care Commission model. I have no doubt that it would provide them with greater freedom and less oversight than the current, and my proposed future, regulatory arrangements, and many more opportunities to lobby for and get more funding, with fewer constraints over time.

Following this report, the Australian Government will be faced with a major decision that will set the scene for the most significant shift in the aged care system in decades—taking it to a rights-based and entitlement-based system, with a considerable increase in aged care expenditure and taxpayer obligations. Such a decision can only be taken responsibly by, and its implementation led by, the Australian Government.

Importantly, an initial decision by Cabinet to embark on creation of the new aged care system Commissioner Pagone and I propose is not the end point. Many more critical and major decisions will have to be taken both in the course of implementation and in response to other developments as they arise and emerging new community needs and expectations. This will not be a one-time 'set and forget' decision. As the aged care system is reformed over the coming decade, there will be repeated instances where the system will need to be shaped and influenced by values-based rather than technical or administrative decisions. The Australian Government is best placed to take these decisions through an active and engaged Minister and Department, rather than officials with little direct accountability to the Government.

For the foreseeable future, most of the funding for aged care will continue to come from taxpayers. At present, the Australian Government contributes around $20 billion each year to the cost of aged care.[57] Under our proposals, that amount is likely to rise to a figure of at least $30 billion. The public rightly expects that there should be a clear accountability and appropriate controls around these funds.

Under the Australian Government's financial arrangements, only non-corporate entities, such as departments, can manage appropriations. This is because only entities that are part of the Commonwealth, such as departments, can legally access the Consolidated Revenue Fund.[58] I consider that aged care entitlements should be funded through a Special (Standing) Appropriation. This means that aged care entitlements could be paid without the need to go back to Parliament each year to seek additional funds.

Recommendation 8 requires that aged care funding be managed by a Department of State. It would not meet the Government's financial management arrangements, and it would not be acceptable to taxpayers, for more than $30 billion of taxpayer funds to be handed over every year to non-elected individuals operating outside the direct control of ministers to be spent as they see fit.

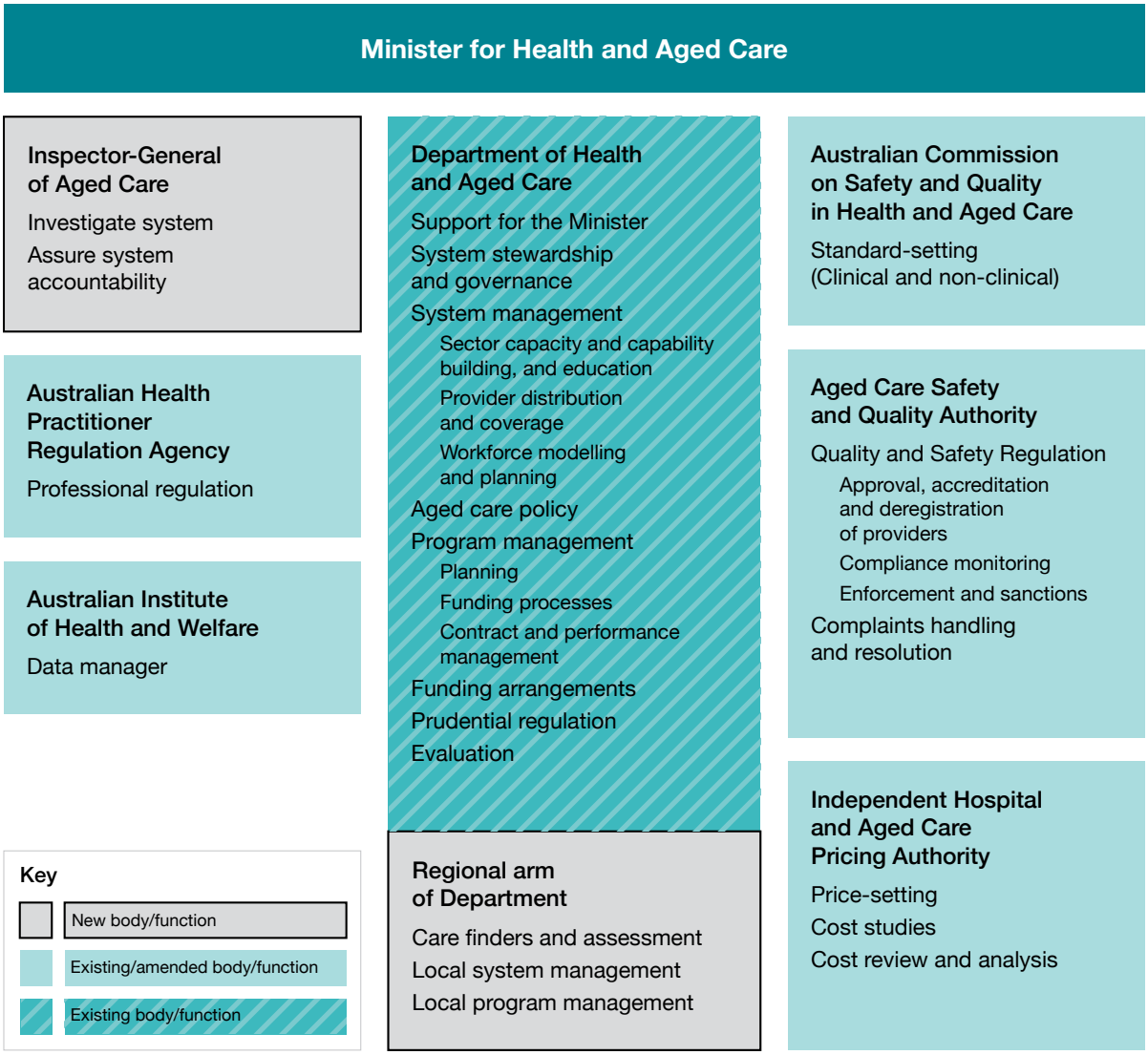
In concluding that ministers and their departments should continue to be responsible for the management and delivery of aged care, I am not arguing for the status quo. The experience of the past 20 years has shown that ministers and their departments have not always demonstrated the compassion and concern for the interests of older people that the public would expect. It is fair to say that many people have lost confidence in the leadership and oversight of the aged care sector.

There is, therefore, a great and pressing need to strengthen the current arrangements if the trust and confidence of the Australian community in the Government's stewardship of the aged care system is to be rebuilt and maintained. These measures should put people first, and ensure that the older people who receive care are the primary focus of system

governance and management, and that the Department gives priority to meeting older people's needs rather than to managing within an ever-decreasing budget. The measures include the creation of The Council of Elders that will consult widely with people; increased reporting and transparency on the performance of the system; and the establishment of a powerful Inspector-General of Aged Care to initiate reviews of any part of the sector and to report to Parliament on the outcome of those reviews. These measures are described in more detail in the sections that follow.

Figure 2 represents the main features of the governance institutions in my Government Leadership model.

Figure 2: Main features of the Government Leadership model



2.4.2 Minister for Health and Aged Care

It has been clear to me throughout this inquiry that issues to deal with older people need to be elevated to be the Cabinet-level of responsibility, in much the same way as health, social services or industry are at the Cabinet level.

We now face a need for significant reform of aged care. This will require Cabinet-level ministerial responsibility if the reforms are to succeed. The Australian Government's submission in response to Counsel Assisting final submissions points out that strong ministerial accountability can build support for a major reform agenda, such as this.[59] The Prime Minister recognised as much on 18 December 2020 when he elevated the Aged Care Portfolio to Cabinet and gave the Minister for Health—now the Minister for Health and Aged Care—the additional responsibility of responding to this Royal Commission.[60]

At Sydney Hearing 1, Mr Rees said that profound reform has to be led by a senior Cabinet Minister:

> There have only been two ministers for aged care in Cabinet since 1985 which says something about political priorities and in both cases major reform resulted. Dementia after centuries of neglect requires sustained and strong political leadership to get on the health and aged map. This has been well demonstrated by countries overseas and in Australia by the aged care reforms of the then Minister for Community Services Don Grimes in 1986, by the Dementia Initiative introduced in 2004 by John Howard's Government, by Living Longer Living Better by Mark Butler as Minister for Mental Health and Ageing and by the $200 million committed for dementia research by Tony Abbott when Opposition Leader.[61]

Aged care deserves a greater level of recognition, including representation in Cabinet, than it has been afforded in recent decades. Many of the people in aged care are powerless, voiceless and alone. In these circumstances, a compassionate government needs to step in and take responsibility. Older people need a champion for their interests in the Cabinet room.

Aged care is inextricably linked to health care. As people age, meeting their health care needs becomes an essential component of their quality of life. It is very important that ministerial responsibility for the aged care system should remain with a Cabinet Minister for Health and Aged Care so that the health and aged care systems can be as integrated as possible and aligned with relevant State and Territory arrangements, thereby delivering the best outcomes for older people.

2.4.3 Department of Health and Aged Care

In our system of government, ministers are supported by a Department of State. This is a key part of collective decision-making. What a department can do well, in a way that is not open to a separate agency, is to lead policy and to coordinate its work with that of other departments. Interactions with other areas of government policy are relevant to the quality of aged care. This is especially true of health, but also of other areas important to older people, such as housing, education and training, infrastructure and transport.

The reforms Commissioner Pagone and I propose represent sweeping changes to the delivery of aged care services and supports. To ensure that the reforms are implemented in the most effective and rapid way, there is a need for a joined-up approach across all the parts of the Australian Government that influence the quality and safety of aged care. We have seen too many examples where government responses to meeting aged care needs have been fragmented and have failed to achieve the objectives sought because they were pursued in isolation.

Notwithstanding this, I have been disappointed during our inquiry by what appeared to be a considerable loss of corporate knowledge and aged care expertise in the Australian Department of Health arising from past organisational changes.[62] We need some stability in institutional structures and continuity of expertise to carry the reforms forward.

It is vital that the Department retains enough corporate memory over the next five years to make the new system work. This includes: knowledge of previous interactions with stakeholder groups; the track record and performance of providers; gaps in coverage and what has been done in the past to address them; and the myriad of systems and processes required for payments and performance monitoring.

Urgent reform of aged care is needed. Further delays while changes to institutional structures are rolled out would leave these urgent problems unaddressed for too long. The Department can hit the ground running and make an immediate start on implementing and embedding lasting reform in a way that an off-site implementation unit will never achieve. I would be surprised if the Department did not already have preparations underway to do so.

The Secretary will need to act decisively to ensure that the Department changes too. As Professor Eagar has said, the Department needs to have a new mandate, adjust its culture, and act quickly to locate the infrastructure and expertise necessary to implement the reforms. [63]

In the new aged care system, the Department will need to be a proactive system leader that drives ongoing reform of the sector and nurtures its numerous components in a coordinated and purposeful way. This will necessarily involve cultural change.

I am therefore proposing an explicit and stronger role for the Department in governance of the aged care system. It is based on the concept of stewardship. The Department as steward of the public resources applied to the aged care system will have an overriding aim of ensuring that all of the component parts of the aged care system work together in an efficient and effective way to achieve high quality and safe care for older people.[64]

Stewardship in the aged care context should have a broad purpose about the careful and responsible management of aged care, befitting this precious and highly valued service that is the responsibility of government and involves older people who are vulnerable and who may have diverse needs. Aged care system stewardship requires a governance system that is characterised by a high level of active engagement, which nurtures, educates, reviews and searches continually for improvements in its efficacy, to ensure that the overall aged care system is the very best that it can be. It also requires active engagement with providers at the local level.

The stewardship and Government Leadership governance model that I propose for aged care would maintain the current close links between policy development and program management, but would go further by giving the Department the authority and capability to be an active and forward-thinking system steward, focused on continually improving outcomes for older people. This involves identifying the characteristics of the aged care system, understanding where gaps exist, and developing strategies to fill those gaps.

An important part of stewardship is responsibility for the evaluation and continuous improvement of the delivery of aged care services. This should include broad educational and support activities directed towards building the capacity of providers through activities such as benchmarking, the encouragement of innovation, research and policy advice, the promotion and sharing of best practice, and targeted investments to support the development of workforce and provider capabilities. The Department will be the custodian of the star rating system and should use that system to support its continuous improvement function and drive improved performance over time.

In recent years, the Australian Department of Health has had neither sufficient resources nor commitment from its leadership or the Government to enable it to undertake this role effectively. This has been recognised by the new Secretary of the Department, who told us

> I think we are obviously aligned with the Royal Commission belief that the system does need a fundamental reset and at the moment the focus, Government's focus has been very much on meeting the demand for Home Care Packages and releasing significant numbers of Home Care Packages, but I think we clearly accept that the system does need significant redesign and including in the costing and funding and transparency of that system.[65]

The reforms that Commissioner Pagone and I propose will require high-level and sustained leadership within the new Department, not only to implement the changes but to lead development of the Department's culture and mindset so that it is more responsive to older people and their needs and more active in responding to them. In my view, the Department should appoint an Associate Secretary to work alongside the Secretary in a new Office of Aged Care within the Department to lead aged care reform, to act as the main adviser to the Minister and Secretary on aged care matters and to drive cultural change and workforce reforms.

In the coming decade, the Department will require two further high-level senior executives at Deputy Secretary-level to guide the aged care reforms. They will have two separate roles, both challenging and requiring senior staff attention:

- Royal Commission policy reform and development of policy and programs for the new system, and negotiating with stakeholders on the details of those
- implementation, including: new planning arrangements; establishment of a network of regional offices; recruiting and training staff for the new people-facing roles required in assessment, care finding and system management; and development of new systems and procedures.

The Department will need a much higher level of recurrent funding to support its enhanced role. The level of funding required should be determined by a thorough capability review to be conducted by an eminent person with experience in public administration, taking account of the Australian Government's response to our recommendations.

Regional presence

Aged care is a complex and changing system. It needs to be led both nationally and locally. Policy development happens nationally, but aged care is always delivered locally, so the Department will need a well resourced and locally-based series of regional offices. Having staff on the ground will enable the Department to connect with older people directly and personally, gain a better understanding of their needs and help connect them with the locally available services.

The Department should approach the planning and development of the aged care system with local solutions for local needs. There should be regular local engagement with older people and with service providers. The Department needs early intelligence on any issues or problems that might emerge at a local level and can play an important role in brokering local solutions. Local approaches to system management are key to achieving lasting change. Through the regional network I recommend, comprising care finders, assessors and program planners, the Department will maintain a local presence to ensure that it is able to listen to the local community, match service solutions to local needs, and provide personal support for older people.

The distribution of regional offices across Australia should be based on the locations of Primary Health Networks and be integrated with them wherever possible. This geographic spread provides a reasonable approximation of the distribution of needs for aged care, but additional offices might be required in some areas where there is a higher proportion of older people or large distances involved. This will deliver a network of around 50 small units dedicated to understanding and meeting the needs for aged care in their locations.

Functions

The functions of the Department should include direction-setting and system development, program design, program implementation, system financing, funding delivery, prudential oversight of providers and day-to-day management of service delivery through the network of service providers, as set out below:

- program design and development, including defining the way in which aged care services are structured and delivered and ensuring appropriate coordination with the health and disability sectors
- funding—paying service providers in accordance with the determinations of the Independent Hospital and Aged Care Pricing Authority and ensuring appropriate acquittal of expenditure on care
- oversight and management of the delivery of services, including defining the terms for service providers' participation in the aged care system, setting conditions of entry, managing the commissioning of service providers, evaluation and review of the operation of the overall system, and managing systemic risks

- evaluating the performance of the system and continuous improvement of services and service delivery
- prudential oversight and regulation for monitoring risks associated with providers' financial management. As well as receiving financial reports as part of these roles, it would, as part of its program management role, receive financial reporting from providers in the nature of acquittal of their care expenditure
- workforce planning and management, including setting minimum staffing levels and minimum qualifications for staff providing care, and ongoing development of workforce capacity through requirements for training and professional development.

The new Act should confer on the Secretary of the Department of Health and Aged Care the powers necessary to deliver the functions listed, together with the following duties related to stewardship of the system:

(a) policy advice and support to the Minister for Health and Aged Care

(b) administration of the Act

(c) leadership, stewardship and guidance of the aged care system to ensure that the system as a whole, and in its component parts, is supported to deliver safe and high quality care to older people

(d) promotion of positive attitudes towards ageing

(e) engagement with older people and the wider community about the aged care system

(f) proactive and ambitious ongoing aged care system reform

(g) ensuring appropriate aged care services are fairly and equitably accessible to older people irrespective of their location, diverse characteristics or ethnicity

(h) facilitating an adequately diverse mix and sufficient providers to enable older people seeking services to exercise informed choice between available providers, wherever possible

(i) building the capacity and capability of new and existing providers to foster best practice and innovation and address any business and service delivery issues that may affect their sustainability

(j) ensuring continuity of services for older people if providers are unable to deliver high quality services or wish to transition out of the aged care system

(k) research, evaluation and statistical analysis in support of aged care management and reform.

Recommendation 8: Cabinet Minister and Department of Health and Aged Care

Commissioner Briggs

1. The Australian Government should ensure in all future Ministerial arrangements that there is a senior Cabinet Minister, preferably the Minister for Health and Aged Care, responsible for aged care.
2. The Department of Health should immediately be renamed the Department of Health and Aged Care.
3. The Department should have an Associate Secretary tasked with day-to-day responsibility for aged care, acting as the principal policy adviser to the Minister and the Secretary, leader of aged care administration, and member of the Aged Care Workforce Industry Council.[66]
4. The Administrative Arrangements Orders should be amended to provide for the Department to also be responsible for the education, training, development and supply of the aged care workforce.
5. The Department of Health and Aged Care should have a focus on:
    a. aged care system renewal consistent with the recommendations of the Royal Commission
    b. personal engagement with older people
    c. promoting positive attitudes towards ageing and encouraging social and community engagement
    d. stewardship of the aged care system and all of its component parts, including:
        i. guiding the aged care sector in the delivery of safe and high quality care
        ii. building providers' capacity and where necessary managing the exit of poor performers
        iii. fostering innovation and continuous improvement
        iv. leadership in support of all Government agencies and aged care and other service providers to ensure that the aged care system as a whole delivers safe and high quality aged care
        v. proactive management of the interface between aged care services, health services, accommodation services, homelessness and disability services and services for those with diverse needs to ensure that barriers to older people receiving fair and equal access to services are removed, and
        vi. performance of the aged care system, including whether it is meeting the objects and principles of the Act

e. a proactive and ambitious ongoing aged care policy reform agenda

f. the planning and delivery of safe and high quality aged care

g. program design, development and delivery

h. research, evaluation and statistical analysis

i. funding for the aged care system

j. determining user contributions to the cost of aged care services

k. prudential oversight and approval of providers, and

l. public information and disclosure, including the star rating system.

6. The Department of Health and Aged Care should have a network of up to 50 small and dedicated regional offices responsible for local planning, engagement with older people, information provision, care finding, assessment, engagement with, and education and support for, providers.

7. The fundamental restructuring of the Department of Health and Aged Care should be supported by an immediate capacity and capability review carried out by an eminent person with experience in public sector administration to determine the nature and level of the resources required to fulfil these functions.

8. The Department will report annually to Parliament on all important aspects of the operation of the new Act, including:

   a. the extent of unmet demand for aged care, including unmet demand for particular services or in particular places

   b. the adequacy of the Australian Government subsidies provided to meet the care needs of people needing or receiving aged care

   c. the extent to which providers are complying with their responsibilities under the Act

   d. the amounts paid by people receiving residential care in connection with their care, including amounts paid for accommodation and daily living needs

   e. the amounts paid for accommodation in the form of lump sum deposits and in the form of daily payments

   f. the duration of waiting periods for assessment, and between assessment and commencement of provision of particular services, including respite and residential care

g. the extent of building, upgrading and refurbishment of aged care facilities, and

h. such other aspects of the operation of the Act as the Department considers relevant to ensure an accurate understanding of the operation of the Act.

9. Commencing in 2024, the Department should provide a triennial 'state of the aged care sector' report to the Australian Parliament on aged care system performance, which would also identify directions for further aged care reform.

2.4.4 The Council of Elders

In undertaking their functions, the Minister and the Department will need to engage directly with older people to ensure aged care meets their needs. To ensure the effectiveness of such engagements, I propose that a high-level and influential body, The Council of Elders, be established.

Recommendation 9: The Council of Elders — **Commissioner Briggs**

The Australian Government should, by 1 July 2021, establish a high-level older people's advisory body—The Council of Elders—with a wide remit to consult older people and advise the Minister and Department on any aspect of aged care from the perspective of the quality and safety of care and the rights and dignity of older people.

The Council of Elders would assist the process of restoring honesty and transparency to the Australian Government leadership of the aged care system by enlisting eminent and powerful older people who can both speak truth to power and provide a continuing voice to the Government from older people throughout the nation. The high calibre of its members should ensure that it can ably represent the views of older people and be heard not only in Canberra, but nationwide. Mr Rees put it to us like this: 'Empowering older people to speak for themselves is the priority'.[67]

Therefore, the Council should be empowered to provide advice to the Minister and Department on any matters of concern in relation to aged care and have the power to issue reports on the state of the aged care sector from the perspective of quality of care and rights and the dignity of older people. The Council should be supported by the Department.

In undertaking its work, the Council should consult widely with older people, including through calling for submissions on particular issues, public meetings or workshops, online consultations and the like. The Department would fund this consultation work to a level sufficient to enable genuine and wide-ranging engagement with older people and their families or representatives.

This is not the only advisory body relevant to overall systems governance, but it will be the most significant in terms of providing a loud voice for older people. For example, in Recommendation 76 Commissioner Pagone and I propose that the Aged Care Workforce Industry Council should in future include both provider and workforce representatives to advise on workforce development and related matters.

Ministers appreciate counsel from good advisers familiar with the aged care system. However, it has been apparent throughout this inquiry that fresh knowledge and experience should be brought to bear in advisory committees, particularly from older people, provider chief executives and the aged care workforce, to keep pace with the rapidly-changing policy and operating environment and to ensure that older people's wellbeing is at the centre of care. I anticipate that the Minister for Health and Aged Care will review advisory committee arrangements in the wake of our Final Report and make arrangements for providers, individually and through representative bodies, and interest groups representing older people to advise the Australian Government on aged care.

2.4.5 Aged Care Safety and Quality Authority

Older people need to have confidence that the aged care quality and safety regulator will be free from political interference, will exercise its powers without fear or favour, and base its decisions on objective and measurable standards.

A compassionate government will want to ensure that there is effective policing of the aged care system, with a regulator that acts promptly and will deal severely with breaches of standards. It is clear to me from evidence I have heard that people receiving aged care and their families want to see a regulator that is a 'tough cop on the beat'.

There is a general presumption in government that regulators should not develop the legislation they are expected to enforce. Good regulatory policy puts in place regulatory instruments designed to achieve desired outcomes—in this case, a safe and high quality aged care system—and then asks the regulator to ensure compliance.

The Productivity Commission in 2011 and the Carnell-Paterson review in 2017 both recommended the separation of the quality regulator from the Australian Department of Health's policy and funding responsibilities. In my view, our consultations with regulatory authorities—and my January 2020 meeting with Harvard University's Professor Malcolm Sparrow, one of the world's leading thinkers on regulation—confirmed the desirability of this structural separation between policy and regulation.

During the Perth Hearing in June 2019, Dr Lisa Trigg, who has conducted research comparing the approach to improving the quality of residential aged care in England and Australia, provided a practical example of why a strong independent regulator is required. She provided her example to explain the importance of a regulator that is more arms-length from policy and funding, as is the case in England, as well as the benefits to having 'multiple stakeholders' in the oversight of quality. She said:

> there are some principles that…could be adopted to stop this kind of single, you know, huge monolithic body looking after care and everything associated with it because it becomes very difficult to make challenging decisions because if—let's take an example, if the Safety and Quality Commission was to say, you know, 'We're going to crack down on psychotropic medication'
>
> …
>
> then the Federal Government also has to foot the bill for what might be needed to do that. So I think there are just tensions within that—the way that's organised and not necessarily healthy challenging and checks and balances.[68]

Although the issue was not raised directly by Counsel Assisting's final submissions, a number of submissions included comments on the importance of a separate regulatory function. As one person making a submission said:

> It is important that the regulator should be focussed on monitoring compliance with the law so as to ensure that people receive safe and high quality care. Co-locating the regulatory function in an organisation responsible for system management will blur this focus. If an unsafe and poor quality provider is the only one in a regional area a co-located regulator may be tempted to soften its position on non-compliance in order to avoid handing the system manager the problem of finding an alternative provider.[69]

COTA Australia said that:

> COTA Australia does not support the proposed Australian Aged Care Commission being responsible for both the management and funding of the system and for standards compliance and complaints. We support a separate regulator for compliance and complaints. Aged care consumer movement organisations and advocates spent decades getting these functions set up independent of the managing Department and we cannot support them being put back again into the one body. It was dysfunctional before and it will be again.[70]

The Victorian Government noted that:

> It will be important to be distinguish responsibilities across governance, regulation, quality and safety and service delivery and be transparent about the separation of these functions. This includes ensuring there are no conflicts between the broad range of functions of the proposed Australian Aged Care Commission. It is vital that the independence and integrity of regulatory decision-making is not undermined by other potentially conflicting objectives that the organisation might have, including the administration of funding.[71]

In response to Counsel Assisting's final submissions, the Australian Government noted that the Australian Aged Care Commission proposal would reverse recent changes to ensure the independence of the regulator:

> the proposal reverses the policy position only recently taken by Government to recognise and realise the benefits in separating the regulator from the system operator… The purpose of the separation was to ensure that the ACQSC [Aged Care Quality and Safety Commission] could carry out its monitoring and assessment tasks in a truly independent way and be protected by separate statutory provisions which joined up all regulatory functions.[72]

I propose that these recent reforms be taken further and that the Aged Care Quality and Safety Commission be reconstituted and revitalised as an independent Aged Care Safety and Quality Authority, working to an independent governing board, with a charter more tightly targeted to it being the 'tough cop on the beat', focused on its compliance and enforcement functions. This approach is aligned with the Productivity Commission and Carnell-Paterson recommendations.

Under these arrangements, the Department would develop policy, including providing the drafting instructions for legislation and subordinate legislation including rules and regulations. The Department would also take on stewardship responsibilities, including education and capacity-building in the aged care sector, promotion of continuous improvement and best practice.

These functions of the Department would be complemented by an independent regulator with a strong focus on gatekeeping, compliance monitoring and enforcement. The independent regulator needs to exercise tight controls on the suitability and capacity of providers entering the sector, ensuring that new providers are able to deliver high quality and safe care before they are approved to provide services. Once providers have begun to deliver services, the independent regulator needs to be vigorous in sanctioning providers that are unable or unwilling to meet the standards expected of them and, where necessary, remove them from the sector, while also recognising good performance through the accreditation process.

The Aged Care Safety and Quality Authority would have responsibility for approval and accreditation of providers, monitoring and enforcing compliance, and handling complaints about provider non-performance within the regulatory framework.

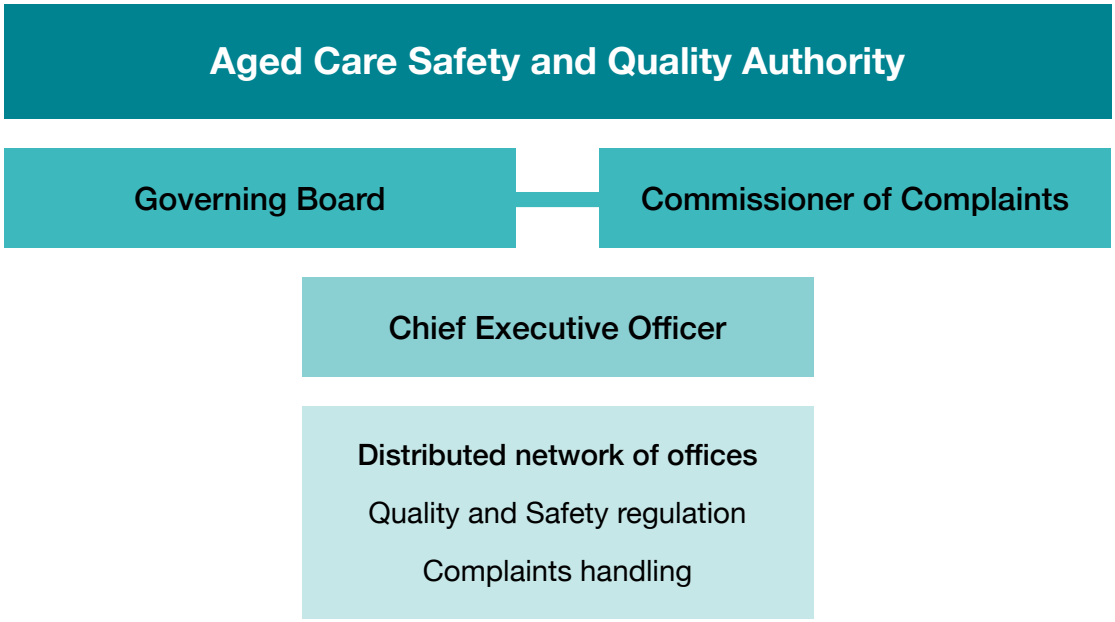
The Aged Care Safety and Quality Authority will need to be more risk-based and more curious and energetic in its pursuit of better aged care service performance than the Commission it replaces. It would need to be resourced to maintain sound regulatory capability. As the Aged Care Safety and Quality Authority would serve the public purpose of holding providers to account for the quality and safety of care they provide, it should be fully publicly funded.

The Aged Care Safety and Quality Authority would have the overarching purpose of safeguarding the quality and safety of aged care through gatekeeping, monitoring, assessing, enforcing, imposing sanctions, and seeking the imposition of penalties by the court in certain serious categories of cases, and reporting publicly on compliance with the Act and the standards.

Its role would not be to soft-handle providers back to regulatory compliance, but to regulate them to protect older people from poor practice and ensure high quality care. The Aged Care Safety and Quality Authority would also be the one-stop shop for all complaints about the aged care system and its services, and would engage actively with older people and their families and carers.

The Authority should be directed by a governing board composed of clinical, professional and community representatives, and chosen by the Minister for Health and Aged Care. The inclusion of a governing board will enhance the Authority's independence and strengthen focus and attention on its primary quality and safety regulatory responsibilities.

Figure 3: Structure of the Aged Care Safety and Quality Authority



The Aged Care Safety and Quality Authority and the Department should work closely together and exchange relevant information that supports both organisations' ability to undertake their functions effectively and to understand emerging risks.

There are important differences between the scope of the Aged Care Quality and Safety Commission's functions under current arrangements and the role I propose for the Aged Care Safety and Quality Authority under the new model. Notably, the Aged Care Safety and Quality Authority would have no prudential regulatory functions and would no longer have responsibility for supporting the education, capacity-building and development of

the aged care sector or consideration of the impact of its decisions on the viability of providers. These functions would revert to the Department to better integrate them with the other responsibilities more appropriately exercised by the Department, while enabling the Authority to focus on its core purpose of safeguarding the quality and safety of aged care.

Recommendation 10: Aged Care Safety and Quality Authority

Commissioner Briggs

1. The Aged Care Quality and Safety Commission should be abolished by 1 July 2022 and replaced by an independent Aged Care Safety and Quality Authority, overseen by a board made up of up to five members, with a Chief Executive Officer responsible to the Authority.
2. The Authority should have the overarching purpose of safeguarding the quality and safety of aged care through enforcing compliance with the Act and Standards. In carrying out this purpose, the Authority should actively engage with older people and their families and carers to ensure that their views are incorporated in the Authority's compliance and decision-making, and are kept informed of the outcome of regulatory activities.
3. The functions of the Authority are to:
    a. approve and accredit providers
    b. monitor and assess compliance with the quality and safety obligations required of providers under the new Aged Care Act
    c. address non-compliance with quality and safety obligations by taking enforcement action including:
        i. enforceable undertakings
        ii. directions
        iii. civil penalties on directors
        iv. amending approval or accreditation conditions
        v. appointing an administrator to assume responsibility for the conduct of a service
        vi. revocation of approval as an approved provider or withdrawal of accreditation of a service
    d. investigate and respond to complaints about the aged care system
    e. provide timely and accurate data as specified by the Department for inclusion in the national information service, including information on compliance and accreditation activities, serious incident reporting and complaints by provider and service

f. publish information on the outcomes of regulatory actions, including information on system-wide regulatory activity and outcomes, and publication of enforcement action taken against individual providers

g. do anything incidental or conducive to the performance of any of the above functions.

4. The Authority should be fully funded from Budget appropriations.

5. The Authority's staff will be employed under the *Public Service Act 1999* (Cth). The Authority should ensure that it maintains an appropriate regulatory capability, including regulatory and investigatory skills, clinical skills, assessment skills, and enforcement skills.

In due course, it may be possible to foresee the Aged Care Safety and Quality Authority and the NDIS Quality and Safeguards Commission coming together into a single strong quality and safety regulator. However, this should not be done now because our timeframe has prevented us from hearing the views of older people and people with disability on this matter, and because both regulatory bodies have a lot of work to do to shore up their effectiveness and to put in place the right levers, risk assessment tools, and information arrangements within their respective regulatory systems before any merger could even be contemplated.

Independent Hospital and Aged Care Pricing Authority

One of the longstanding shortfalls in the aged care system, and a direct contributor to its current parlous financial circumstances, is the absence of any firm basis on which to adequately fund the aged care sector. Funding levels are based largely on historical precedents and ad hoc decisions, which bear little direct relevance to the actual cost of delivering care. This situation is not sustainable for a system that spends well over $20 billion in Australian Government outlays and is destined to spend much more in response to changing demographics.

Commissioner Pagone and I agree that it is very important that an independent agency should be responsible for determining the costs of providing safe and high quality aged care services (see Recommendations 6 and 11).

However, I am not in favour of creating a new body for this purpose. Since its establishment in 2011, the Independent Hospital Pricing Authority has developed considerable expertise in collecting and analysing cost data and developing and refining classification systems for public hospitals. All these tasks would be involved in establishing a robust system for determining the costs of aged care. Mr James Downie, Chief Executive Officer of the Independent Hospital Pricing Authority, said that the Authority has the expertise to carry out the necessary work to implement a classification-based funding system for aged care.[73]

Mr Downie also observed that:

> The ability to attract and retain the right people is a key challenge for IHPA [Independent Hosptial Pricing Authority]. There is significant competition for people with the requisite skills and experience in the market, both within the health system (public and private hospitals, government and insurers) and more broadly, particularly for data science (finance, banking, manufacturing all have significant investments in data science).
>
> IHPA supplements in-house skills with contractors and consultants as required. This usually occurs when significant projects are undertaken (e.g. costing studies and initial classification development work) or when independent analysis is required (e.g. quality assurance of the national pricing model).
>
> There is a relatively small pool of these external providers available, and IHPA has expended considerable time in engaging a wider pool of providers in an attempt to bring more depth to the available providers.[74]

If a standalone aged care costing authority was to be established, it would be competing with the Independent Hospitals Pricing Authority for these scarce skills. This would not be efficient. Establishing a new agency takes time; staffing it to perform effectively in this specialised area would take even longer.

It is far more sensible to expand the functions of the Independent Hospitals Pricing Authority to allow it to carry out the necessary work for the aged care sector. It would be able to begin work as soon as the functions were conferred upon it. Over time, i t would be able to recruit additional staff who could expect a better career path and more diverse and interesting work in a larger organisation with a broader scope.

I do not agree that an independent pricing authority should be responsible for setting or regulating the level of fees or other contributions to be paid by people receiving aged care. These decisions should be made by a Minister who is accountable to the Parliament and the electorate. This is not to say that the Authority should not provide advice, based on its knowledge of costs and the structure of the sector, but it should not be the decision maker. I have made recommendations to this effect in Chapter 21, on funding the new aged care system.

Recommendation 11: Independent Hospital and Aged Care Pricing Authority

Commissioner Briggs

The legislation establishing the Independent Hospital Pricing Authority should be amended by 1 July 2021 to rename the Authority as the Independent Hospital and Aged Care Pricing Authority and confer upon it the functions relating to aged care set out in Recommendation 115.

2.4.6 Conclusion on Government Leadership model

We expect the recommendations we make in this report to lay crucial foundations for the delivery of high quality and safe aged care in line with our purpose and our overarching principles for the aged care system.

It is important to appreciate that the success of our reforms will require purposeful and strategic governance to steer the system in the desired direction, and constant monitoring and refinement of arrangements for the continued effectiveness of high quality care in the future. It would be wrong to assume that changing organisational structures and institutional arrangements alone will be sufficient to fix the aged care system. They are only one part of a very much larger solution to problems with the aged care system.

Organisational change needs to be considered very carefully if it is to be effective. There have been many occasions within government where structural and organisational change has failed to deliver and has foundered under a sea of unintended consequences associated with the disruption, uncertainty and staff churn, expertise and memory loss involved in the change, ultimately resulting in even more organisational change, greater cost and further disruption to business.

Sensible and sound organisational change needs to be undertaken judiciously and purposefully to deliver successfully the many major reforms that we envisage arising from our recommendations for reform of the aged care system.

The best way to do that is to refine the existing agencies' functions and set clear directions for how they are to undertake them. This will necessarily require the Department of Health and Aged Care to step up to a more proactive management and stewardship role across the aged care system, to engage much more locally and nationally with older people, service providers and other stakeholders, and to plan and fund services more strategically and sustainably. It will require an independent pricing authority to cost and determine the right funding mechanisms for the system. It will require a much more focused quality and safety regulator. And it will require Cabinet Minister leadership and engagement.

2.5 Inspector-General of Aged Care

We both recommend the establishment of an independent office of the Inspector-General of Aged Care.

2.5.1 Inspector-General of Aged Care

At present, the aged care system does not have an entity that is tasked with conducting systemic reviews and providing independent oversight of the system. We consider that the systemic investigation and review function is an important part of the future aged care system and should be restored. Consumer groups and other stakeholders support the restoration and enhancement of the function as it will provide an important check and balance on the processes and decisions of the System Governor and other government institutions. It will deliver more accountability and transparency to the aged care system.

Inspectors-General are independent of the bodies over which they have oversight. They guard rigorously against the influence of those bodies, and are careful to maintain independence from ministerial direction or sway. They have the power to make determinations and publish reports.

An Office of Inspector-General of Aged Care should be established to ensure that the governance of the aged care system is subject to ongoing scrutiny, and ensure that the bodies undertaking governance, regulatory and pricing roles we recommend are held accountable for their performance. The Inspector-General should be separate to the proposed System Governor and from the other agencies that will have aged care responsibilities.

Recommendation 12: Inspector-General of Aged Care

1. The Australian Government should establish an independent office of the Inspector-General of Aged Care to investigate, monitor and report on the administration and governance of the aged care system. This should be done by:
    a. conducting reviews on its own motion and/or at the request of the System Governor or the Minister or Parliament to ensure the quality and safety of aged care
    b. reviewing regulator decisions on a systematic basis to ensure regulator integrity and performance
    c. reviewing the performance of functions by the System Governor, the Quality Regulator, the Prudential Regulator and the Pricing Authority
    d. monitoring the adequacy of aged care data collection and analysis
    e. monitoring the implementation of the reforms recommended by the Royal Commission, and
    f. reporting annually to the Australian Parliament on systemic issues in the aged care system and the extent to which the aged care system attains the objects of the new Act.

2. **The Inspector-General should have a statutory right of access to all documents and data related to aged care held by the System Governor, the Quality Regulator, the Prudential Regulator and the Pricing Authority.**
3. **The Inspector-General of Aged Care should have responsibility for dealing with complaints about the System Governor, the Quality Regulator, the Prudential Regulator and the Pricing Authority.**
4. **An Inspector-General should be appointed under interim administrative arrangements, and should in due course be established formally under the new Act.**
5. **The Inspector-General should have a separate appropriation and its own staffing, and be housed separately from the System Governor.**

There have been numerous inquiries and reviews into the Australian aged care sector over the last two decades since major reforms were introduced through the Aged Care Act.[75] These have addressed recurring issues within the aged care system, many of which remain unaddressed by the Australian Government. Professor John Pollaers AM, former Chair of the Aged Care Workforce Strategy Taskforce, cautioned that the issue of whether or not the Government responds to the Royal Commission's recommendations is a 'clear and present danger'. Professor Pollaers said that 'once the Royal Commission concludes there is no process to hold them accountable for including those learnings or executing those recommendations'.[76] We consider that the Inspector-General of Aged Care would perform a critical role in monitoring and reporting on progress of implementation of our recommendations.

Our inquiry into responses to the COVID-19 pandemic demonstrates the importance of independent review in the context of unforeseen or unusual events. That inquiry extended beyond an examination of the actions of individual providers, and identified a lack of clarity in the roles of the Australian Department of Health, the aged care regulator, State Government officials and the approved provider in the response to the outbreak at Newmarch House.[77] This suggests the need for a body with ongoing oversight of the aged care system, one which can receive complaints and feedback about aged care governance and which can conduct reviews and make recommendations on its own initiative.

There are a number of inspector-general roles operating in other areas. The model we propose is similar to the Inspector-General of Taxation and Taxation Ombudsman, which is an independent statutory office whose functions include improving taxation administration.[78] However, there are important differences between the system for the administration of taxation and the aged care system.

The primary functions of the proposed Inspector-General of Aged Care should be to identify and investigate systemic issues in the provision or regulation of aged care, to make and publish reports of its findings, and to make recommendations to the System Governor, and the Minister. The Inspector-General should have a broad scope to review all aspects of the aged care system, including the functions and processes of the System Governor, the Quality Regulator and the Prudential Regulator, and systemic issues relating to the performance of providers and treatment of people who need care.

The Inspector-General should have the power to conduct an investigation on their initiative, or at the request or direction of the relevant Minister.

Complaints are a key source of information about systemic problems. They provide a practical sense of issues facing people receiving aged care and their families. If a systemic oversight role is conferred without any responsibilities for complaint-handling, there is a risk that the oversight body will never develop the understanding it needs to identify systemic issues. Likewise, if a complaints function is conferred without a systemic oversight function, there is a risk that attention will only ever be given to individual problems, without ever leading to systemic changes. We recognise, however, that the Inspector-General should maintain a focus on systemic issues. That means that it would be inappropriate for the Inspector-General to be given primary responsibility for administering the scheme for handling aged care complaints.

The appropriate balance is that the Quality Regulator should conduct the complaints scheme, and that any person who is dissatisfied with the way their complaint has been handled by that body, or considers the complaint otherwise warrants the attention of the Inspector-General, may refer the matter to the Inspector-General. The Inspector-General may review complaints data and records as part of its oversight of systemic issues.

The Inspector-General should have powers to obtain documents and information, examine witnesses and enter premises.

The Inspector-General should be required to monitor and report on the adequacy of aged care data. Accurate and accessible data will provide early indications of systemic issues in the aged care system, and will assist the Inspector-General, as well as government bodies and providers, to make robust evidence-based decisions.

Upon commencement of the new Act, the Inspector-General should be provided with annual budget allocations in the amount required to enable the Inspector-General to engage the staff and other resources reasonably necessary for the performance of those functions.

The Inspector-General should ensure that governments and the community have access to transparent and independently verified information on the response to our recommendations. In this way, it will play a role in holding governments and providers accountable for their response to the work of this Royal Commission.[79]

2.6 Conclusion

Although we differ on certain details of the institutional arrangements that we recommend for the future aged care system, we are united in urging the Australian Government to establish an enduring institutional framework that will provide:

- proactive system governance that takes account of the complex, adaptive and open nature of the aged care system and steers it to deliver high quality and safe care in the interests of older people
- independent review of costs, leading to funding that enables delivery of high quality aged care
- robust and focused quality, safety and prudential regulation, and vigilant monitoring of risks to continuity of high quality and safe care
- effective complaints handling, engaging with the needs and perspective of people using the system
- independent systemic oversight
- a focus on elevating the voice of older people to influence the direction of the system, and ensuring that aged care is receptive to the needs of older people, including people of diverse experience or background and—in particular—Aboriginal and Torres Strait Islander people
- a focus on the support and continued development of the aged care sector's most precious resource: its dedicated and caring workforce
- a focus on the improvement of ways in which aged care for older people can be enhanced by better coordination with other related services, including health, housing, welfare services and recreational and social resources at the local community level, including by action at the intergovernmental level.

During our last series of hearings, in September 2020, Ms Rosemary Milkins PSM reminded us of how important it is to achieve the kind of system governance that older people deserve:

> It should be brave, it should be innovative. It should actually fix some of the issues that people constantly talk about, rather than pointing at others: it's not me, it's yours. It needs to be more audacious than it is. It clearly is the lost land. And that really is an indictment of our values. It needs, above all, stronger leadership.[80]

We urge the Australian Government to take this advice to heart in its deliberations on the models we have offered, and to be brave and innovative in its response. We urge the Australian Government to implement one of our models promptly and in full, providing all the necessary resourcing and political support that will be required to achieve this, and then to continue providing the ongoing support that will be needed to embed the reforms that older people so richly deserve.

Endnotes

1 The Home and Community Care programs in Victoria and Western Australia transitioned to the Commonwealth Home Support Programme in 2016 and 2018 respectively.
2 *Aged Care Legislation Amendment (New Commissioner Functions) Act 2019* (Cth).
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7 Australian Department of Health, *Home Care Packages Program: Data Report 1st Quarter 2020-2021*, 2020, p 12 (Table 12).
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16 Australian Departments of Health and Family Services and Finance, 'Cabinet Memorandum, Residential Aged Care – Long Term Outlays and Issues for Funding Structures', pp 3 [4], 4 [9], 5 [11], National Archives of Australia, part of NAA: A14370, JH1997/158 (Exhibit 22-01, Final Hearing, RCD.9999.0539.0001).
17 Exhibit 22-1, Final Hearing, Residential aged care – long term, RCD.9999.0539.0001 at 0007 [9].
18 Exhibit 22-1, Final Hearing, Residential aged care – long term, RCD.9999.0539.0001 at 0008 [11].
19 Australian Department of Health and Family Services, *Annual Report 1997-98*, 1998, p 8, https://nla.gov.au/nla.obj-1665690507/view?sectionId=nla.obj-1770405595&partId=nla.obj-1674550542#page/n0/mode/1up, viewed 23 November 2020.
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23 Submission of Roger Beale and Peter Freckleton, Response to Counsel Assisting's final submissions, 2 November 2020, RCD.0013.0001.0005 at 0006–0007.
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42 Submission of Ansell Strategic, Response to Counsel Assisting's final submissions, 12 November 2020, RCD.0013.0012.0075.
43 Submission of the Australian Government, Response to Counsel Assisting's final submissions, 12 November 2020, RCD.0013.0014.0037.
44 Submission of Glenn Rees, Response to Counsel Assisting's final submissions, 12 November 2020, RCD.0013.0008.0209.
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56 Submission of COTA Australia, Response to Counsel Assisting's final submissions, 12 November 2020, RCD.0013.0014.0097; Submission of Combined Pensioners & Superannuants Association, Response to Counsel Assisting's final submissions, 12 November 2020, RCD.0013.0013.0051 at 0053.
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64 See, for example, The Institute of Government, *System Stewardship: The future of policy making,* 2011. See also the Merriam-Webster Dictionary, which defines 'stewardship' as 'the conducting, supervising or managing of something *especially*: the carerful and responsible management of something entrusted to one's care': https://www.merriam-webster.com/dictionary/stewardship, viewed 21 December 2020.
65 Transcript, Sydney Hearing 5, Brendan Murphy, 18 September 2020 at T9414.4–9.
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3. Quality and Safety

3.1 Introduction

This Royal Commission was established to examine quality and safety in the aged care system. We are tasked with inquiring into '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'.[1] We draw particular attention to the expression 'high quality'. Our recommendations are directed at establishing an aged care system that will consistently deliver high quality aged care to older people in Australia. That is what our Terms of Reference require.

The evidence before us reveals that there are some shining examples of high quality aged care, provided within the funding and other constraints of the current system. There are providers that value their staff and attract loyalty in return. This enables the consistent staffing that promotes high quality, relationship-based care. These providers are well governed and value feedback from the people to whom they provide aged care services and their families, friends and advocates. However, as Professor Kathy Eagar, of the Australian Health Services Research Institute, University of Wollongong, explained, the current aged care system contains only 'pockets of excellent practice'—the current average practice is a long way from uniformly good practice.[2]

The challenge is to make these 'pockets of excellence' the norm and not the exception—to flip the figures so that the majority of providers are providing high quality care. There should be no place for substandard or low quality care in the future aged care system.

High quality care will cost more to deliver than the care that is currently provided for by the Australian Government. Funding levels will need to increase. Quality of care to older people should never be compromised by cost. That is why we recommend in Chapter 2 that an independent Pricing Authority be responsible for ensuring that funding levels are appropriate to enable the high quality of care that older people deserve.

In this chapter, we make recommendations directed to ensuring that the aged care system delivers high quality and safe aged care. First, we identify the high quality of care that should be delivered in the new aged care system. The definition of high quality care needs to be measurable and it needs to be refined over time. We make a recommendation about embedding high quality aged care (Recommendation 13), in which we define 'high quality' care. We then recommend that a general, positive and non-delegable statutory duty to provide high quality and safe care be imposed upon aged care providers (Recommendation 14).

We identify four areas for immediate improvement: food and nutrition; dementia care; the use of restraints; and palliative care. We make a recommendation, in Chapters 17 and 21, aimed at improving the quality of food in residential aged care. Particular measures are needed to ensure that people living with dementia receive high quality and safe aged care. In Recommendation 15, we propose a dementia support pathway. Recommendation 16 is directed to specialist dementia services. We address the regulation of restraints in Recommendation 17.

Quality Standards are a powerful tool to maintain and improve quality of care across the aged care sector. We recommend that Quality Standards should, in future, be set by the renamed Australian Commission on Quality and Safety in Health and Aged Care (Recommendation 18). An urgent review of the existing Aged Care Quality Standards is required (Recommendation 19). There should then be ongoing periodic reviews of those Standards (Recommendation 20) that prioritise certain issues for review (Recommendation 21).

Quality needs to be capable of being measured through quality indicators (Recommendation 22) and these should be used for continuous improvement (Recommendation 23). Finally, we recommend the implementation of a star rating system so that people seeking care and their families, friends and advocates can assess and compare the quality of the aged care delivered by different providers (Recommendation 24).

It is important to recognise that while we have selected particular quality and safety matters to highlight here, this chapter cannot be read in isolation. All our recommendations are directed at achieving high quality and safe aged care for older people, as this is the core of our inquiry.

3.2 Quality levels in the current system

One of the important pieces of research commissioned by us during the course of our inquiry is a study undertaken by a team from the University of Queensland entitled *The cost of residential aged care*.[3] The authors examined both quality and efficiency in residential aged care. While this study has limitations because of the incompleteness and unevenness of the data, it does suggest that there is a lot of aged care in Australia which is, at best, of average quality.[4]

In measuring aged care quality, the authors of the study drew on the seminal work of health services researcher, Avedis Donabedian, whose well-known quality model 'remains the dominant theoretical framework for assessing the quality of health care' and which has, in recent years, 'been extended to measure the quality of aged care'.[5] Donabedian proposes a three-dimensional approach to quality of care which considers structure, process and outcomes.[6] The authors of the University of Queensland study draw on Donabedien's work, explaining that:

> *Structure* refers to the attributes of the setting in which care is provided. *Process* refers to the components of care delivery. *Outcome* refers to the changes in care recipients that can be attributable to the care.[7]

Donabedian explains that these three dimensions are interrelated and that any comprehensive assessment of care quality needs to consider a combination of all three.[8] The University of Queensland report built on this theoretical framework and assessed quality in aged care by reference to a set of quality indicators or measures they chose. They considered the clinical health outcomes of residents, the Accreditation Standards and service experience indicators.

These data were combined into a composite quality index, which was in turn used to group residential aged care facilities into categories of differing levels of quality: Q1 (highest quality); Q2 (medium quality); and Q3 (lowest quality).[9] Only 11% of facilities were in the highest quality category. These facilities 'had met all accreditation standards, had no issues or complaints, a higher customer rating, and lower utilisation of high-risk medicines'.[10] Eleven per cent were in the lowest category, and had 'lower customer experience ratings, a higher failure of meeting accreditation standards and higher number of complaints and issues'.[11] The overwhelming majority (78%) provided average quality aged care. In this larger category, facilities had a 'low failure of meeting accreditation standards, a moderate level of customer experience ratings, potentially suboptimal use of high-risk medicines and a low number of complaints and issues'.[12]

It is noteworthy that the residential care services that were found to be providing Q2 level quality were still failing Accreditation Standards, albeit not with the frequency of those in Q3. Facilities providing Q1 quality were not necessarily exceeding the minimum standards. In other words, the pass mark in aged care is low.

As the authors of the University of Queensland report note, the three quality levels they devised 'are not intended to reflect the future quality levels that the Australian community might aspire to achieve or that the Royal Commission is considering'.[13] The vision we have is for high quality care to be more than merely meeting Accreditation Standards. Similarly, we consider that average quality care cannot be provided in a facility that fails to meet such standards, even if only sometimes.

3.3 High quality aged care

High quality care must be the foundation of aged care. There needs to be a universally shared understanding, by approved providers, government and older people and their family, friends and advocates, of what high quality in aged care in Australia means.

What do we mean by 'high quality aged care'? The Caring Futures Institute at Flinders University completed a large-scale study for us that assessed the views and preferences of the general public about the quality of aged care and the future funding of quality aged care.[14] In excess of 10,000 people completed a survey as part of the study.

The study found 'high levels of agreement among members of the general public about what constitutes quality in aged care'.[15] It concluded that the 'Salient characteristics consistently rated as highly important in encapsulating quality in aged care service delivery are largely reflective of the fundamentals of care', being:

- 'older people being treated with respect and dignity'
- 'aged care staff having the skills and training needed to provide appropriate care and support'
- 'the provision of services and supports for daily living that assist older people's health and wellbeing'
- 'older people feeling safe and comfortable'.[16]

Respondents felt 'very strongly that an older person has a right to be treated with respect and dignity by a skilled and trained workforce should they need to access aged care'.[17] Being supported to make your own decisions about care and services was among the less influential characteristics.[18]

The authors of the Caring Futures Institute study noted that the findings concurred with a 2018 COTA Australia study of older people and family carers which found 'being treated with respect and dignity and the qualifications and skills of staff were among the most important characteristics that they would look for when choosing an aged care provider'.[19]

The Caring Futures Institute study revealed that only a small proportion (5%) of people consider that the current aged system does not achieve these characteristics at all. About half of respondents thought that the characteristics are achieved 'sometimes'.[20]

More recently, the National Ageing Research Institute conducted a study into the perspectives of people receiving residential aged care services, entitled *Inside the system: aged care residents' perspectives*.[21] The Institute surveyed 391 residents or their representatives about how they felt about their lives and the care they received. A 'significant share' of those surveyed 'indicated that some aspect of the quality of their care and services was failing them'.[22] The share was at least one third of residents, and is higher depending on one's perspective.[23]

The National Ageing Research Institute study also showed about 41% of residents were 'rarely' or 'sometimes' satisfied with the amount of time staff members spent with them.[24] In a parallel survey of people receiving home care, Commonwealth Home Support Programme respite or residential respite care, the Institute surveyed 1223 people receiving care or their representatives. A 'significant proportion' of respondents felt that 'their needs are not met in one or more aspects of their care'.[25] The share of people whose needs were met 'sometimes' or less often in any area of care were 44% for home care, 46% for residential respite, and 51% for Commonwealth Home Support Programme respite. The study also showed that about 33% of Home Care Package respondents had concerns about staffing, including continuity of staff (18%) and inadequately trained staff members (15%).[26]

Drawing on the results of these studies and the evidence that we have heard about the attributes of high quality aged care, we propose that the following summary of those attributes should feature in the new aged care system.

High quality aged care puts older people first. It assists older people to live a self-determined and meaningful life through expert clinical and personal care services and other support, provided in a safe and caring environment. High quality aged care is respectful, timely and responsive to older people's preferences and needs, and assists them to live a dignified life. High quality aged care is provided by caring and compassionate people who are skilled in the care they provide. It enables older people to maintain their capacities for as long as possible, while supporting them when they experience functional decline or need end-of-life care. High quality aged care delivers a high quality of life. It enables people to engage in meaningful activities that provide purpose, and provides the opportunity for people to remain connected to their community.

In practice, high quality care should also mean a standard of care that meets the particular needs, aspirations and preferences of people receiving aged care. It is provided on the basis of a clinical assessment, and regular clinical review, of an older person's health and wellbeing. High quality care enhances, to the highest degree reasonably possible, the physical and cognitive capacities and the mental health of older people, and supports participation in social and recreational activities. It is delivered with compassion and respect for the individuality and dignity of the people receiving care.

A measurable definition of high quality care needs to be formulated and refined over time. There are a number of measures that can indicate high quality aged care. These measures may include matters such as the amount of time staff spend caring, changes in the reported quality of life of the people receiving care, and the incidence of particular health problems experienced by people receiving care.

High quality care should be measurable by the amounts of time care staff with different identified skills provide each day in caring for a person, according to the person's casemix classification. This will enable the costs of high quality care to be estimated, and that estimate may be iteratively reviewed and refined over time by the Pricing Authority. This is an example of the linkages between different aspects of the reforms we are proposing: quality of care, workforce requirements, and pricing and funding of care. It highlights the importance of implementing the entirety of our recommendations as a complete package. Over time, however, we would expect that high quality care should be measured on the basis of outcomes for older people. We expect the System Governor to work towards that.

Recommendation 13: Embedding high quality aged care

1. The *Aged Care Act 1997* (Cth) should be amended to provide that the Australian Commission on Safety and Quality in Health and Aged Care, in setting and amending safety and quality Standards for aged care (under the functions referred to in Recommendation 18), give effect to the following characteristics of high quality aged care:
    a. diligent and skilful care
    b. safe and insightful care
    c. caring and compassionate relationships
    d. empowering care
    e. timely care.
2. 'High quality' care puts older people first. It means a standard of care designed to meet the particular needs and aspirations of the people receiving aged care. High quality care shall:
    a. be delivered with compassion and respect for the individuality and dignity of the person receiving care
    b. be personal and designed to respond to the person's expressed personal needs, aspirations, and their preferences regarding the manner by which their care is delivered
    c. be provided on the basis of a clinical assessment, and regular clinical review, of the person's health and wellbeing, and that the clinical assessment will specify care designed to meet the individual needs of the person receiving care, such as risk of falls, pressure injuries, nutrition, mental health, cognitive impairment and end-of-life care
    d. enhance to the highest degree reasonably possible the physical and cognitive capacities and the mental health of the person
    e. support the person to participate in recreational activity and social activities and engagement.

3.3.1 Quality of life

We consider that the task of embedding safe and high quality aged care begins first with an older person's quality of life and their wellbeing. As we say in Chapter 1 of this volume, quality of life extends beyond health and personal care to social and emotional fulfilment. We aspire to a future where older people are supported and enabled to enjoy life to the fullest extent possible. As far as possible, they should be supported to do what they like and what they can do, rather than the focus being on what they cannot do.

High quality aged care requires social connection. Like everyone, older people want to be heard, seen and respected. Relationships are the foundation of human engagement. Relationships built on dignity, trust and respect help to mitigate disempowerment and helplessness—the key barriers to quality of life.[27] Strong relationships are central to wellbeing and they make a huge difference to older people's quality of life and their aged care outcomes.

Importance of social connection

High quality clinical and personal care are necessary for many older people to have a high quality of life. A healthy mouth is, for example, necessary to enjoy food, to smile and laugh, and to socialise.[28] But high quality clinical care is not sufficient for quality of life. It is equally important that people experience a sense of wellbeing, social participation, meaningful activity, purpose and joy.

Aged care in Australia is not there yet. Ms Karn Nelson, the Executive General Manager of Strategy and Innovation at aged care provider Whiddon, said that one of the most common pieces of feedback from family members of residents is 'all I want is for Mum / Dad to be safe and secure'.[29] Older people have every right to expect more than this.

The new aged care system we propose has a more ambitious view of what older people, and the broader community, should expect from aged care. The aged care system should deliver high quality clinical and personal care *and* quality of life. Consistent with the new purpose of aged care that we propose in Recommendation 1, aged care should assist older people to live an active, meaningful and self-determined life, *lived* with dignity.

Accessing aged care should help older people achieve happiness and fulfilment. Like everyone, older people want the chance to experience joy, meaning and purpose. This does not change simply because a person needs aged care services. The capacity of the aged care system to support quality of life, as well as to provide quality clinical and personal care, is a key part of achieving the vision for high quality care that we set out in this report.

We heard that for many people, the experience of growing old is a lonely one. It can be isolating to be reliant on others for essential physical and social support. Declining cognition and mobility and increasing frailty can make it harder for those receiving care at home to maintain contact with family and friends. Loneliness and social isolation are often exacerbated by mobility issues and difficulties in accessing transport to leave the house.[30]

It is very important that older people receiving care at home have the opportunity to stay connected to their local community and participate in meaningful and purposeful activities. The Australian community as a whole must do more to support older people to live more fulfilling and connected lives. Neighbours, friends and family members of people receiving aged care can all play a role here, as can community organisations. Our Recommendation 4(2)(b) is designed to develop these opportunities systematically and nationwide.

The transition into residential care can require a person to let go of a past way of life and of the people and things they love. People may leave their local area and move away from a community they have been part of for some time. They may have to give up personal possessions or pets, and they may fear losing a sense of 'belonging' to a social circle or hobbies they have enjoyed their whole life, such as gardening and cooking. There is evidence before us that people in residential care may be left for the majority of the day without human contact, feeling isolated, forgotten or bored.[31]

For too long, residential aged care has been largely segregated from the broader community by an 'out of sight, out of mind' mentality. These older members of our community are being isolated and ignored. This is not high quality care, and we all have a responsibility to address it.

COVID-19 put a magnifying glass on the issues of isolation and the importance of connectedness. Ms Merle Mitchell AM acknowledged the success of her residential care provider in keeping the virus out, but asked 'at what cost?'[32] The COVID-19 pandemic has made it clear that visits from family and friends are not just matters of lifestyle. Visits are an integral part of health, enablement and happiness.

In the new aged care system we propose, the transition into residential aged care should be more like moving house and less like leaving a whole life behind, and it should remain home-like for the duration of a person's stay.

Spending time with family and friends provides an opportunity for conversation, exercise and a break from routine, as well as maintaining a connection to the community. Visits from family and friends are critical to the physical, mental and emotional health and wellbeing of people living in residential aged care. They also mean a great deal to the friends and families who visit. Residential aged care needs communal spaces that are inviting for friends and family to gather and spend time in, and also enable them to just 'pop in' and see someone, as happens in the community.

Having your own community come to you is of fundamental importance to many older people with diverse needs. At Melbourne Hearing 2, Ms Samantha Edmunds, Policy and Research Manager at the National LGBTI Health Alliance, described how upskilling young LGBTQI youth and fostering intergenerational engagement with the LGBTQI communities can help older community members feel at ease:

> that sense of people coming into my home are people from my community and who understand my experiences and understand what I go through and what I have done, and I actually don't have to explain anything because they get it because they're from my community.[33]

Ms Moreen Lyons, a Jaadwa woman of the Wotjobaluk nations and Chief Executive Officer of Aboriginal Community Elders Services Inc, said that Elders give a lot back:

> It's certainly seen as part of the role of an elder and a recognised elder to guide, support and mentor young counterparts…it happens organically and it's very… nice how these relationships grow amongst different generations.[34]

It just needs a little thought and sensitivity to make these activities a normal part of the culture and practice of aged care services throughout the country.

Many of the solutions lie beyond the residential aged care service or an individual provider. For example, thoughtful urban planning that connects people receiving aged care—both at home and in residential settings—to the broader community is an important part of this puzzle. So, too, is facilitating integration with the community. This could include co-locating community services with residential aged care—for example, community services like schools or childcare, or small businesses like cafes or hairdressers, on the same premises as, or nearby, residential aged care. Other innovative ideas from both Australia and overseas include university students living with a person accessing aged care or young volunteers reading to people in residential aged care.[35] It would be wonderful to see the community encouraging creative ways to connect with people receiving aged care.

The architectural design of residential aged care buildings can also help encourage social interaction and bring a welcome sense of connection. Mr Bryan Lipmann AM, founder and Chief Executive Officer of the aged care provider Wintringham, explained the importance of the verandas surrounding their accommodation units in providing an unforced opportunity for people to interact:

> So we find the verandas are a huge way of giving an opportunity to our guys to interact. Because our guys are full of—men and women, full of extroverts, full of very shy people. They're a total cross-section of the community, just like the people in this room. So those people who do want to interact can sit on the veranda. They can meet people as they go past, they can talk to them, they can interact.[36]

Quality of life is also about making a purposeful contribution. Activities in aged care should do more than just fill time and keep people busy. Some of the activities in residential care are patronising or stereotypical, making no allowances for creativity and diversity of interests. On this, Ms Janette Maguire said:

> I thought I was being treated like a five-year-old. The facility would have silly games like bingo and things. Some people might have liked it, but it wasn't right for me. It was patronising. We are people with minds and brains.[37]

Finding ways to allow people to continue the hobbies they love, or contribute to the running of the premises, can be fulfilling and give a sense of purpose. Activities like helping to prepare meals or tending to the garden are tasks that many people have done all their lives. The availability of chess sets and other stimulating games is important. If people want to continue doing these things, they should be supported to do so.

High quality aged care should support people to continue finding meaning and purpose, and to be able to share their lifetime of knowledge and experiences with others. 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 about older Aboriginal and Torres Strait Islander people:

> And they are living connection to a wealth of wisdom and lessons and experience of stories, of traditional ecological knowledge, cultural practices and fluent language speakers.[38]

Intergenerational programs bring a sense of purpose and give older people an opportunity to share their wisdom, knowledge and skills with others.[39] But more can and must be done to support older people to remain connected to the people they care about and to engage in activities that provide meaning and purpose.

3.3.2 The personal touch

In our view, the personal touch in the way care is delivered is fundamental to whether or not older people receive high quality aged care. The way that people relate to each other contributes to their sense of dignity and purpose. We consider that care should be delivered in a way that is personal and engaging and enables older people and their carers to live a meaningful life. This involves supporting older peoples' sense of who they are and their identity through building respectful and trusting relationships that are grounded in knowing and responding to each person as an individual.

Public views on this issue were captured in the Caring Futures Institute survey commissioned by us, which found that approximately 85% of the 10,315 respondents saw it as 'important' or 'very important' that staff members knew and valued the identity, culture and history of the older person.[40]

Caring relationships take time to establish, and work best when carers get to know older people well and when carers are qualified and supported to provide the best care possible. This suggests the need for continuity of staff. Where continuity of staff and effective training is in place, changes in older people's conditions are more likely to be detected earlier and supported more safely. But where older people do not feel a connection to the people around them, physical harm and emotional distress can and do occur.

Respect is a necessary part of caring relationships. It involves respecting the individuality of older people receiving care, no matter their cognitive function and how challenging their care.

Where respectful relationships are in place, it is much easier for the care workforce to understand and act on the needs, goals and preferences of older people. Care planning will also be much more effective because it will identify quality of life and quality of care measures, which may trigger the involvement of multidisciplinary, specialist or other care and support services.

A challenging part of the new aged care arrangements we recommend is to bring these important wellbeing, quality of life, and personal touch issues to bear at a more formal level. The next sections and chapters provide some guidance as to how this might be done.

3.4 Approved providers must have a statutory duty of care to people receiving care

The *Aged Care Act 1997* (Cth) contains no clear statement outlining the basic responsibility of approved providers to ensure that the care they provide is safe and of high quality. This is a major gap in the current legislative scheme.

Recommendation 14: A general duty to provide high quality and safe care

1. **The new Act should include a general, positive and non-delegable statutory duty on any approved provider to ensure that the personal care or nursing care they provide is of high quality and safe so far as is reasonable, having regard to:**
    a. **the wishes of any person for whom the provider provides, or is engaged to provide, that care**
    b. **any reasonably foreseeable risks to any person to whom the provider provides, or is engaged to provide, that care, and**
    c. **any other relevant circumstances.**
2. **Any entity that facilitates the provision of aged care services funded in whole or in part under the new Act should have a duty to ensure that any worker whom it makes available to perform personal care work has the experience, qualifications, skills and training to perform the particular personal care or nursing care work the person is being asked to perform.**

Section 54(1)(a) of the Aged Care Act imposes a responsibility on an approved provider 'in relation to the quality of aged care that the approved provider provides' to 'provide such care and services as are specified in the Quality of Care Principles'.[41] The Principles in turn require the provision of the care and services specified in Schedule 1 of the Act, 'in a way that complies with the Aged Care Quality Standards set out in Schedule 2'.[42]

Importantly, it is not an offence for an approved provider to fail to comply with this duty; nor may a civil penalty be imposed. The consequences of such a failure are outlined in Part 7B of the *Aged Care Quality and Safety Commission Act 2018* (Cth).

The effect of the lack of a clear statement of responsibility to provide care that is safe and of high quality was apparent in the evidence at the Hobart Hearing. The evidence revealed that an approved provider, Bupa Aged Care Australia Pty Ltd, introduced a policy entitled 'save a shift' under which, to reduce costs, workers who were on sick leave would not be replaced for that shift. Such policies will invariably have a deleterious effect on quality and safety of care.

There should be a general duty on an approved provider to ensure, so far as is reasonable, the quality and safety of its aged care services. This would send a clear message to providers, the community and the Quality Regulator about the primary duty of an approved provider: to protect the health, wellbeing and safety of its residents. This amendment should be made in the existing Aged Care Act and transferred into the new Act we are recommending.

The duty we propose is based in part on an employer's duty under occupational health and safety law—a duty that the vast majority of approved providers already owe to their employees and contractors.[43] Such a duty has operated in Australian law since the 1980s. It has been described as requiring employers to 'take an active, imaginative and flexible approach to potential dangers'.[44] It requires employers, guided by experts, to be proactive, not reactive.[45] It requires employers to ensure that their staff are instructed, informed, trained and supervised so that they can work safely.[46]

Approved providers currently have a non-delegable common law duty to exercise reasonable care for the health and safety of residents. The notion of 'reasonable care' is not fixed but evolves as scientific and medical knowledge increases and in line with changing community expectations.[47]

The duty we are proposing is in addition to this common law duty. It will encourage an approved provider to do more than merely meet Accreditation Standards. It will clearly state that the duty of a provider is to service the needs of residents first and foremost. To adopt the words of Professor Joseph Ibrahim of Monash University, accreditation should be a by-product and not the focus of providers.[48] That focus needs to be to provide the highest quality care that is reasonable, while also respecting the dignity and choices of individuals receiving care.

In addition to providing clarity for residents and their families, the inclusion of such a duty in aged care legislation would provide a focus for the compliance and enforcement work of the aged care regulator, a point we address later in this volume.

Our recommendations about the consequences for a breach of the general duty, and the role of the regulator in response to any such breach, are discussed in the later chapter regarding effective regulation. We propose that the Quality Regulator, and people harmed by the conduct that breaches the duty, should have an ability to hold relevant approved providers and their key personnel accountable.

The new Act should also include a provision like section 96-4 of the Aged Care Act. This provision should state that for the purposes of the new Act, including the new general duty, a reference to care provided by an approved provider includes any care provided by another person on behalf of the approved provider under a contract or arrangement entered into between the approved provider and the other person. In addition, and for the avoidance of doubt, the new provision should state that a reference to care provided by an approved provider includes any care provided by a third party under an arrangement between an older person and the third party, where that care is funded by a subsidy being administered by the approved provider. These provisions are intended to address the

circumstance where the actual provision of care is undertaken by a third party, such as a worker engaged through a labour hire firm or through an online brokerage service, and not by an employee of the approved provider.

Finally, the new Act should impose a duty on any entity which facilitates the provision of subsidised aged care services. In Sydney Hearing 4, which examined matters relevant to the design of the home care system, there was evidence about the various models used by organisations like Mable Technologies Pty Ltd (Mable) and Hireup Pty Ltd (Hireup) to provide aged care or disability support workers. They arrange for care workers to provide care under arrangements with people seeking care or with approved providers.[49] In such models, there may not be any direct relationship between the provider and the care worker.[50] We discuss the implications of these arrangements in more detail in our chapter about the aged care workforce.

The question here is how the law can ensure that care provided in such circumstances is of high quality and safe. In addition to the duty on the approved provider in such circumstances, there also needs to be a duty on the party we are describing as the facilitator of the labour. Unless the workers sourced through such arrangements are appropriately supervised, trained and qualified, there is a risk that they will not provide care to the desired standard.

One approach to this issue is to deem such a facilitator of labour to be an approved provider of aged care services for the purposes of the general duty. However, such an approach has a degree of artificiality about it and could lead to unintended consequences. We favour a more limited duty that is proportionate to the risk, as was proposed by Counsel Assisting in their final submissions.[51]

A facilitator of care through a platform such as Mable is not just offering a directory service to the general public. The facilitator is holding itself out as a reliable source for those in need of, and seeking, care. It may be that such a facilitator may be held liable under ordinary principles of consumer protection. However, there should be no doubt that an entity which enters the market for profit to facilitate links between carers and the person receiving care will have duties that cannot be avoided. A facilitator of labour, such as an online platform like Mable or Hireup, should have a duty to ensure that any worker who they make available to perform care work has the experience, qualifications, skills and training to perform the particular care work they are being asked to perform. This will require, at the very least, that the platform:

- investigate the work and the circumstances in which it is to be performed
- investigate the particular worker who is to perform the work
- ensure that the worker has the experience, qualifications, skills and training that match the job.

The general duty would require the entity to be active in ensuring that the workers it is offering receive regular training. For example, it will not be enough to make training available via a portal—the entity will need to ensure the training is completed by taking an active, not passive, approach.[52] The duty will be ongoing so that any change in the nature of the work would require reconsideration of the worker's suitability. The duty we have in mind is similar to the duty such entities already owe to third parties under work health and safety legislation as the conductors of businesses or undertakings.[53]

In its response to the final submissions of Counsel Assisting, Mable supported the imposition of such a duty 'in principle'.[54] Mable submitted that 'such a duty should be focussed on confirming that the worker is registered on the AHPRA [Australian Health Practitioner Regulation Agency] Register of Personal Carers'.[55]

The time for this important reform is now.

3.5 Areas for immediate improvement

While the evidence before us has reflected a wide range of concerns about aged care quality and safety, four concerns are worthy of special mention and attention. They are food and nutrition, dementia care, the use of restrictive practices, and palliative care.

This is not to downplay the importance of other concerns. However, these four areas should be a central focus of all aged care services to achieve high quality in aged care. All approved providers that provide clinical and personal care should, for example, be equipped to deliver high quality dementia care and palliative care, and to deliver care without routinely relying on practices that restrict a person's free movements or ability to make decisions. It is unquestionable that all providers who provide food as part of their services should serve nutritious and tasty food. We highlight these areas as they should be the subject of immediate action for improvement, as set out in the recommendations that follow.

3.5.1 Food and nutrition

The quality and quantity of food that is available in residential aged care is central to the quality of that care. While not all people living in residential aged care have the same needs, they all need to eat—at least three times a day, every day—and to drink so that they remain hydrated and healthy. Many need assistance to eat and drink; many have difficulty chewing; and some lack either the motivation or cognitive capacity to know that they need to eat and drink regularly.

The evidence before us indicates that this issue greatly concerns many people. And rightly so.

A number of witnesses who gave evidence as part of the case studies raised concerns about the quality and quantity of food in residential care. For example, Ms Johanna Aalberts-Henderson described the meals her late mother received in residential aged care:

> Some of the evening meals that I saw were terrible—some nights Mum was given soup, bread and cheese, which was fine. But other nights they served meals with very little nutritional value.[56]

This is not high quality aged care. Ms Aalberts-Henderson's evidence was that meals were prepared off-site and brought in by a contractor. The food was put in plastic containers and then dispensed by the staff.[57] Such arrangements are not unusual in aged care.[58]

The Darwin and Cairns Hearing in July 2019 had a particular focus on food and nutrition. People who are experts on the nutritional needs of older people shared their practical suggestions for improvements to residential care services.

Ms Maggie Beer AM, a former Senior Australian of the Year and a well-known celebrity cook, gave evidence in Cairns. Ms Beer explained that older people have:

> a reduced capability to detect the flavours and aromas that they enjoyed when they were younger; they may have reduced appetites; they may also have difficulty chewing and swallowing; and they may have conditions that require specific dietary construction.[59]

Dr Sandra Iuliano, Senior Research Fellow at the Department of Medicine, University of Melbourne, was the principal investigator in a representative study of 60 Australian residential aged care services which was conducted in 2017. The study concluded that a staggering '68% of residents were malnourished or at risk of malnutrition'.[60] Dr Iuliano explained that poor nutrition in residential aged care is related to an increased incidence of falls, fractures, pressure injuries and unnecessary hospitalisation.[61]

National quality indicator data for the first quarter of 2019–20 shows that, on average, one in every 11.1 residents in for-profit residential aged care services, one in every 11.8 residents in not-for-profit residential aged care services and one in every 15.6 residents in government residential aged care services experienced 'significant unplanned weight loss'—defined as unplanned weight loss equal to or greater than three kilograms over a three month period.[62]

Ms Beer spoke about the Maggie Beer Foundation that she established in 2014 to transform the food experience of older people.[63] The Foundation delivers education about food and nutrition to aged care staff. It adopts a 'train the trainer' approach and promotes fresh seasonal food that is full of flavour.[64]

Ms Beer said:

> there are so many people in aged care working so hard but often without the support or being empowered to do things better but when given the respect together with the skill, the practical ideas along with the inspiration, it is an incredibly powerful thing that we have seen individuals bring about amazing change.[65]

Dr Iuliano referred to a 2016 Australian study led by Dr Cherie Hugo that collected data from 817 residential aged care facilities. The study reported that, in 2016, the average expenditure of food for people living in residential aged care in Australia was just $6.08 per resident per day. Despite rising prices, this food allocation had declined from $6.39 per resident per day in the previous year while expenditure on protein supplements increased from $0.39 to $0.89 over this period. This allocation of funds to feed residents is less than money spent in corrective services ($8.25 per day) and nearly one-third the average daily household expenditure on food and drinks in older adults in the community.[66]

Dr Iuliano advocated that food and beverage expenditure must be sufficient to meet the nutritional needs of people living in residential aged care, taking into account their specific needs and preferences. Nutritional adequacy can be modelled based on the Australian Guide to Healthy Eating. The mean expenditure of $6.08 is insufficient for nutritional adequacy to be achieved.[67]

The results of Dr Hugo's 2016 study were consistent with the evidence given by Mr Nicholas Hall, Mr Timothy Deverell and Ms Lindy Twyford, the first two working in aged care as chefs while Ms Twyford worked as a hospitality manager. They described the significant link between food budgets in residential aged care and the quality and quantity of food provided. Mr Hall and Mr Deverell described the immense difficulties of working with insufficient funds for food, including their observation of practices such as recycling leftover food and reducing portion sizes for residents.[68]

A 2015 study by the University of Queensland examined menu planning in Australian residential aged care facilities. The authors concluded that 'when asked to rate the importance of control and choice over certain areas of their everyday life in a home, residents prioritised having choice over their foods as the most important'.[69]

The study concluded that 'regulation and monitoring of the [Aged Care] Standards needs to be strengthened to mandate improvement of the choice and variety offered to residents, particularly those on texture modified diets'.[70] The authors were critical of the previous Standard (Standard 2.10), which they said did 'not provide guidance on the process for achieving adequate / any choice in menu planning'.[71]

A 2017 Australian study of people's preferences in residential aged care and willingness to pay for food service highlighted that 'strategies to maintain and improve taste of the food provided are critical to consumer satisfaction in the area, and these should be prioritised'. The authors provided an example of an appropriate food preparation strategy that echoes the evidence given by Ms Beer:

> maintaining food preparation and cooking within facilities (so that residents can smell food as it is being prepared, and to minimize loss in flavour compounds during transport and reheating), access to professional development and improved education for food service professionals, and investment toward better quality ingredients.[72]

There is nothing more basic than food. People living in residential aged care have no choice but to eat the food they are served. There are real questions about the nutritional standards of the food in Australia's aged care homes despite the needs older people have for nutritious meals that are high in protein.

Fresh and appetising food is about more than meeting basic nutritional needs—it can be central to older people's happiness and wellbeing. Having the kitchen as the hub of an aged care service can be a way to encourage people to congregate and connect. The smells and the sounds of a kitchen can contribute to the area feeling like the 'soul' of the home and create a natural place for interaction. People living in residential aged care should be able to smell their food being cooked. That is one of the joys of life. They should be able to cook their own meals or at least participate in the preparation. These are practical, simple aspects of quality of life. They are also relevant to maintenance of physical and cognitive capacity.

The current Aged Care Quality Standards are a slight improvement on the previous Standard 2.10. The current Standard 3(f) provides that 'where meals are provided, they are varied and of suitable quantity and quality'. However, this leaves much to the discretion of the provider and it is not easily enforceable. How 'varied' do meals have to be? What does 'suitable' mean? The practical suggestions Dr Iuliano made, as noted earlier, are a good basis for the review of that Standard that we recommend.[73]

The process of reviewing the Standards, as proposed in Recommendation 19 below, will necessarily take some time. However, there is an urgent need for action. The evidence before us about the levels of under-nutrition in residential aged care is very concerning. People living in residential aged care today should not have to wait.

It is clear that nutrition is affected by a number of factors, including how food is served, the capacity and skills of staff members to assist with eating, and people's oral health. However, as the evidence demonstrates, sufficient spending to ensure the quality of food is a critical first step to address the issue of poor nutrition.

As we explain later in this report, the cost of food in residential aged care is covered by the Basic Daily Fee, which is capped at 85% of the basic single aged pension. In the funding chapters of this volume, we recommend an immediate conditional increase to the Basic Daily Fee of $10 per resident per day.[74] The additional funds are to be spent on daily living needs, especially nutrition.

Finally, the evidence before us is that staff training programs specifically tailored to nutrition requirements for people living in residential aged care are currently available, but many staff members working in aged care lack this kind of training.[75] Training that is specific to preparing and serving food in a residential care setting should be standard practice in the aged care system. An example is provided by the training programs, both face-to-face and online, that have been developed by the Maggie Beer Foundation.[76]

3.5.2 Caring for people living with dementia

Our Terms of Reference specifically direct us to consider how best to deliver aged care services to the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services.[77] The aged care system needs the leadership and capacity to ensure that people living with dementia receive high quality care. Dementia care must be core business for approved providers.

The Australian Institute of Health and Welfare estimates that in Australia in 2020, between 400,000 and 459,000 people have dementia.[78] Approximately one in five of the people living with dementia have a cultural and linguistically diverse background.[79] The rate of dementia experienced in regional, rural and remote Australia is similar to that in metropolitan areas. Around 7% of people aged over 65 years living in regional, rural or remote Australia experience dementia, compared with around 8% in major cities.[80] The Aboriginal and Torres Strait Islander population experiences a much higher incidence and prevalence of dementia-related risk factors and dementia diagnoses than non-Aboriginal and Torres Strait Islander people.[81]

The number of older people who are living with dementia is expected to increase in line with the ageing population.[82] The Australian Institute of Health and Welfare suggests there will be between 550,000 and 590,000 people in Australia living with dementia by 2030. Approximately 57% of these people will be aged 84 years or less, with 43% aged 85 years and older.[83]

The Australian Department of Health has estimated that just over half of the people living in permanent residential aged care in 2019 had a diagnosis of one of the forms of dementia.[84] But the real percentage could be as high as 70%, given the prevalence of undetected dementia.[85] Despite this, our inquiry has revealed that the quality of aged care that people living with dementia receive is, at times, abysmal. This is particularly so for those with more complex needs. We have heard time and time again that staff members do not have the time or the skills to deliver the care that is needed. The response is often to rely on restrictive practices, which restrict a person's freedom and diminish their quality of life. The quality of dementia care in the aged care system needs significant and immediate improvement.

All mainstream aged care services should be able to deliver safe and high quality aged care for most people living with dementia. This requires having the right number and mix of staff who are trained in dementia care, having the right physical environment (in residential care), and having the right model of care. Approved providers should continue to be supported with specialist advice and services where people receiving aged care have complex needs.

Ensuring people living with dementia receive the support and services that they need does not begin when they access aged care services. Dementia care extends across a continuum from diagnosis through to palliative care, and this includes prevention, primary care and hospital care.[86] It is important that people diagnosed with dementia have a clear and accessible pathway post-diagnosis, which is critical to managing their condition, enhancing their quality of life, and addressing their need for aged care.

A dedicated dementia support pathway

Unlike other significant conditions such as diabetes, cancer or pneumonia, there is not yet an established support pathway for people who are diagnosed with dementia in Australia.

This impacts on how people manage the condition and how and when they interact with the aged care system. Ms Kate Swaffer, who lives with dementia and is Chair and Chief Executive Officer of Dementia Alliance International, explained that she was not easily able to access any support for 18 months following her diagnosis of dementia.[87] She said that after her diagnosis, rather than being offered 'disability assessment and advice towards continuing living', she was advised to get her 'end of life affairs in order and to get acquainted with aged care'.[88] Ms Swaffer's first exposure to aged care services only arose when colleagues working in the aged care system recognised that she needed support.[89]

The lack of a dedicated support pathway also affects the quality of life for those living with dementia, and the family and friends who support them. Mr Trevor Crosby, who gave evidence about living with Lewy body dementia, described his frustration at experiencing a lack of ongoing programs and support available for people diagnosed with dementia, which would 'lift their quality of life from low to something meaningful'.[90]

Recommendation 15: Establishment of a dementia support pathway

1. **By 1 January 2023, the Australian Government should establish a comprehensive, clear and accessible post-diagnosis support pathway for people living with dementia, their carers and families. This should involve:**
    a. **providing information and advice on dementia and support services, including the aged care system**
    b. **facilitating access to peer support networks**
    c. **providing education courses, counselling and support services**
    d. **providing assistance with planning for continued independent living and access to care, including regular and planned respite for carers.**
2. **The Australian Government should provide information and material to general practitioners and geriatricians about the pathway and encourage them to refer people to the pathway at the point of diagnosis.**

The Australian Government first provided specific funding for dementia services in 1983–84.[91] Since 2015, the Australian Government has funded and prioritised particular activities for dementia care, including information and awareness activities, training, dementia behaviour advisory services, incentives to meet the extra costs of dementia

care, and research.[92] The World Health Organization's 2018 guide to developing a dementia plan proposed:

- the development of a coordinated care pathway for people with dementia
- the development of health and other care providers' knowledge and skills
- an improvement in the quality of care towards the end-of-life
- a shift from hospitals to multidisciplinary, community-based settings
- an enhancement of access to person-centred, gender-sensitive, culturally appropriate care.[93]

Professor Henry Brodaty AO, an internationally recognised expert on dementia care, stated that Australia does not have a clear dementia support pathway.[94] His view was that the current pathway generally ceases after people are referred by their general practitioner to a specialist for diagnosis.[95]

In contrast, Scotland's National Dementia Strategy has 21 commitments developed through consultation with people living with dementia and carers, as well as other stakeholders across Scotland.[96] The strategy focuses on high quality post-diagnostic support, care coordination in the community and a commitment to supporting people with advanced dementia through to end-of-life.[97] Every person newly diagnosed with dementia is offered a guaranteed minimum of one year of appropriate diagnostic support, with an assigned 'Link Worker'. This post-diagnosis support can transition into greater care coordination in the community, involving: a dementia practice coordinator with other supports for carers; personalised support; community connections; environment; mental health care and treatment; general health care and treatment; and therapeutic interventions.[98]

An Australian national dementia support pathway, perhaps modelled on the approach in Scotland, has the potential to assist people living with dementia to navigate the complex systems through which care is presently provided. Importantly, early interventions and support for some people diagnosed with dementia may not involve aged care services at all. Dementia care and support must not be seen as a function only of the aged care system.

Dementia support pathways are a means to achieve the goals established in dementia plans. These pathways are reported to improve standards of quality, multidisciplinary communication and care planning, communication with older people, and their carers and providers. They are reported to decrease unwanted practice variation.[99] A dementia support pathway describes the information, coordination, care, education and social support services to be provided when, and in what order, to meet the needs of people living with dementia and their carers across the dementia continuum. As Ms Swaffer explained:

> If we don't fix the root cause which is increased diagnosis rates and then change what happens at the time of diagnosis to enable people to live more independently for longer, then everything we do after that is a very expensive bandaid.[100]

Recommendation 16: Specialist dementia care services

1. By 1 July 2023, the Australian Government should review and publicly report on:
    a. whether the number of Specialist Dementia Care Units established or planned to be established is sufficient to address need within the areas and populations they are designed to cover
    b. the capacity of those Units to address the needs of people exhibiting extreme changed behaviour and whether any further resources are required, and
    c. the suitability of the Units for shorter-stay respite for people living with moderate to extreme changed behaviour
2. The outcome of the review should be implemented by the Australian Government as a matter of urgency.
3. The Australian Government should immediately ensure that the specialist dementia service it funds provides treatment to people with a mental health condition if they meet other eligibility criteria (including, for instance, a diagnosis of dementia).

Even with care workers receiving additional training on dementia and the introduction of a dementia support pathway, the aged care sector will continue to require ongoing specialist support and advice on dementia care, particularly to assist people with complex symptoms.

In Australia, approaches to dementia policy and planning have been influenced by the seven-tiered model of management, known as the 'Brodaty triangle', of the 'behavioural and psychological symptoms of dementia'—which we describe as 'changed behaviours'. The model identifies that as symptoms increase in severity they decrease in prevalence. However, the 'boundaries between tiers are not distinct, and movement between levels is not necessarily stepwise'.[101]

The Australian Government has a three-tiered approach to support the care of people with dementia who exhibit changed behaviour:

1. Dementia Behaviour Management Advisory Service
2. Severe Behaviour Response Teams
3. Specialist Dementia Care Program.[102]

These tiers generally align with the tiers in the Brodaty triangle. They range from informal advice and upskilling of those providing care through to specialist units for short-term interventions.

Associate Professor Stephen Macfarlane, Head of Clinical Services, Dementia Centre at provider HammondCare, oversees clinical services for Dementia Support Australia and leads the team of clinical associates who work with the Dementia Behaviour Management Advisory Service and a Severe Behaviour Response Team. Associate Professor Macfarlane explained that specialist dementia care services have a 'strongly positive impact' on the behaviours of those people receiving the services and that, in his experience, there is an increasing demand for these services.[103]

The Australian Department of Health's Specialist Dementia Care Program is the most recently established form of support for people living with dementia. When completed, the program will comprise a national network of Specialist Dementia Care Units.[104] The program supports people exhibiting very severe changed behaviours associated with dementia who are unable to be appropriately cared for in mainstream aged care services.[105] It is expected there will be 35 Specialist Dementia Care Units, with at least one unit operating in each of the 31 Primary Health Networks by full rollout in 2022–23.[106]

Because the Specialist Dementia Care Program is so new, there has been no evidence about its effectiveness. However, Associate Professor Macfarlane explained that the program may address a small part of the unmet need to provide safe and quality care for people living with dementia.[107] It is unclear if this program will be able to care for, and meet the needs of, people experiencing the most severe and extreme changed behaviours.[108] There is also concern that the proposed number of units, with only eight or nine beds per unit, is insufficient to meet demand.[109]

We therefore recommend a review of the capacity of the program, once the rollout of the proposed units is complete, with appropriate action to be taken by the Australian Government in light of the findings of the review to ensure sufficient capacity for this important program.

3.5.3 Eliminating or reducing restrictive practices

The overuse of restrictive practices in aged care is a major quality and safety issue. Urgent reforms remain necessary to protect older people from unnecessary and potentially harmful restraint.

In the Interim Report, Commissioners Tracey and Briggs found that there has been little progress in the aged care system to address the use of restrictive practices effectively. Comprehensive systemic changes to improve the quality of care across the aged care sector are required to reduce or eliminate restrictive practices. A strong framework to regulate and monitor the use of restrictive practices in aged care should also be implemented as a matter of priority.

Recommendation 17: Regulation of restraints

1. The *Quality of Care Principles 2014* (Cth) should be amended by 1 January 2022 to provide that the use of restrictive practices in aged care must be based on an independent expert assessment and subject to ongoing reporting and monitoring. The amendments should reflect the overall principle that people receiving aged care should be equally protected from restrictive practices as other members of the community. In particular, restrictive practices should:
    a. be prohibited unless:
        i. recommended by an independent expert, accredited for the purpose by the Quality Regulator, as part of a behaviour support plan lodged with the Quality Regulator and reviewed quarterly by the expert, with reports on implementation of the behaviour support plan being provided to the Quality Regulator on a monthly basis, or
        ii. when necessary in an emergency to avert the risk of immediate physical harm, with any further use subject to recommendation by an independent expert under Recommendation 17(1)(a)(i), and with a report of the restraint to be provided with reference to the matters in Recommendation 17(1)(b) as soon as practicable after the restraint starts to be used; and
    b. only be used:
        i. as a last resort to prevent serious harm after the approved service provider has explored, applied and documented alternative, evidence-based strategies to mitigate the risk of harm
        ii. to the extent necessary and proportionate to the risk of harm
        iii. for the shortest time possible to ensure the safety of the person or others
        iv. subject to monitoring and regular review (to be stipulated in the behaviour support plan) by an approved health practitioner
        v. in accordance with relevant State or Territory laws and with the documented informed consent of the person receiving care or someone authorised by law to give consent on that person's behalf
        vi. in the case of chemical restraint, if prescribed by a doctor who has documented the purpose of the prescription.
2. In making these amendments, the Australian Government should consider whether any adjustments or additions are warranted as a result of the statutory review of Part 4A of the *Quality of Care Principles 2014* (Cth).

3. The amendments should also provide that:
    a. any use of restrictive practices that is not in accordance with the statutory scheme should be reportable under the updated serious incident reporting scheme, and
    b. any breach of the statutory requirements should expose the approved provider to a civil penalty at the suit of the regulator. If a person directly affected by the breach wants to be compensated, the regulator or the person should have the power to seek an order for compensation.
4. In the interim, the repeal of Part 4A of the *Quality of Care Principles 2014* (Cth) should be delayed until 31 December 2021.
5. Following the conclusion of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, the Australian Government should consider the applicability to aged care of any findings from that Royal Commission about restrictive practices and make further legislative amendments required to ensure that the treatment of people receiving aged care services is consistent with the treatment of other members of the community.

The term 'restrictive practices' refers to activities or interventions that have the effect of restricting a person's free movement or ability to make decisions. A restrictive practice could involve secluding a person in their room or it might involve a physical restraint or one achieved by the administration of a drug, commonly known as a 'chemical restraint'.[110] Types of restrictive practices used in aged care include applying lap belts, locking over bed or chair tray tables, seating residents in deep chairs from which they are unable to stand, and removing mobility aids. Restrictive practices may also include confining a person in a residential facility or a specialised unit.

The nature and extent of restrictive practices in aged care are discussed in Volume 2. Their use raises fundamental human rights questions and must be addressed to ensure that older people receive high quality aged care, in accordance with human rights principles as set out in the new Act we are proposing.

Restrictive practices impact the liberty and dignity of people receiving aged care. The right to personal autonomy is recognised in domestic laws and international human rights instruments. International human rights conventions, to which Australia is a signatory, recognise rights such as self-determination, liberty and security of the person, and recognition and quality before the law. The common law in Australia recognises that each person has the right to choose what occurs with respect to their own body.[111] Providing care or treatment, or detaining someone without their consent, can be a civil wrong or a criminal offence.

The evidence we have heard is that changed behaviours, often associated with dementia, can be distressing for the person with dementia and their family and friends. Such changes in behaviour can also be disruptive and even dangerous for others, including informal carers, aged care staff members, and other people living alongside them. Changed behaviours can, at times, be very difficult to manage, particularly in residential aged care facilities where there are inadequate numbers of staff and inadequate access to expertise and resources. These are complex issues.

An aged care worker told us that:

> There is an over-reliance on chemical restraint in the ACFs [aged care facilities]; however alternatives such as support staff spending more one to one time with clients cannot effectively happen because the support staff are so busy performing the tasks they are expected to do…I think it would be good to have a staff member with therapeutic skills who can be on site for all the shifts…[112]

In Chapter 8 of the Interim Report, Commissioners Tracey and Briggs expressed serious concerns about the overuse of restrictive practices in aged care. The report noted that:

> 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.[113]

In response to the Interim Report, the Australian Government announced an increased focus on minimising restraints in aged care, including in relation to use of medicines and access to expertise in dementia care.[114]

We recognise that regulation alone will not reduce or eliminate restrictive practices. The broader systemic changes we are proposing by our recommendations must be implemented to improve safety and quality across the system. This includes legislation that enshrines and promotes the dignity of older people and their right to make choices about their care. Aged care services must also be adequately resourced with appropriate facility design and sufficient numbers of skilled staff to care for people with complex needs. The care needs of older people must be comprehensively assessed and they must have access to adequate health care, including specialist practitioners and reviews of medication. Implementation of these recommendations will reduce, or perhaps even eliminate, the use of restrictive practices. A strong and effective regulatory framework controlling their use is a further part of this systemic approach.

A consistent approach

Regulation of restrictive practices in aged care is lacking. There is a mixture of Australian Government and State and Territory legislation and policy, with disparities in the principles and approaches to consent to care and treatment and restraint. There are also disparities in the approach between the related sectors of aged and disability care.

The Council of Attorneys-General launched the *National Plan to Respond to the Abuse of Older Australians [Elder Abuse] 2019–2023*, which identified the need to review State and Territory legislation to strengthen safeguards for vulnerable people but did not specifically address the issue of restrictive practices.[115] The States and Territories have variously embarked on review and reform of legislation in this area.

In 2014, the States and Territories committed to advance towards a national approach to reducing and eliminating restrictive practices in the disability sector, as described in the *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector*.[116] The *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018* (Cth), made under the *National Disability Insurance Scheme Act 2013* (Cth), set out rules for the use of restrictive practices that apply to providers registered under the National Disability Insurance Scheme. These apply together with obligations under State and Territory laws.[117] The Australian Law Reform Commission has recommended that there should be a nationally consistent approach to the regulation of restrictive practices in sectors, including aged care.[118] It has also said that a consistent approach to restrictive practices in aged care and disability services is desirable, 'both as a matter of principle and pragmatism'.[119] We agree.

Inconsistencies in the definition of 'restraint' contribute to uncertainty about its prevalence and lawful justification for its use. For example, secluding a person in a residential unit or confining a person to a place where they are not free to leave is restrictive and may deprive the person of their liberty. A national approach should clarify definitions of restrictive practices, as well as the circumstances in which a person may be detained and the legal safeguards that apply.

The inconsistencies in the definition also make it challenging to identify what constitutes a restraint that should be regulated. Whether something is a restrictive practice that requires regulation often depends on the particular circumstances. Placing a person in a deep chair from which they are unable to stand may be appropriate because it is done for the person's comfort and with their informed consent. However, placing a person in a deep chair to prevent their free movement, or without regard to the effect of this on their free movement, is restrictive and should be regulated. However 'restraint' is defined, identification of whether a practice is a restraint should focus on whether the practice restricts free movement or capacity to make choices. This should not be confused with any purpose or justification for the practice.

While uniformity is desirable, some features of the present regulatory approach in the disability sector may not be appropriate in aged care. For example, under the National Disability Insurance Scheme approach to the regulation of restrictive practices, a chemical restraint is not a 'regulated restrictive practice' if it involves 'the use of a medication prescribed by a medical practitioner for the treatment of, or to enable the treatment of, a diagnosed mental disorder, a physical illness or a physical condition'.[120] The most common form of dementia is Alzheimer's Disease, which means that medication prescribed to enable the treatment of a person suffering from this disease would be excluded from the definition of a 'regulated restrictive practice' if the National Disability Insurance Scheme definition was applied. As Associate Professor Macfarlane explained, excluding treatment of changed behaviours associated with dementia from the definition of restrictive practices

would significantly reduce the effectiveness of the regulatory requirements in aged care.[121] It would reduce the scope for regulating the inappropriate prescription of antipsychotics, which are a form of psychotropic medication used to sedate.[122]

Minimum requirements for aged care

Deficiencies in regulation of restrictive practices have been identified as a significant human rights issue in Australia.[123] Recent changes to regulation of restraint in aged care have not adequately addressed this important issue.

Regulation of restrictive practices should be informed by respecting and supporting people's rights, dignity and personal autonomy, while providing clarity about the circumstances in which care or treatment including restrictive practices may be authorised.

Previous inquiries and reviews have recommended strong regulation of restrictive practices in aged care.[124] New aged care Quality Standards concerning restrictive practices under the Aged Care Act came into effect on 1 July 2019 with the insertion of Part 4A into the *Quality of Care Principles 2014* (Cth).[125] Part 4A is made under section 54-1(l)(h) of the Aged Care Act and imposes 'other responsibilities' on an approved provider of aged care that is either residential care or flexible care in the form of short-term restorative care provided in a residential care setting.[126] Part 4A provides that both physical and chemical restraints are to be used only 'as a last resort' and where specified conditions are met.[127] However, these requirements are time limited because Part 4A is due to be repealed, with effect from 1 July 2021.[128]

Section 15H of the Quality of Care Principles requires the Minister for Aged Care to ensure that there is a review of Part 4A by 31 December 2020. That review must 'make provision for consultation' and 'must consider the effectiveness' of Part 4A 'in minimising the use of physical restraints and chemical restraints by approved providers in relation to consumers in the period 1 July 2019 to 30 June 2020'.[129] A copy of the report of the review is required to be published on the internet and tabled in the Australian Parliament. However, there is no requirement for the Minister for Aged Care to give effect to any recommendations that might be in the report. In its response to a 2019 inquiry by the Parliamentary Joint Committee on Human Rights, the Australian Government noted that:

> The review must make provision for consultation. It is intended consultation will include engagement with a range of key stakeholders such as state and territory public guardians and public advocates, and state and territory tribunals which can appoint decision makers for consumers and/or give consent themselves.
>
> It is also expected the review will consider concerns raised by the Parliamentary Joint Committee on Human Rights in its report, in addition to concerns raised by other individuals and groups, including consideration of the approach taken by the National Disability Insurance Scheme.[130]

Associate Professor Macfarlane told us about the operation of Part 4A of the Quality of Care Principles. He said that the requirements in Part 4A 'have some limitations which may prevent them from being an effective tool in regulating the use of physical and chemical restraints for people living with dementia in residential aged care facilities'.[131] In addition to this concern about the definition of 'chemical restraint', noted above, Associate Professor Macfarlane explained that:

- the obligations are not imposed directly on medical practitioners
- there is no requirement to investigate alternatives to chemical restraints
- it is unclear what an 'assessment' involves—would a phone call suffice?[132]

As noted above, a review of the operation of Part 4A was conducted in 2020, but our requirement to report by the end of February 2021 means that we were unable to take into account the contents of that report. The need to address the issue of restrictive practices in aged care is urgent—it cannot await the outcome of yet another review. New requirements must be in place in advance of the repeal of Part 4A on 1 July 2021 or the repeal timeframe must be delayed.

The Australian Government should amend the existing Quality of Care Principles to ensure that restrictive practices are only used in specified circumstances, based on an assessment of a person's needs and informed by an expert accredited for that purpose by the Aged Care Quality and Safety Commission. The framework we are proposing aligns with the approach in the *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018* (Cth), which require restrictive practices only to be used under plans prepared by accredited experts.

The National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules impose requirements on the use of 'regulated restrictive practices' by registered National Disability Insurance Scheme providers.[133] These Rules contain a comprehensive suite of requirements, including the need for 'behaviour support plans' prepared by 'specialist behaviour support providers'.[134] A specialist behaviour support provider must also be registered and such registration is subject to the condition that 'a behaviour support plan for a person with disability that contains a regulated restrictive practice must be developed by an NDIS [National Disability Insurance Scheme] behaviour support practitioner engaged by the provider'.[135] Any behaviour support plan containing a regulated restrictive practice must be lodged with the NDIS Quality and Safeguards Commissioner and monthly reports must also be given regarding the use of regulated restrictive practices.[136] The behaviour support plan must also be reviewed by a behaviour support practitioner at least every 12 months, and earlier if there is a change in circumstances which requires the amendment of the plan.[137]

Caring for older people should be based on an understanding of their needs and preferences. That is no less the case for people who have impaired cognitive capacity or have changed behaviours arising from illness or deterioration in physical function. Restrictive practices should only be used in relation to a person when recommended by an independent expert, and where alternative strategies to meet the person's needs have

been tried and found to be unsuccessful. Any exception that applies if a restrictive practice is necessary in an emergency should only apply for a short period, such as to prevent a person from imminent risk of significant harm.[138]

An assessment of whether it is necessary or appropriate to provide care in a way that is restrictive should consider the risks associated with the treatment or practice, as well as the risk that the person may cause harm to themselves or another person without the restrictive care or treatment. That is particularly so because restrictive practices not only affect the dignity and right to personal autonomy of older people, but also because there is evidence that restrictive practices can have harmful physical and psychological effects and may not be effective in managing changed behaviours.

The evidence is that changed behaviours of people receiving aged care can be caused by unaddressed needs, including physical needs such as pain, and that restrictive practices can be reduced or avoided by identifying and addressing underlying unmet needs or triggers.[139] Access to specialist advice is therefore imperative and should be legally required.

This change is urgently needed. However, we recognise that it is unlikely that the Aged Care Quality and Safety Commission will be able to implement a scheme to accredit individuals as independent experts for the purpose of developing behaviour support plans before Part 4A is due to be repealed on 1 July 2021. We therefore propose that the repeal of Part 4A should be delayed until 31 December 2021 to allow time to make arrangements for accreditation of independent experts by the Aged Care Quality and Safety Commission. This may have implications for staffing of that Commission. For example, it may find that having only one Chief Clinical Adviser working less than full-time is inadequate.[140]

In the interim, we encourage providers to go beyond the requirements of Part 4A and to seek independent expert advice, particularly where use of a restrictive practice is part of the routine management of a resident. In addition, the Aged Care Quality and Safety Commission could look to experts who provide advice through the Dementia Behaviour Management Advisory Service and the Severe Behaviour Response Teams as being a suitable source of independent expert advice. People accredited under the National Disability Insurance Scheme, and who have appropriate skills relating to dementia and aged care, might also be suitable.[141] For the reasons we explained earlier about chemical restraints and dementia, the Aged Care Quality and Safety Commission must, before recognising such a person's credentials, ensure that they are suitably skilled in the challenges associated with dementia and aged care.

An approved health practitioner, defined in the existing aged care scheme as a medical practitioner, nurse practitioner or registered nurse, should monitor the person subject to restraint and review the support plan regularly. If there is any change in the person's condition, the approved health practitioner should not only identify any signs of distress but also ascertain whether the restraint remains necessary and proportionate to a risk of harm.[142]

Our recommendation about regulation of restrictive practices sits within a broader context of recommendations which, in combination, are intended to change the approach to restrictive practices in aged care. Among the proposed rights to be included in the new Act is the right to liberty, freedom of movement and freedom from restraint (Recommendation 2). Implementation of detailed quality indicators, including on the use of restrictive practices, creates accountability and supports benchmarking to improve performance across the aged care sector (Recommendations 22 and 23). Recommendation 65, restricting the prescription of antipsychotics, will assist in monitoring the prescription of medications that can be used as a form of chemical restraint. Recommendations in the aged care workforce chapter for training on dementia (Recommendation 80) and minimum staff time for residential care (Recommendation 86) will ensure staff have both the skills to respond to challenging behaviours and the time to do so.

There has been concerning evidence about people receiving care who have been subjected to restrictive practices without informed consent being provided by either the person or their legally authorised representative. Poor recording of informed consent was a particular feature of evidence in Sydney Hearing 1.[143] Dr Juanita Westbury (now Breen), registered pharmacist and senior lecturer in dementia care at University of Tasmania, explained that in her research, family members of people receiving aged care she had spoken with often said the first they were aware their relative was taking medications was when they received the pharmacy bill.[144]

The aged care legislation should make clear that restrictive practices are not permitted, other than with the documented informed consent of a person or otherwise authorised in accordance with State or Territory law. A behaviour support plan should not be approved unless there is informed consent in writing from a person who is entitled to give that consent. This must be clearly understood by medical practitioners, aged care providers and staff members.

Although there is significant public concern about the use of restrictive practices in aged care, we are aware of a few cases in which existing avenues for review and redress, in respect of unlawful restraint, have been pursued.[145] Submissions to us have identified limitations and barriers to people pursuing concerns about their care or treatment.[146] In its 2014 report, the Australian Law Reform Commission also reported receiving a number of submissions about the form that the regulation of restrictive practices should take, but deferred to the expertise of the Council of Australian Governments and others to determine the best path for reform.[147]

The legislative regime needs to be backed by strong regulatory requirements. A behaviour support plan, under which restraints are applied, should be lodged with the Quality Regulator, the functions and powers of which should include oversight of restrictive practices.

An incident of restraint that is not authorised under the statutory scheme should be reportable under the serious incident reporting scheme we are proposing, as discussed in our chapter on quality regulation and advocacy. Where an approved provider fails to comply with the restrictive practices requirements, it should be exposed to the full range of enforcement powers available to the Quality Regulator to respond to serious incidents.

For example, a breach of restraint requirements by an approved provider should expose it and, in appropriate cases, its key personnel, by way of accessorial liability, to a civil penalty at the suit of the Quality Regulator.[148] This is consistent with the approach under the National Disability Insurance Scheme.[149] The regulator should also be empowered to seek an order from a court that the approved provider and a person involved in the contravention pay compensation to the person unlawfully restrained, if that is the person's wish.

People receiving aged care should receive the same level of protection from restrictive practices as other members of the community. Following the conclusion of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, it would be appropriate for there to be a further review of the arrangements for restrictive practices in aged care. Any such review should consider the relevance to the aged care sector of any recommendations of that Royal Commission to ensure that the treatment of people receiving aged care services is consistent with the treatment of other members of the community.

3.5.4 Palliative care

Compassionate, respectful and individualised support for older people approaching the end of their life is a necessary component of aged care services. The need for skilled provision of palliative and end-of-life care in aged care services is likely to increase with an ageing population that will experience higher rates of chronic illness, including cognitive impairment. The clear delineation of aged care providers' responsibilities and increased workforce expertise and capability in palliative care is urgent and essential. Older people with complex care needs should also have equitable access to specialist palliative care services.

High quality palliative care is essential to ensuring that older people can live as fully and as comfortably as possible, even as their lives are coming to an end. It is clear that too few people in aged care receive the evidence-informed end-of-life care that they need. This must change.

Palliative care must be a core component of aged care services. Dr Elizabeth Reymond, Deputy Director, Metro South Palliative Care Service, said:

> Palliative care cannot, and should not, be considered an optional extra within the aged care system. It needs to be an integral part of any aged care service.[150]

Research conducted by the Australian Institute of Health and Welfare has found that the majority of older people who die over the age of 65 years, or over the age of 50 years in the case of Aboriginal and Torres Strait Islander people, use aged care services in some form before their death.[151] Almost one-third of people using residential aged care will die in the year that they enter care.[152] Death is the most common reason for ceasing residential aged care.[153]

The Australian Institute of Health and Welfare has reported that in the five years to 2018–19, the number of people in residential care who have been assessed by providers as requiring palliative care attracting aged care funding has trended downwards. Between 2013–14 and 2018–19, the number of permanent residents assessed by providers as requiring funding for end-of-life palliative care decreased from 8781 to 4341.[154] The Australian Institute of Health and Welfare concluded that this downward trend is more likely to reflect changes in the application of the Aged Care Funding Instrument than a change in the need for palliative care.[155]

Fundamental to providing palliative care is the ability and time to talk to older people and their families about death and dying in an informed and compassionate manner. Understanding cultural elements that surround death and dying is important in providing individualised care and overcoming barriers to accessing palliative care. Witnesses said that overcoming the reluctance to discuss death and dying is necessary to improve palliative care.[156] Dr Reymond stated:

> To provide sensitively-delivered, timely information tailored to the individual's needs requires advanced communication skills which, like any other skill can be taught and mentored. The conversation begins with understanding who that person is, what they value, believe, wish for, and how and where they would want to die.[157]

We were told about the importance of adequate bereavement support in palliative care.[158] Ms Mitchell said 'I strongly believe that every facility should have a bereavement counsellor not only to help those experiencing bereavement but also to train the staff'.[159] Dr Reymond said 'bereavement support is an important clinical gap across all palliative care providers'.[160]

We also received evidence of the importance of ongoing assessment and timely identification of palliative care needs to ensure that appropriate palliative care is provided.[161] Knowledge about the course of a person's illness and the ability to pre-empt or recognise and respond to changes in their condition is essential to providing good palliative care.[162] Professor Jennifer Tieman, Professor in the College of Nursing and Health Sciences and Director of the Palliative Care, Death and Dying Research Centre at Finders University, said:

> a skilled, knowledgeable and capable aged care workforce that can respond to identified palliative care needs and that is able to plan and manage anticipated and unexpected issues is needed but still emerging.[163]

Many older people have predictable needs that can be met through adequately resourced aged care services, in conjunction with the person's usual health practitioners. Not all older people with life-limiting illness will require specialist palliative care. However, some older people will develop more complex needs and will require support through specialist palliative care.[164] Aged care staff need to be able to identify when specialist palliative care is required and be able to access such specialist care when appropriate.[165] Good palliative care requires a coordinated approach with improved frameworks for engagement between aged care and specialist palliative care services.[166] Specialist palliative care clinicians provide evidence-based expertise in prognostication, pain management and medication,

and can support decision-making by identifying the benefits and burdens of treatment in difficult cases.[167] Mr Joshua Cohen, a palliative care nurse practitioner, said that in his experience:

> because the PC [palliative care] skills in many RAC [residential aged care] facilities I work with is variable at best, even the management of simple pain and PC distress often needs to be identified and initiated by a PC health professional.[168]

Appropriate access to specialist palliative care services should be available, when required, to meet the needs of older people with complex palliative care needs. Specialist palliative care services have the potential to build capacity within residential care services by providing education and training.[169] We received evidence of successes achieved in building capacity of aged care staff through education and mentoring, including fewer transfers to hospital.[170] The transfer of skills in this way should be encouraged.

We have made a number of recommendations intended to ensure that high quality palliative care becomes core business for aged care services. Recommendation 2 proposes that the rights of people receiving aged care includes the right to fair, equitable and non-discriminatory access to palliative and end-of-life care. Recommendation 19 proposes urgent consideration of how palliative care is addressed in the Aged Care Quality Standards. Recommendation 80 proposes that all aged care staff be required to undertake regular training in palliative care. We have made recommendations to improve interfaces between aged care and health services, including access to specialist palliative care (see Chapter 9 of this volume).

3.6 Aged Care Quality Standards

Quality Standards are a powerful tool to maintain and improve quality of care across the aged care sector. They are statutory-based obligations of services, which set the characteristics of aged care and the care environment that contributes positively to, or alternatively places at risk, the safety, health, wellbeing and quality of life of people receiving care.[171] Standards also function as motivators for providers to achieve quality expectations, and set the regulatory parameters for 'objective, consistent assessment and reporting of provider performance'.[172] The formulation of suitable Quality Standards is central to achieving and measuring high quality care.

3.6.1 Setting aged care Standards

The existing Aged Care Quality Standards do not define quality, or high quality, aged care. By their nature, they set out the minimum acceptable standards for accreditation. Section 54-2 of the Aged Care Act provides that the Aged Care Quality Standards 'are standards for quality of care and quality of life for the provision of aged care'. Here, 'aged care' means 'residential care', 'home care' or 'flexible care'.[173] The section also provides that Quality Standards may be set out in the *Quality of Care Principles 2014* (Cth).

The Quality of Care Principles are made by the Minister pursuant to section 96-1 of the Aged Care Act in the form of a legislative instrument. There is no guidance in the Act on the process by which such legislative instruments are made. In practice, the Australian Department of Health develops the Standards for the Minister's consideration, in consultation with the aged care sector and the aged care regulator. While the Department consults relevant experts, the evidence suggests that the views of such experts are not always followed.[174]

By contrast, Quality Standards for the health sector are made by a specialist statutory body, the Australian Commission on Safety and Quality in Health Care. That Commission is established with the express purpose of formulating written Standards, guidelines and indicators relating to 'health care safety and quality matters'.[175] It operates under an appropriate governance framework for the task.

The Australian Commission on Safety and Quality in Health Care answers to an independent board, made up of nine members appointed by the Australian Minister for Health after consulting with each of the State and Territory Ministers for Health.[176] To be eligible for appointment to the board, a person must have 'substantial experience or knowledge' and 'significant standing' in at least one of a range of fields, which include public administration in relation to health care, provision of professional health care services, financial management, corporate governance, representation of the interests of consumers or law.[177] The Australian Minister for Health must ensure that the members of the board 'collectively possess an appropriate balance of experience and knowledge' in the identified fields.[178]

The Chief Executive Officer of the Australian Commission on Safety and Quality in Health Care, Professor Debora Picone AO, gave evidence in the Brisbane Hearing. Professor Picone explained that there are currently eight National Safety and Quality Health Service Standards, developed by the Commission, which apply to all hospitals and day procedure services.[179] They also apply to residential aged care services provided by State and Territory authorities and to Multi-Purpose Services.[180] The Australian Commission on Safety and Quality in Health Care has also developed an 'Aged Care Module', which is designed for application in these services.[181]

Professor Picone considers that there should be 'greater harmonisation between the quality standards that apply in health care and those standards that apply in aged care'.[182] We agree. The statement she provided to the Royal Commission sets out a core set of safety standards below which care 'must never fall'.[183] She considers that a core set of Standards could be developed and implemented in the health and long-term aged care sectors. This would both improve quality and safety and reduce the regulatory burden that arises currently from the requirement for providers to comply with more than one set of Standards on the same or similar topics.[184]

In addition to the Clinical Standards it has made, the Australian Commission on Safety and Quality in Health Care has also developed and validated certain quality of life measures which may be applicable in aged care settings.[185]

The question of how aged care Quality Standards should be set in the future aged care system is a difficult one to answer. The function could sit with the System Governor, with the Quality Regulator or with a specialist standard-setting body.

We recommend that this function go to the Australian Commission on Safety and Quality in Health Care. This will involve expanding its existing statutory remit. The obvious advantage of this approach is that it is an existing body with the governance arrangements and processes in place to perform the role. It is well-respected and has many years of experience in setting health Standards. As Professor Picone explained, there is good reason to have consistency or even uniformity across the aged care and health sectors.[186] Further, as noted above, some aged care facilities are already required to comply with the National Safety and Quality Health Service Standards.

The Standards prepared by the Australian Commission on Safety and Quality in Health Care appear to us to be far more comprehensive, rigorous and detailed than the existing Aged Care Quality Standards. For example, the Australian Commission on Safety and Quality in Health Care's Clinical Governance Standard contains 33 actions, each of which has an intent, some reflective questions, some key tasks, strategies for improvement, and examples of evidence of compliance. By contrast, Standard 8(3)(e) of the Aged Care Quality Standards merely states that an approved provider is to demonstrate that it has a clinical governance framework including, but not limited to, antimicrobial stewardship, minimising use of restraints and open disclosure.

One issue with the standard-setting role being transferred to the Australian Commission on Safety and Quality in Health Care is that aged care quality is about more than health care, as important as that is. The Australian Government, in its response to the final submissions of Counsel Assisting, pointed out that aged care Standards are 'much broader' than health care Standards, 'covering many domains not related to the delivery of clinical care'.[187] We agree that it will be necessary for quality of life aspects of aged care to be the subject of appropriate Standards. In this regard, we note the work that the Australian Commission on Safety and Quality in Health Care has already done on quality of life measures.

The Australian Government also submitted that an 'alternative and less complex way to involve the Australian Commission on Safety and Quality in Health Care would be to engage it to complete a body of work on the Standards relevant to the provision of clinical care in the aged care setting'.[188] However, a difficulty with this narrow approach is that it would exclude the Australian Commission on Safety and Quality in Health Care from developing a standard in relation to provider governance. As we discuss in the chapter on provider governance, the input of the Australian Commission on Safety and Quality in Health Care is needed in this area.

On balance, the advantages of the role being transferred to the Australian Commission on Safety and Quality in Health Care outweigh any disadvantages. In consultation with the States and Territories, the Australian Government should seek to amend its constitutive statute and it should be renamed the Australian Commission on Safety and Quality in Health and Aged Care.[189]

Clearly, the Australian Commission on Safety and Quality in Health Care will need additional resources and it will need to liaise closely with the proposed System Governor in its standards development work. Appropriate changes to the board of the Australian Commission on Safety and Quality in Health Care may need to be made. This might be achieved by adding aged care as an additional area of expertise relevant to eligibility for appointment to the board. The Australian Commission on Safety and Quality in Health Care might also employ experts in aged care as staff or engage them as consultants.[190] Short-term secondments from the staff of the proposed System Governor may be appropriate.

The work of the Australian Commission on Safety and Quality in Health Care in setting aged care Standards should be kept under review by the System Governor and the Inspector-General of Aged Care in its oversight of the implementation of these reforms.

Recommendation 18: Aged care standard-setting by the renamed Australian Commission on Safety and Quality in Health and Aged Care

1. Section 9 of the *National Health Reform Act 2011* (Cth) should be amended to:
    a. rename the Australian Commission on Safety and Quality in Health Care as the 'Australian Commission on Safety and Quality in Health and Aged Care', and
    b. confer upon that body the functions of formulating standards, guidelines and indicators relating to aged care safety and quality.
2. Amendments to section 10 of the *National Health Reform Act 2011* (Cth) should also be made to provide for a consultation process for the Commission's aged care functions.

3.6.2 What should happen to the existing Standards?

On 1 July 2019, eight new Aged Care Quality Standards replaced the 44 previous Accreditation Standards, Home Care Standards and those for the National Aboriginal and Torres Strait Islander Flexible Aged Care Program (known as NATSIFACP) and Transition Care.

The former Standards were specific and prescriptive. For example, there were 17 Standards in the category of 'Health and Personal Care', including 2.4: 'Care recipients receive appropriate clinical care'; 2.10: 'Care recipients receive adequate nourishment and hydration' and 2.11: 'Care recipients' oral and dental health is maintained'.

By contrast, the current Aged Care Quality Standards are far more general. They address:

- consumer dignity and choice
- ongoing assessment and planning with consumers
- personal care and clinical care
- services and supports for daily living
- an organisation's service and environment
- feedback and complaints
- human resources
- organisational governance.[191]

The current Standards were developed through consultation with 'consumers' and the aged care sector and are intended to focus on outcomes for 'consumers' rather than provider processes.[192] They are the existing aged care system's articulation of quality for accreditation processes. They operate universally, and are intended to set standards for identifying and addressing people's individual care needs, regardless of setting or need and inclusive of individual choices and preferences.

The evidence received by us about the Standards was mixed. There was support for what was described as their 'consumer' focus.[193] However, experts in a number of fields were critical of their lack of detail and lack of objective measurements. For example, Dr Iuliano, a nutrition expert, considered that the Standards need quantifiable measures against which compliance can be assessed.[194]

Dr Iuliano gave an example of how the human resources Standard (Standard 7) could be modified so that it required that 'food service staff are specifically trained in food provision in residential aged care'.[195] Similarly, Dr Iuliano suggested that Standard 3, the personal and clinical care Standard, could include a requirement that menu details include quantities of serves of each of the food groups, so the adequacy of the menu can be benchmarked against Australian standards.[196] Dr Iuliano explained that she had made these, and other such practical suggestions, in response to the draft Standards when they were released for public comment.[197] We endorse Dr Iuliano's evidence as a practical approach to the development of Aged Care Quality Standards. Any such Standards must clearly communicate what providers must do to deliver high quality aged care. Experts in the fields of dementia care, continence care, palliative care and oral health care expressed similar concerns about the existing Quality Standards.[198]

The lack of objectively measurable Standards in aged care is concerning. Standard 7, which requires that a provider has a workforce 'that is sufficient, and is skilled and qualified to provide safe, respectful and quality care and services', provides a good example. The lack of any clarity about the meanings of 'sufficient', 'skilled' and 'qualified' serves no one's interests—not people receiving care, not approved providers and not the regulator itself.

Further, changes to the aged care Standards have sometimes been developed in isolation from other changes to the broader system, in response to a particular issue of public concern, and therefore lack any strategic context.[199]

Despite having these concerns, we are conscious that the current Aged Care Quality Standards have only relatively recently come into effect and are the result of an extensive process of consultation with providers, people receiving care, experts and others. We are therefore not calling for a new set of Standards at this time.

However, it is appropriate for the Australian Minister for Health to ask the Australian Commission on Safety and Quality in Health and Aged Care, as the expert and independent body that we propose should have the task of maintaining the Standards, to review the Standards as a matter of urgency. This review should have regard to a list of matters that have been identified in the evidence before this inquiry. The Australian Commission on Safety and Quality in Health and Aged Care should consult as it considers necessary, including with people receiving aged care. It should pay particular heed to the views of experts, including those who have given so generously of their time to assist us. As one large approved provider submitted in response to the final submissions of Counsel Assisting, 'the aged care system needs to better utilise subject matter experts in clinical and care requirements'.[200]

Recommendation 19: Urgent review of the Aged Care Quality Standards

1. By 15 July 2021, the responsible Minister should refer to the Australian Commission on Safety and Quality in Health and Aged Care the following matters for urgent review and, if the Commission considers appropriate, amendment of the Aged Care Quality Standards:
    a. requiring best practice oral care, medication management, pressure injury prevention, wound management, continence care, falls prevention and mobility, and infection control, and providing sufficient detail on what these requirements involve and how they are to be achieved
    b. imposing appropriate requirements to meet resident nutritional needs and ensure meals are desirable to eat, having regard to a person's preferences and religious and cultural considerations
    c. sufficiently reflecting the needs of people living with dementia and providing high quality dementia care
    d. provider governance, and
    e. high quality palliative care in residential aged care, including staff capacity (number, skill and type), processes and clinical governance, for recognising deterioration and dying.
2. The Australian Commission on Safety and Quality in Health and Aged Care should complete its review by 31 December 2022.

Recommendation 20: Periodic review of the Aged Care Quality Standards

The renamed Australian Commission on Safety and Quality in Health and Aged Care should complete a comprehensive review of the Aged Care Quality Standards within three years of taking on the standard-setting function and every five years after that. It should also be empowered to undertake ad hoc reviews and make corresponding amendments either of its own motion or where issues are referred to it for consideration by the System Governor, the Inspector-General of Aged Care or the responsible Minister.

Recommendation 21: Priority issues for periodic review of the Aged Care Quality Standards

By 1 July 2022, the responsible Minister should refer the following matters for the Australian Commission on Safety and Quality in Health and Aged Care to consider as part of its first comprehensive review of the Aged Care Quality Standards:

a. imposing appropriate requirements relating to the professional development and training for staff

b. including sufficient reference to and delineation between staff practice roles and responsibilities

c. requiring providers to assist people receiving care to make and update advance care plans if they wish to, and ensuring that those plans are followed

d. reflecting the Aged Care Diversity Framework and underlying Action Plans, including considering making them mandatory

e. incorporating elements of care delivery which reflect a focus on the quality of life of people receiving care.

3.7 Measuring aged care quality

The aged care system should adopt evidence-based and continuous improvement strategies to allow for transparent measurement and reporting of the quality of care being delivered to older people. We propose three linked mechanisms to measure high quality care—regular reporting on quality indicators, a star rating system and the use of benchmarking.

Older people and their families should know how approved providers are performing and whether they can meet their needs before choosing them. Having public reporting of quality indicators, and a star rating and benchmarking system, will enable this.

3.7.1 Quality indicators

If the Aged Care Quality Standards set the rules for the quality of aged care, quality indicators enable that quality to be measured. There needs to be an alignment between the two—what the Standards identify as high quality aged care ought to be measured. To take a simple example, if there is a Standard for skin integrity that requires the prevention of pressure injuries, approved providers should have to report on the numbers of pressure injuries developed by people in their care. That way, the regulator and members of the public can know how providers are performing.

Professor Picone described the role of quality indicators in achieving quality care:

> Measurement of indicators…is fundamental to advancing safety and quality improvement—meaningful metrics are required to understand what the major safety issues are across the care continuum, to proactively mitigate patient safety risks and stimulate improvement.[201]

Recommendation 22: Quality indicators

1. By 15 July 2021, the responsible Minister should refer to the Australian Commission on Safety and Quality in Health and Aged Care responsibility for the introduction, implementation and amendment of aged care quality indicators, including:
    a. ongoing research into the use and evidence basis for quality indicators
    b. publication of guidance on use of indicator data to identify risks and to undertake evidence-based risk management.
2. By 1 July 2023, the Australian Commission on Safety and Quality in Health and Aged Care should:
    a. expand the quality indicators for care in residential aged care
    b. develop quality indicators for care at home, and
    c. implement a comprehensive quality of life assessment tool for people receiving aged care in residential care and at home.
3. In the interim, in addition to the existing commitment to implement quality indicators in the new domains of falls and fractures and medication management, the Australian Government should expand the National Mandatory Indicator Program, as set out in the 2019 PwC Consultation Paper 'Development of Residential Aged Care Quality Indicators', to use more comprehensive indicators for the existing domains of pressure injuries, physical restraint and unplanned weight loss.

Recommendation 23: Using quality indicators for continuous improvement

By 1 July 2022, the Australian Government should implement reporting and benchmarking of provider performance against quality indicators. To achieve this:

a. **the Australian Commission for Safety and Quality in Health and Aged Care should develop a methodology to enable providers to be benchmarked against similar providers**

b. **the Australian Government should track sector and provider performance and set progressive improvement targets to raise performance against quality indicators over time**

c. **the Australian Government should publicly report on sector and provider performance against benchmarks.**

In Volume 2 of this report, we note how difficult it has been to assess the extent of substandard aged care in Australia. This is in no small part because of insufficient quality indicator data.

Quality indicator data can, and should, be used for a range of purposes, including measuring and monitoring care quality and safety, identifying issues in care performance, prompting improvements to care and providing transparency to people receiving care, their families and advocates.[202]

Quality indicators are used in Australian hospitals to report publicly on 'key quality metrics such as hospital acquired infections, wait lists, costs and time to admissions'.[203] Internationally, in the aged care setting, quality indicators are also used as a basis to help inform people's choice of an aged care provider. For example, in the United States, residential aged care providers are given a star rating based, in part, on performance against a wide range of quality indicators. These indicators include hospitalisations, antipsychotic medication use, urinary tract infections, use of catheters, weight loss, changes in mobility, and flu vaccinations.[204]

Quality is not adequately measured in the Australian aged care system.

When this Royal Commission was first established on 8 October 2018, there were no sector-wide quality indicators for the Australian aged care system. A National Quality Indicator Program was not introduced into residential aged care until 2016.[205] That program was introduced on a voluntary basis and only 8% of residential aged care services were participating, as at 30 June 2018.[206] Until 2019, there were no mandatory quality indicators. Under the Australian National Mandatory Quality Indicator Program, there are presently three that are used in residential aged care. Each residential aged care service is required to report on pressure injuries, use of physical restraint and unplanned weight loss.[207] There are no quality indicators applicable to home care.

In Volume 2 of this report, we refer to research that indicates superior performance by government-run aged care facilities on a wide range of quality indicators, especially when compared with the for-profit sector. Apart from the obvious difference that such facilities are operated by governments and not privately, there are also minimum staffing ratios and a history of measuring quality in the public sector. Neither is present in the private sector. In its response to the final submissions of Counsel Assisting, UnitingCare Australia referred to this research and pointed out that appropriate quality indicators and data collection will assist in understanding the underlying reasons for this difference.[208] We agree with this and consider that it is vital that the Australian Government has a clear view about what drives good aged care performance.

It is important that the Australian Government can accurately assess the quality of aged care. At Sydney Hearing 5, the Secretary of the Australian Department of Health, Dr Brendan Murphy, was asked by Senior Counsel Assisting about funding shortfalls in the aged care system. While Dr Murphy acknowledged that there had been significant reductions in government funding for approved providers in real terms in recent years, he responded to the suggestion that the funding shortfalls may have caused deficiencies in the quality of the care delivered by those providers by saying that 'we don't have any evidence at the moment that there is an impact on quality and safety from financial performance'.[209] This indicates a serious lack of curiosity on the Government's behalf.

We consider that without robust processes in place to allow the measurement of aged care quality, it is not possible for the Australian Government to be reassured that aged care funding reductions have not impacted negatively on the quality of care. This requires immediate correction.

The usefulness of the Australian National Mandatory Quality Indicator Program has been questioned by witnesses before us because of its limited scope. Complaints about the program include that the suite of current indicators is too clinically focused and that they do not adequately measure the experience of care from a person-centred, or quality of life, perspective.[210] It has also been said that the current indicators do not capture many characteristics that impact wellbeing or characteristics which people receiving aged care believe are important.[211] As a result, the program does not address the information asymmetry which exists between providers and people accessing aged care. There has also been a lack of digital development regarding the collection and collation of this data which places an administrative burden on approved providers.[212] Finally, as noted in a research paper prepared by staff of the Office of the Royal Commission, the indicators are 'self-reported by aged care facilities and are therefore subject to reporting bias'.[213]

We note there is evidence that poor use and implementation of quality indicators data can lead to unintended consequences. Some of these consequences were outlined by Dr Lisa Trigg, Assistant Director of Research, Data and Intelligence at Social Care Wales, at the hearing in Perth:

> These unintended consequences include tunnel vision, where an emphasis is placed on what is measured, at the expense of what is not; myopia, a focus on short-term objectives at the expense of longer term benefits; gaming, where actual behaviour (rather than just reporting) is manipulated, for example, risk selection and cream skimming; and measure fixation, or 'hitting the target and missing the point'.[214]

To avoid such consequences, care must be exercised in the selection of aged care quality indicators. The implementation of any quality indicator program must also be carefully monitored over time. Any necessary adjustments must be made by the Australian Commission for Safety and Quality in Health and Aged Care, in conjunction with the System Governor.

A 2019 review of the National Mandatory Quality Indicator Program highlighted deficiencies in the scope of the current indicators and recommended the introduction of two new indicators, relating to medication management and falls and fractures.[215] Evidence from the Australian Government is that it plans to introduce these new quality indicators, with effect from July 2021.[216]

While this is a positive first step, in our view these two additional indicators do not go far enough. A much more comprehensive suite of quality indicators is required.

We referred earlier to the Australian Commission on Safety and Quality in Health Care in the context of standard-setting. It also has significant expertise in developing quality indicators for use in health care settings.

In her evidence before us, Professor Picone, the Commission's Chief Executive Officer, said that through its recent experience in developing, implementing and evaluating health safety and quality indicators, the Australian Commission on Safety and Quality in Health Care has 'developed and refined a process [that] may be applicable to the aged care sector'.[217]

Just as the body headed by Professor Picone is responsible for the development of *health* care Standards and quality indicators, we consider that it should also be responsible for *aged care* Standards and quality indicators. Accordingly, we recommend that the Australian Commission on Safety and Quality in Health and Aged Care should be tasked with developing a more comprehensive suite of quality indicators for residential aged care and aged care in the home (Recommendation 22). This part of its work should also be performed in close consultation with the System Governor.

In undertaking this task, the Australian Commission on Safety and Quality in Health and Aged Care should be informed by the following three matters:

- First, indicators related to measuring quality of life outcomes should be included. Quality of life is a measurable outcome of good person-centred care, and good quality of life is shown to have positive impact on clinical outcomes.[218]
- Second, quality indicators should be formulated in a way that efficiently harnesses data from providers' clinical information technology systems. Commissioner Pagone considers that there is currently a burden on approved providers and their staff to meet reporting requirements, which are predominately based on clinical observations by staff. This burden could be reduced by designing the scope of the reporting requirements to inform compliance with quality indicators so it aligns with data available in the clinical information technology systems used by approved providers.

- Third, appropriate benchmarks need to be set for each of the quality indicators against which providers can measure and improve their own performance and the Quality Regulator can judge performance across the system. Data collected should be used as part of the star ratings system that we recommend should be established (Recommendation 24).

Using quality indicator data in aged care

An example of how quality indicator data can be used in the Australian aged care setting exists in Victoria. Victoria's quality indicator program has been operating successfully for over a decade. Its design and outcomes should be considered closely in the implementation of any quality indicator program by the Australian Government and Australian Commission for Safety and Quality in Health and Aged Care.

Since 2006, all Victorian public sector residential aged care services have collected and reported data on five different quality indicators. These are the three indicators used presently in the National Mandatory Quality Indicator Program, as well as additional indicators for medication management and falls and fractures.[219]

Quality indicator information is collected by the Victorian Government for the purpose of improving monitoring processes and quality, with the important caveat that quality indicator data have not been used for regulatory findings.[220] The Victorian Government has amassed a substantial amount of data and has been able to use it to develop benchmarks for different quality indicators. These benchmarks help residential aged care services identify whether they fall into a category of concern and to identify areas of potential improvement.

The primary purpose of Victoria's quality indicator program is to support residential aged care services to drive their own continuous improvement and promote care excellence.[221] The program also aims to assist services to report publicly on quality of care to people receiving aged care and their families, visitors such as medical and other health professionals, and the broader community.[222]

Information is collated, calculated and summarised in reports provided to services. Different reports are provided to cater to clinical, executive and consumer perspectives.[223] There is a focus on providing comparative and trend analysis information, specific to each of the five indicators. A particular feature to aid services is comparisons of their performance against State rates and other similar services, or services in the same region, and against their own past performance to identify positive or negative trends.[224]

The quality indicator program implemented in Victoria has also enabled the Victorian Government to monitor progress in different indicators over the past decade. At Melbourne Hearing 3, Ms Kym Peake, then Secretary of the former Victorian Department of Health and Human Services, described the significant reduction observed in pressure injuries and physical restraint.[225] The program has also prompted 'sector first' research regarding medication use in residential aged care.[226]

3.7.2 Star ratings

We consider that an effective and comprehensive performance rating system needs to be introduced to allow older people accessing care, approved providers and others to differentiate between aged care services and providers. The system should be informed by supporting information and data, including information from older people and their families and advocates, quality indicator outcomes, serious incidents reports, complaints data and staffing levels.

Recommendation 24: Star ratings: performance information for people seeking care

1. By 1 July 2022, the Australian Government should develop and publish a system of star ratings based on measurable indicators that allow older people and their families to make meaningful comparisons of the quality and safety performance of services and providers. The star ratings and accompanying material should be published on My Aged Care.
2. The star ratings should incorporate a range of measurable data and information, including, at a minimum:
    a. graded assessment of service performance against Standards
    b. performance against relevant clinical and quality indicators
    c. staffing levels
    d. robust information from people receiving aged care services, their families and advocates, when available.
3. The overall star rating should be accompanied by appropriate additional information on performance and outcomes, in a readily understandable form and capable of comparison across services and providers. This should include all performance information that is relevant to the performance of a service, even if it is not reflected in the overall star rating outcome. For example, it should include:
    a. details about current and previous assessment by the Quality Regulator, including notices of non-compliance, sanctions, withdrawal of accreditation or approved provider status
    b. benchmarked performance for all quality indicators that are suitable for publication, including changes in performance over time
    c. information from older people, their families and advocates
    d. serious incident reports data
    e. complaints data.
4. The Australian Aged Care Commission should assume responsibility for the star ratings system from 1 July 2023 onwards.

Commissioner Pagone

It is critical that the public has access to information that provides a meaningful overview of the performance of individual services and providers, in an accessible and easy-to-understand form. As UnitingCare Australia put it in its submissions in response to the final submissions of Counsel Assisting, 'meaningful, comparable and accurate indicators of aged care service quality are important to assist people in understanding the standard and quality of care provided by a particular facility'.[227]

This is particularly important for older people who are choosing an aged care service. Equally, those who are receiving care have a right to know about how the performance of their service provider compares to others so that they can make informed decisions about whether to change providers. It is also important that families and friends of older people, advocacy organisations, policymakers, legislators and the media have access to this information.[228]

The Service Compliance Ratings system, introduced by the Australian Government, falls short of the system that we consider is needed. Under it, residential aged care services are presently given an overall rating of between one and four dots based on compliance with the Aged Care Quality Standards.

Four dots indicates that the service is meeting requirements; three means that some improvements are needed, as some Aged Care Quality Standards requirements have not been met; two indicates that significant improvement is needed, with a notice of non-compliance having been issued; and one dot is a rating of 'inadequate', where there is a current sanction or Notice to Agree.[229]

An effective performance rating system will enable high quality care to be recognised. The highest rating in an effective system should go further than reflecting that a service meets the minimum standards. This is particularly important in circumstances where, in recent years, over 90% of providers have been assessed as meeting all minimum standards and outcomes.[230]

Under the current ratings system, services that meet all minimum standards, and have no current sanctions, are automatically given the highest rating.[231] The ratings do not recognise or assess whether and, if so, by how far, care exceeds the minimum standards—let alone whether the care is high quality. The Australian Government has stated that it is considering, as a 'potential future direction', developing an additional rating within its current system to 'show aged care services that are performing at a particularly high level'.[232]

The system of star ratings and benchmarking that we are proposing relies in part on a new approach by the Quality Regulator to assessments of services against the Aged Care Quality Standards. We outline our recommendation for graded assessments in the chapter on effective regulation later in this report.

This graded assessment against the Aged Care Quality Standards should be a central part of the new star rating scheme and could reflect the following assessment outcomes:

- 5 star—Excellent
- 4 star—Exceeding national quality standard
- 3 star—Meeting national quality standard
- 2 star—Working towards national quality standard
- 1 star—Significant improvement needed

However, the star rating scheme should incorporate a wider range of measurable data and information to allow meaningful comparison which reflects the elements of high quality care. This wider range of information should include:

- performance against relevant clinical and quality indicators[233]
- staffing levels[234]
- information from older people, their families and advocates.

Information from older people, their families and advocates is an important aspect of measuring the quality of aged care. As set out at the beginning of this chapter, the perspectives of people receiving care, and their representatives, reveal important information about features of quality care such as respect, dignity, appropriate staffing and support for health and wellbeing. The Quality of Care Experience questionnaire, developed by the Caring Futures Institute at Flinders University and used in surveys conducted for us, is one tool which measures the experiences of those receiving care.[235] Analysis of this questionnaire demonstrated its validity as a 'fit for purpose tool to assess the quality of care experience from the perspectives of older people and family carers in residential aged care and home care settings'.[236] In light of this finding, the Quality Regulator should consider the Quality of Care Experience questionnaire in the development of future measures of the experience of people receiving care.

Another shortfall of the current rating system is that it reflects only existing accreditation and compliance information. This is not new information—the My Aged Care and Aged Care Quality and Safety Commission websites already list this information. The Service Compliance Ratings system does not take into account, or draw together, other key information such as staffing numbers, complaints levels or performance against mandatory quality indicators.

The UK Care Quality Commission has performance-rated care homes since 2014.[237] The Care Compare Five-Star Quality Rating System used in the United States is another example of a performance ratings system that incorporates information and data from a range of sources.

The overall rating given to services by the United States system is based on separate ratings for three domains: health inspections, staffing and quality measures.[238] These measures incorporate data including certification and assessment, complaints, weighted measures of staffing hours and clinical indicators.[239] In addition to the star ratings, users can access information for each of the three domains in greater detail, which includes full reports from health inspections, staffing statistics and quality measures at the indicator level.[240] Results can also be easily compared to other facilities and, in the case of staffing information, with State and national averages.

The Australian star rating system should draw on a wider range of information than is used in the United States to provide meaningful comparisons between services. There should also be scope for people to access more detailed information about accreditations or other performance or benchmarking information.

The presentation of this information is important. A person using an aged care service should, for example, be able to see the graded assessment or rating given to the service on each of the Aged Care Quality Standards and drill into that rating to see more detailed information. In relation to the staffing Standard, they should be able to see both the rating and more detailed information about staffing levels and how they compare with the mandatory minimum staffing levels.

Each service, and each approved provider, should be given an overall rating, as well as ratings for the key domains underpinning that overall rating, in a way that makes it easy to compare services and providers.

The type of system that we are proposing is vital but is not a simple fix. It is complex and sophisticated. It will require a considerable investment to develop and refine. It will require calibration over time. This investment has long been called for and is well overdue.

3.8 Conclusion

A shared vision of high quality care is a critical part of the future aged care system. The recommendations in this chapter seek to put this vision into practice.

This vision includes high quality clinical and personal care. It equally includes helping older people achieve and maintain their quality of life and wellbeing, though social and emotional fulfilment.

The new vision for high quality is more than an aspiration. It is grounded in a statutory duty imposed on providers of aged care and updated Quality Standards. In defining high quality aged care and its characteristics, we seek to set a new bar for aged care in Australia. We have also identified a number of specific areas for urgent improvement, including the quality of food and nutrition in residential aged care, the care of people living with dementia, and the provision of palliative care services. We also make a recommendation to reduce and regulate the use of restrictive practices.

In addition, the aged care system needs to deliver high quality care consistently. Quality should be comprehensively measured, with benchmarking used to improve results progressively. People seeking care and their family and advocates should have access to information to compare the quality of different aged care providers, including through a star rating system.

Our entire report is dedicated to aged care quality and safety, so a chapter on the same topic is necessarily only part of the story. However, the vision for high quality care we have laid out here is one of the key building blocks for the future aged care system. Australia's future aged care system should be ambitious in what it seeks to achieve for older people and it should welcome accountability against that vision.

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4. Program Design

4.1 Introduction

This chapter sets out our recommendations for a new program to deliver high quality and safe care to older people in their homes, in the community and in residential facilities. The recommendations are informed by evidence about what works under the current program and what does not. They reflect our vision for better outcomes for older people who need care, and the beneficial impact on our communities and society when older people are supported to live independent and meaningful lives.

The central task of our inquiry is to recommend ways to improve aged care for Australians. Improving aged care requires the system to be redesigned to put older people first. Aged care services need to meet the needs of older people when and where they need that care and in time for that service to be of use. Alongside Medicare, the Pharmaceutical Benefits Scheme and Age Pension, the aged care program should be seen as something that older Australians can rely upon when they need it.

Our recommendations in this chapter are about how a redesigned aged care program can improve the experience of aged care. This requires that the many disparate aged care programs, each with their particular eligibility criteria, assessment processes and budget allocations should be consolidated and simplified.

4.2 A new aged care program

As people age, they may experience deterioration in cognitive or physical abilities, chronic health issues and other challenges to independent living. Each person has unique needs and will need a different mix of supports. Aged care should fit seamlessly into people's lives and help older people to age happily and comfortably, including where they are experiencing physical decline or cognitive change. People do not relinquish their rights to, and aspirations for, quality of life simply because they need or use care as they age.

We have heard of the challenges posed by the multiplicity of programs and services in aged care, the eligibility criteria and the pathways to gain access to support and care. The three main aged care programs need to be transformed, with a single entitlement to care. Information services should be more accessible and older people need more support to help them find the right services.

Given the diversity of needs, the range of services, and the many types of service providers, we consider that the aged care system will always have underlying complexity. That complexity should be addressed by those responsible for managing the program by working together 'behind the scenes', rather than left to older people and their families to negotiate and navigate.

Our recommendations are aimed at achieving the following outcomes:

- person-first—care and supports which address physical, social, psychological, cultural and spiritual needs, supporting people to function independently for as long as possible
- simplicity—one aged care program, one set of eligibility criteria and one assessment process
- accessibility—information that is easy to locate and understand with face-to-face supports
- universal entitlement—once entitled to care, guaranteed access to the care and supports assessed as needed
- timeliness—assessments and reassessments of need occur when required and services commence within one month of assessment
- choice of settings—in the home, community and residential care
- inclusiveness—recognises a person's diverse characteristics and delivers culturally safe and trauma-informed care.

Despite incremental reform, the programs in the aged care system retain the basic structures they had when the *Aged Care Act 1997* (Cth) commenced. In many ways, it is a structure inherited from the *National Health Act 1953* (Cth) and associated grant programs. The result is an uneasy mixture of complex programs operating under a range of different guiding principles, within a structural framework that was not designed for them to operate together with optimal efficiency and effect. The recommendation for a new program simplifies the complexity of the current system but the essential structural components remain. They still include aged care in a residential setting for people with high levels of need; aged care in the home and community, from low to high levels of need; and respite to support informal carers. However, the recommendation proposes a vastly different operating arrangement, with common national settings, an entitlement to care, services based on need but delivered flexibly so that older people's preferences are respected, and much greater funding certainty.

Recommendation 25: A new aged care program

By 1 July 2024, the System Governor should implement a new aged care program that combines the existing Commonwealth Home Support Programme, Home Care Packages Program, and Residential Aged Care Program, including Respite Care and Short-Term Restorative Care. The new program should retain the benefits of each of the component programs, while delivering comprehensive care for older people with the following core features:

a. **a common set of eligibility criteria identifying a need (whether of a social, psychological or physical character) to prevent or delay deterioration in a person's capacity to function independently, or to ameliorate the effects of such deterioration, and to enhance the person's ability to live independently as well as possible, for as long as possible**

b. **an entitlement to all forms of support and care which the individual is assessed as needing**

c. **a single assessment process based upon a common assessment framework and arrangements followed by all assessors**

d. **certainty of funding and availability based upon assessed need**

e. **genuine choice and flexibility accorded to each individual about how their aged care needs are to be met (including choice of provider and level of engagement in managing care, and appropriate and adapted supports to enable people from diverse backgrounds and experiences to exercise choice)**

f. **access to one or multiple categories of the aged care program simultaneously, based on need**

g. **portability of entitlement between providers throughout Australia.**

4.2.1 Accessible information

An entitlement to aged care must mean that older people are able to find and use the care and supports that they are assessed as needing, as is their right.

Information about aged care services should be easy to understand, access and use. This is necessary to allow people to plan ahead for older age and to plan when seeking aged care supports and services.

Improving public awareness

Mr Paul Versteege, Policy Manager, Combined Pensioners and Superannuants Association, stated that Australians experience 'an enormous information deficit' when it comes to accessing aged care.[1] The deficit can be partly attributed to a lack of planning for aged care. Professor John McCallum of National Seniors Australia explained:

> the data show that 85 per cent of people think they're going to live longer. 22 per cent have no plans. About 50 per cent have financial plans. 46 per cent have health plans so that sort of planning is going on. If you ask them, and do you plan to spend more money on residential care? They're not thinking about that late stage in life. Do you plan to spend more money later in life? Only three per cent are thinking about that.[2]

Many people do not adequately plan for care in old age. Often, people's attention is only turned to aged care when it is unavoidable, such as after a medical crisis.[3] Information about aged care services that is easy to understand, access and use should facilitate earlier planning.

There are unavoidable fears that come with thinking about a time in life when you are frail and dependent. To a certain extent no aged are system, no matter how well designed, can completely erase the unease that comes with this decline. But it is also the case that public information about aged care can be much better designed to provide reassurance to people that they will be well looked after and that, importantly, they will have greater control over their last years of life. The aged care system does not need to be alien at the point that someone starts to engage with it.[4] People need to be presented with a much easier path to obtaining information about aged care, even before the use of aged care is a necessity.

General practitioners and other health professionals have an important role to play in recognising a person's increasing frailty, and ensuring timely referrals are made to assessment services. Dr Harry Nespolon, then President of the Royal Australian College of General Practitioners, explained:

> as GPs we try to prepare our patients for difficult parts of their lives and this [ageing] is perhaps one of the most difficult parts of life.[5]

Care finders and the assessment workforce measures that we recommend will also assist older people to find and access services appropriate to their needs. Family, friends and carers should be included in this process in recognition of the vital role they play in supporting our aging population.

Resources and education should be made available to enable general practitioners and the range of health professionals, approved providers and organisations working with older people to take a more active role in people's planning for aged care. It is equally important that information is accessible to their family and friends so that they can easily find out what steps need to be taken to help their relative or friend gain entry to the aged care system and choose the right providers.

Improved public awareness will require a cooperative approach, with all levels of government aligning their goals in working with older people to boost their literacy around health, finances and ageing. On a regular basis, the System Governor should review the strategy put in place, to ensure that the information, resources and education are achieving the intended outcome of engaging people in planning for ageing and for potential aged care needs.

Recommendation 26: Improved public awareness of aged care

1. By 1 July 2022, the System Governor in cooperation with other levels of government, and working with health professionals, aged care providers and Primary Health Networks, should fund and support education, and the dissemination of information, and strategies to:
    a. improve public awareness of the resources available to assist people to plan for ageing and potential aged care needs
    b. improve knowledge about aged care among those responsible professionals with whom older people have frequent contact
    c. encourage public discussion about and consideration of aged care needs.
2. These strategies should be implemented by 1 July 2022 and should:
    a. support continual planning for ageing, including consideration of health care preferences, finances, housing and social engagement
    b. bring older people's general practitioners to the centre of planning for ageing and aged care; and
    c. be evaluated and revised annually by the System Governor.

Improving My Aged Care

The official government information service for the aged care system is My Aged Care. Through a contact centre and website, My Aged Care provides information on aged care and helps people find appropriate care services in their local area.[6] My Aged Care refers people for assessment of their eligibility for Australian Government-subsidised aged care services.

The Carer Gateway and Integrated Carer Support Service are avenues for informal carers of older people to access information on carer supports and respite options. The Carer Gateway is operated by the Australian Department of Social Services and is separate to My Aged Care. This is discussed in Chapter 5, on informal carers.

In the Interim Report, Commissioners Tracey and Briggs were critical of many aspects of My Aged Care.[7] There have been four sets of changes to My Aged Care since this Royal Commission commenced. Three were made after the Interim Report.[8] My Aged Care needs to be kept under regular review. A lot more remains to be done to support older people to choose the right services and the best possible providers to meet their personal needs and circumstances.

My Aged Care will remain an entry point to aged care, but it will not be the only entry point. Digital gateways can present a barrier for some in accessing information and services, especially older people who may not be computer literate, people with cognitive decline, those who speak languages other than English or those who do not have access to computing services.

We consider that the Australian Government should publish up-to-date and readily accessible information on the My Aged Care website about the nature and extent of aged care services available in local areas across Australia. This should include any lack of access to a particular kind of aged care service or to locally-sourced aged care services.

In making future improvements to My Aged Care, it is clear that the System Governor should include comprehensive information about relative approved provider performance. This information should support people to make informed choices about the services and providers that they will use. For example, the approved provider search and comparison function on My Aged Care should be further refined to include:

- detailed information on the kinds of services the approved provider delivers, service capacity and use and any limitations in the types of services provided in particular localities
- information on star ratings and other performance indicators, when those systems are established—see Chapter 3, on quality and safety
- annual reports from approved providers about their operation and performance, as described in Chapter 13, on provider governance.

The information on My Aged Care should be presented in a standardised and accessible manner, and should be verified to the satisfaction of the System Governor.

After hearing, over much of 2019, the frustrations of many people with the aged care system, Commissioner Briggs makes a specific recommendation about the information that should be available on My Aged Care to support people to make informed choices.

Recommendation 27: More accessible and usable information on aged care

Commissioner Briggs

The Australian Government should continue to enhance My Aged Care to ensure it is the Government's official source of consistent, accessible, inclusive, reliable and useful information about the aged care system and aged care providers. This should include developing a comprehensive provider search function on My Aged Care that allows people to review and compare:

a. information on the kinds of services the provider delivers, including whether providers of home care services offered in regional, rural and remote areas are locally available.

b. information on service capacity and use

c. information on star ratings and other performance indicators (as detailed in Recommendation 24 in the quality and safety chapter)

d. annual reports from approved providers about their operations and performance (as detailed in Recommendation 88 in the provider governance chapter)

e. all information at (a) to (d) will be standardised and verified by the System Governor.

4.2.2 A single avenue of assessment

Each person seeking aged care of any kind should receive timely access to a scalable assessment through a single assessment process, conducted by competent independent assessors. A person receiving aged care should receive timely re-assessment where required.

Recommendation 28: A single comprehensive assessment process

1. By 1 July 2023, the Australian Government should replace the Aged Care Assessment Program and the Regional Assessment Services with one assessment process. That assessment process should:

   a. be undertaken by an assessor who is independent from approved providers, so that a person's level of funding should be determined independently of the approved provider

   b. occur, wherever possible, before funded services commence, although funded services may be offered on an interim basis pending assessment where this is necessary in the opinion of a care finder

c. be efficient and scalable according to the complexity of needs and vulnerability of the older person

d. be forward-looking and promote older people's autonomy and self-determination

e. include assessment of the need for care management and the intensity and complexity of that need

f. include an assessment of any informal carer's needs

g. use multidisciplinary teams for more complex needs.

2. People should be provided with details of their assessed need and funding level at the conclusion of the assessment process.

3. Reasonable requests for reassessment of need can be made by a person receiving care (or their informal carer, close family or other representative), their care finder, or their approved provider.

4. The determination referred to in 1.a may involve consultation with providers or prospective providers, provided final assessment decisions affecting eligibility for funding are made by independent assessors.

Commissioner Pagone

Commissioners Tracey and Briggs heard that the process of obtaining aged care is complex and prone to inefficiency and duplication.[9] Older people and their families reported the experience as time-consuming, overwhelming, frightening and intimidating.[10] We consider that the process of assessment should be streamlined, efficient and effective. It should also be helpful, so that older people feel they have some control over their circumstances and the care that they will receive.

Mr Ahilan St George is a Director and Co-Founder of Vitality Club, an approved home care provider that also operates a Regional Assessment Service. He told us that having a single assessment workforce is 'probably the most important reform issue' and merging of Aged Care Assessment Teams and Regional Assessment Service teams could go a long way towards creating 'a more seamless journey for a client going through the aged care system'.[11]

Mr Paul Sadler, Chief Executive Officer of Presbyterian Aged Care, described the dual streams for assessment—Aged Care Assessment Teams and Regional Assessment Services—as inefficient and unnecessary.[12] Ms Rita Kersnovske and Ms Ruth Harris told Commissioners Tracey and Briggs about the multiple assessments required when trying to access aged care services. They said the assessment result often does not align with the service provided.[13]

These are not new concerns. Mr David Tune AO PSM recommended integration of the assessment processes in his 2017 review of the Living Longer, Living Better reforms made since 2012.[14]

The Australian Government is looking at streamlining the assessment model and has stated:

> Under a streamlined assessment model, it is envisaged that assessment providers would be responsible for delivering 'aged care assessment' encompassing home support and comprehensive assessment as well as potentially residential care funding assessments.[15]

We agree that assessment needs to be streamlined. This should be progressed as a priority to redress people's experiences of inefficiency, duplication, poor resource use and unsatisfactory service.[16]

There is strong support for assessments to be independent of approved providers and to ensure equity of access to services for all older people while avoiding any perception of over-servicing.[17] We agree, but acknowledge that a different approach may be required for vulnerable older people, such as those at risk of homelessness or from diverse backgrounds, where a person may not feel comfortable disclosing their needs to an unknown assessor.[18] In those situations, it may be appropriate for an approved or prospective approved provider to be involved in discussions with the individual and the assessor regarding that person's needs and goals, provided this is in accordance with the older person's wishes.

An independent assessment should establish funding for those seeking access to aged care services. Funding of a person's aged care should be driven by their individual care needs, assessed in a convenient and timely manner and should provide access to all the aged care services that an older person needs. To ensure consistency, the assessment workforce must be equipped with standardised assessment framework and be sufficiently skilled to apply those tools.[19] Assessments must be conducted by qualified assessors, and the assessment process must be transparent about how assessment outcomes are determined.[20]

We have been told that assessment needs to be flexible, allowing a relatively light touch assessment for some people, while others with higher or complex care needs may require a full comprehensive assessment conducted by a multidisciplinary team.[21] We agree. The assessment should focus on a person's needs—social, emotional, spiritual and clinical—as well as their goals in accessing aged care.[22] Wherever possible, the assessment should be conducted face-to-face, and should also include the needs of the carer in their own right to ensure that the caring relationship is sustained. In our chapter on informal carers and volunteers, we recommend that the needs of informal carers are assessed.

A person's entitlement for care management will also be determined as part of the assessment process. We discuss this further in Recommendation 31: Approved provider's responsibility for care management.

Assessments must be timely and reassessments conducted when necessary. This is not only good practice and effective service delivery, but it will also enable an older person to benefit from access to short-term intensive restorative and reablement interventions which may avoid their rapid deterioration following a significant event, such as a fall.[23]

4.2.3 Local assistance to gain access to services

Each person seeking aged care should have access to personalised and local services to help them access and make use of aged care services in their area. People should not have to fend for themselves when starting out with aged care.[24]

We have heard throughout this inquiry that aged care needs to have a much greater face-to-face presence.[25] We agree. 'Care finders' should assist older people and their carers to receive the information they need to engage with their local assessment team, approved providers, and aged care services and supports. A care finder should commence assisting a person on receipt of a request for assistance, made either directly or indirectly. This request can be made by an older person seeking aged care, or any other person making a request on an older person's behalf such as an informal carer, family member, legally appointed representative, health professional or social worker.

The degree of involvement by the care finder will vary depending on the complexity of the person's needs and their assessed vulnerability. Research commissioned by the Australian Department of Health in 2013 identified six risks that could be prioritised for inclusion in a definition of 'vulnerability': unstable housing—or the individual is already experiencing homelessness; poor mental health; living alone or socially isolated; financial disadvantage; Aboriginal and Torres Strait Islander background; or a culturally and linguistically diverse background.[26]

Care finders should give consideration to the number and intensity of risk factors that are experienced by an individual, and provide supports accordingly. However, the care finder service should be available to all older people seeking aged care.

The functions of care finders are to assist people seeking aged care services, and their informal carers, family or legally appointed representatives, with information about the aged care system and to provide additional assistance in the nature of case management, appropriate to the individual's circumstance and wishes, namely to:

- provide face-to-face assistance to help older people and their informal carers understand the processes involved in obtaining aged care
- understand the expressed needs and goals of the older person and help the person to make a plan for the services they wish to receive
- assist the older person to understand, gain access to and participate in assessments and reassessments of needs and eligibility for aged care, and work closely with the local assessment team to facilitate the assessment process
- ascertain the best options for services in the local area and link the person to these options, either through providing information to the person, or (with the older person's approval) directly contacting the relevant service provider and referring the person to them. This may also involve linking the person to support outside the aged care system (for example, housing or mental health)
- follow up to make sure that the referrals have been accepted and the support and care identified in the assessment is in place

- conduct regular check-ins with the person receiving aged care services to ensure that the services are meeting their needs
- where changes in the older person's needs occur, or services are not meeting the older person's needs, take any necessary steps in consultation with the person receiving aged care services, including arranging reassessments or referrals to other services.

Commissioner Pagone supports a mechanism for care finders to be funded and to be available wherever they are needed throughout Australia. There are, however, many practical difficulties in how this can be done. Several mechanisms have been suggested to us. One suggestion is that the Australian Government fund care finders employed directly by local governments.[27] That would ensure that they would be located throughout Australia and would be subject to the disciplines of public sector employment. Other models have been suggested and are worthy of exploration. The need is there and its provision should not be delayed by debates about the mechanism to meet it.

Commissioner Briggs is confident that care finders will be able to be recruited from locations across Australia. She makes the following recommendation about the introduction of care finders and the mechanism for their establishment.

Recommendation 29: Care finders to support navigation of aged care

Commissioner Briggs

1. **From 1 July 2023, the Australian Government should fund the engagement of a workforce of personal advisers to older people, their families and carers, called 'care finders'.**
2. **The function of care finders will be to assist older people seeking aged care services with information about the aged care system and case management services by:**
    a. **providing face-to-face support to older people to help them identify the best options for care to meet their individual needs and goals, to exercise informed choice, and to understand their entitlements. That support should be scalable and proportionate to need and vulnerability**
    b. **assisting older people to understand, gain access to and participate in assessments and reassessments of needs and eligibility for aged care, and work closely with the local assessment team to facilitate the assessment process**
    c. **ascertaining the best options for services in the local area and link them to these options. This may also involve linking the older person to services outside the aged care system, such as housing, mental health or health care more generally**

d. following up to make sure that referrals have been accepted and the support and care identified in the assessment is in place

e. conducting regular check-ins with the older person to ensure that the services are meeting their needs

f. where changes in needs occur, or services are not meeting needs, taking the necessary steps in consultation with the older person, including reassessment or referrals to services.

3. Care finders will be employees of the System Governor, a State or Territory or a local government body, who are suitably qualified in aged care, health care or social work.

Implementation of care finders | Commissioner Briggs

Many people struggle to negotiate the aged care system. They want personalised support and information to help them understand the aged care system, navigate its processes, and find aged care services. The Australian Government recognises that this service is missing, and has been working with COTA Australia to trial a navigator service across aged care. An interim evaluation of the COTA Australia-led trials found that the majority of users of the navigator service had improved their knowledge of the aged care system and how to access it, and felt more confident in accessing services.[28]

The navigator trial has been a step in the right direction, but it needs to go further. The Australian Government must invest more funding in the services that help people understand and navigate aged care. With the new care finder network, people will be supported locally to recognise and find the aged care that they are assessed as needing. And with better information, they will be able to make informed choices about the services they access.

A key part of the care finder's role will be to have up-to-date knowledge about services that are available locally and to help older people engage with local approved providers that might suit them and be able to deliver on their needs. While maintaining the independence of the assessment process, there should be scope, if an older person wishes, for consultation between a provider, the assessment team and the care finder about the person's preferences and available services before the assessment is finalised.

Care finders should be embedded as part of the assessment workforce to ensure they have access to detailed knowledge of the service and community networks in their regions, and to minimise any unnecessary delay between a person receiving their assessment and actually being able to access appropriate services.[29] It is critical that the care finder workforce is embedded in the local community as part of regional network of the System Governor.

The introduction of the care finder role will ensure that older people and their carers will have increased face-to-face contact with a well trained and knowledgeable person, rather than being forced to interact with a web page or call centre when their needs change. As government employees, care finders will be independent from approved providers or other organisations connected with the delivery and management of aged care services or facilities.[30] They will also be bound by their respective government employer's policies and code of conduct in performing their duties and be trained in culturally sensitive and trauma-informed care delivery.

Capabilities in human services, health, aged care and local knowledge are critical to the care finder role. Care finders should be trusted advisors who work face-to-face with the older person and their carer. People want an empathetic and authoritative person they can turn to, to seek support and advice at a critical juncture in their lives. This is not a role that can be undertaken by existing government services such as Services Australia, as it is of a qualitatively different nature to that of typical Australian Government customer services. It is about working with an older person about what they need and what they want, and how they get access to it.

4.2.4 Recognising diversity and individuality

To deliver high quality and safe care, those providing services must respect the diverse backgrounds and life experiences of every older person, and tailor the delivery of care to meet their individual needs. Diversity should be core business in aged care.

Recommendation 30: Designing for diversity, difference, complexity and individuality

1. From 1 July 2022, the System Governor should:
    a. require that:
        i. as a condition of approval or continued approval of providers, training on cultural safety and trauma-informed service delivery be provided for all workers engaged by providers who are involved in direct contact with people seeking or receiving services in the aged care system
        ii. comparable training be provided for people engaged to provide care finder and assessment services
        iii. as a condition of approval or continued approval, providers verify to the satisfaction of the System Governor that the provider has proper grounds for making any representation of being able to provide specialised services for groups of people with diverse backgrounds and life experiences

b. formulate a standard dataset and data collection mechanism for collecting, monitoring, analysing and using data about the diverse backgrounds and life experiences of older people seeking or receiving aged care, including, as considered appropriate, people whose circumstances are not currently included in the 'special needs' provision, such as those living with mental illness, dementia or disability, and

c. commence collection and analysis of those data for the purpose of identifying variations in and improving equity of access to, and use of, aged care by people of diverse backgrounds and experiences (subject to the operation of the *Privacy Act 1988* (Cth)).

2. The System Governor should:

a. by 1 July 2024, in consultations with representative and peak organisations, complete a national audit evaluating regional and local variation in levels of services for people from diverse backgrounds and life experiences, including consumer experience information, and, in light of the outcomes of the national audit, thereafter undertake commissioning arrangements to address deficits in meeting the needs of people from diverse backgrounds on a regional and local basis as required

b. by 31 December 2024, report to the Inspector-General and the public on the extent to which the needs of diverse older people are being met by the aged care system and what further steps need to be taken for the aged care system to meet the needs of diverse older people.

The aged care system is presently structured and subsidised by various responses to 'special needs', a term defined in the Aged Care Act. Aspects of the aged care statutory framework are intended to provide an incentive to approved providers to give priority to people with so-called 'special needs'.[31]

The Aged Care Act identifies nine groups of people as having needs that warrant special consideration and makes reference to a mechanism for the identification of other groups. They include people who: identify as Aboriginal and Torres Strait Islanders; have culturally and linguistically diverse backgrounds; live in rural or remote areas; are veterans; are homeless or at risk of homelessness; are care leavers; are parents forcibly separated from their children; and LGBTI people.[32] Other aged care programs, such as the National Aged Care Advocacy Program, acknowledge the special circumstances of other people such as those living with a disability, who have mental health problems and mental illness, and people living with cognitive impairment such as dementia.[33]

Commissioner Briggs believes that 'special needs' can have a pejorative connotation and does not capture the emerging needs of people with diverse backgrounds and life experiences across and between the groups listed.

The term 'special needs' should not be used in the new aged care Act. 'Diversity' has different meanings for different people. For some people and in some contexts, diversity is something to be celebrated. For others, their diverse experiences are related to hardship and trauma. There are significant challenges in choosing better language in this area.[34] In this report, we have generally used the term 'people with diverse backgrounds and life experiences'.

Trauma

We heard and acknowledge the high prevalence of trauma experienced within our community. Sadly, we heard that for some it is thought to be expected and not the exception.[35] We also heard that people from diverse backgrounds and life experiences are likely to have experienced more trauma, potentially for longer, and for those who identify with multiple diverse groups, potentially from multiple angles.[36]

Ms Janette McGuire told us about her childhood trauma as a Forgotten Australian. She was raised in an institution where she was beaten and mistreated. She had recently stayed in residential aged care while recovering from surgery. She explained the terror Forgotten Australians experience at the thought of entering aged care:

> We are scared of going back to an institution and having experiences similar to when we were younger. In my experience with an aged care facility you are not in control. You are told what to do all the time….We are scared of having all the painful memories from our childhood come back to us…Being triggered takes us back to feeling powerless like we did when we were young. The strict routine, being told what to do all the time, being talked down to…We panic and feel helpless.[37]

Witnesses spoke of the need to acknowledge trauma as part of the tapestry of a person's life and respond to it as a core element of service delivery.[38] Dr Duncan McKellar, Head of the Older Persons Mental Health Service in Northern Adelaide Local Health Network, South Australia, described a trauma-informed response as 'part of a framework to service design and delivery that actually informs everything that we do'.[39] He explained that trauma-informed care is required to not re-traumatise people. He viewed it as a 'universal precaution…just the same as we teach all health practitioners to wash their hands; we should also be ensuring that all care providers are trauma-informed'.[40]

Approved providers, assessors, care finders and others involved in aged care need to be mindful that trauma can re-emerge at any time during a person's interactions within the aged care system. All aged care staff need to be trained to deliver care in a culturally safe and trauma-informed way. This will include communicating in a way that takes into account the individual characteristics of each person seeking care. We recommend that all workers engaged by providers who are involved in direct contact with people seeking or receiving aged care services are regularly trained in cultural safety and trauma-informed approaches to delivering care. Commissioner Briggs further recommends that the national audit should involve consultation with local and regional representative and peak bodies so some of the difficulties that come with having to rely on self-identification can be overcome.

Communication barriers

Many witnesses spoke of the impact of having poor or no ability to communicate when accessing aged care. This includes social isolation and loneliness, being unable to access information or make a complaint, being unable to control their care plan and care experience, and being vulnerable to abuse.[41] One witness felt that the inability to communicate posed a safety risk.[42]

Older people from a culturally and linguistically diverse background are vulnerable in culturally unsafe environments where they cannot communicate in their primary language.[43] Aboriginal and Torres Strait Islander people are similarly at risk.[44] Additionally, people living with dementia are more likely to resort to their primary language as their cognitive abilities decline.[45]

The 2016 Census reported that almost two in 10 older Australians report speaking a language other than English at home.[46] Amongst those aged 65 years or more, 12% spoke another language but also spoke English well, 5% spoke English poorly and 1% did not speak English at all.[47] A total of 10% of Aboriginal and Torres Strait Islander people spoke at least one of 150 traditional Aboriginal and Torres Strait Islander languages at home.[48]

We heard that to break the 'cycle of invisibility' for people with diverse backgrounds and life experiences, data collection is paramount. Without this, 'people go back into the closet, hide themselves, hide who they are...They become even more invisible in the service'.[49]

The Australian Government acknowledged that 'in some aspects of the aged care system the lack of data collection limits the understanding of how people with diverse needs access and experience the system'.[50]

We recommend that the Australian Government complete a national audit evaluating regional and local variation in levels of services for people from diverse backgrounds and life experiences, and use this information to undertake commissioning arrangements to address deficits in meeting the needs of people from diverse backgrounds on a regional and local basis as required. The Australian Government should ensure that representatives from diversity groups, including peak bodies, consumer organisations and advocacy groups, as well as older people from diverse backgrounds and life experiences, are involved in designing for this data collection to ensure that questions are delivered in a culturally safe and trauma-informed way.[51] The national audit should include consumer experience information.

Diversity Framework and Action Plans

The Australian Government published the Aged Care Diversity Framework in 2017.[52] Since then it has progressively released Action Plans for providers to improve services to Aboriginal and Torres Strait Islander people, LGBTI people, people from culturally and linguistically diverse backgrounds and shared actions to support all diverse older people.[53] The Aged Care Diversity Framework and four provider Action Plans are currently voluntary and do not form part of the accreditation regime.[54]

The Australian Government has acknowledged that the Aged Care Diversity Framework and provider Action Plans represent an excellent resource for providers.[55] These resources should continue to be promoted as a mechanism available to 'demonstrate…ways in which providers can actually be providing higher and better care'.[56] A number of submissions in response to Counsel Assisting's final submissions advocated for the Action Plans made under the Aged Care Diversity Framework to be made mandatory.[57]

Each of the Action Plans contains a set of guidelines directed at aged care providers, and each of those guidelines sets out actions that are at three different levels: 'Foundational Actions', 'Moving Forward' and 'Leading the Way'.[58] The Action Plans point the way to real change in the sector. In Chapter 3: Quality and safety, Recommendation 21, we recommend that, as part of the first comprehensive review of the Aged Care Quality Standards, the Australian Commission on Safety and Quality in Health and Aged Care should reflect the Aged Care Diversity Framework and underlying Action Plans and consider making them mandatory.

We recommend that aged care providers that promote themselves as capable of providing specialised services to sections of the Australian community must verify, to the satisfaction of the System Governor, that the provider has proper grounds for doing so. The Action Plans will be a very important resource in that regard.

In Commissioner Briggs's view, the recommendations here and in other parts of this report will result in increased awareness and accommodation of the differences and experiences of a broader range of individuals within the Australian community. With improved data, there will also come opportunities to identify gaps in aged care service provision and an obligation for the active commissioning of appropriately tailored services

4.2.5 Care management

'Care management' can be essential to achieving good outcomes in aged care.[59] It is especially important for people who have complex needs or needs that require multiple or intensive responses.

The terms care management, case management, client coordination and other related terms are used interchangeably within the aged care sector. They have different nuanced meanings in different service settings across aged care, disability, health and other sectors. We use 'care management' to mean the day-to-day coordination of care. This involves the care manager creating, in conjunction with the older person and their carer, a care plan that: outlines the detail of expected services; manages and organises the services; refers and subcontracts to other services as needed to provide the full suite of services outlined in the care plan; monitors the services delivered; monitors and reviews the care plan as needs change; and refers the older person for reassessment when their needs change.

Recommendation 31: Approved provider's responsibility for care management

1. From 1 July 2022, a person's approved provider must assign a care manager to the person unless an assessment team has assessed the person as eligible for home care and, in future, 'care at home' without the need for any care management.
2. In the case of home care and, in future, 'care at home', if the person has more than one approved provider, the person's lead provider must assign a care manager to the person.
3. Care management should be scaled to match the complexity of the older person's needs and should be provided in a manner that respects any wishes of the person to be involved in the management of their care.
4. The care manager should:
    a. have relevant qualifications and experience suitable for the range and complexity of the care needs of the people to whom the care manager provides care management
    b. consult with the person and, if applicable, their carer, to develop a comprehensive support and care plan, including activities to promote various aspects of health and wellbeing and to enhance their ability to live or participate in the community and address their strengths, capability, aspirations and goals
    c. implement, monitor and review the support and care plan, and adjust as appropriate
    d. meet the requirements for care management set out in the person's care plan and (if applicable) personalised budget for home care and, in future, 'care at home'
    e. for residential care:
        i. identify when the older person accessing aged care services requires additional care beyond the usual services provided by the approved provider
        ii. take reasonable steps to ensure that the older person in aged care accesses appropriate health care at an appropriate time
        iii. take reasonable steps to ensure that any health care plan is implemented on an ongoing basis and updated as required
        iv. liaise with general practitioners, other primary health care providers, including allied health care providers, specialists and multidisciplinary outreach services; and take reasonable steps to ensure that staff of the provider are available to support visiting health practitioners
        v. liaise with the person's family and staff of the aged care provider.

To ensure that the benefits of care management are adequately recognised in the future, a person's assessment will include consideration by the assessor of the complexity and intensity of a person's care management needs. A person's aged care entitlement will be adjusted to reflect that need.

Mr Brian Corley, Chief Executive Officer of Community Options ACT Incorporated, explained the targeting of care management or coordination is important. He described it as 'a valid and vital service for those who need it', but said that if it is not directed to the people who need it then it can be 'a waste of time'.[60] It is conceivable that some people may be assessed as needing some basic form of care in the home and be assessed as not requiring care management. However, in every other case the lead provider must deliver care management in accordance with a person's assessed need and in a manner that will best suit that person.

A care manager must work in partnership with the person receiving care, and any informal carers, and must understand their preferences for what care they wish to receive, when and how.[61] This must be documented in a care plan.

For people who are receiving care in the home and community—'care at home' in the new aged care program—the care manager, on behalf of the approved provider, is responsible for ensuring that care and support is provided to an older person in accordance with their care plan and assessed needs. This will include any supports the person receives from any other aged service categories.

People receiving residential care usually have more complex needs, which require multiple or intensive health care responses. This will necessarily require higher-level care management, so that older people get access to the health and related services they are entitled to receive.

We have given consideration to a submission by Counsel Assisting that care managers should have relevant qualifications and experience as a registered nurse or allied health professional to ensure appropriate clinical expertise.

There was only limited support for this submission, in responses made to Counsel Assisting's final submissions. The submission was criticised as being too clinically focused and lacking recognition of other aspects of a person's needs.[62] Baptist Care Australia persuasively argued that a range of different professional backgrounds could be suitable, that care managers are generally not employed as nurses even if that is their original discipline, that they may not have maintained the relevant training and professional development, and that in any event there may not be enough registered nurses and allied health professionals in Australia willing to fill all of these roles.[63]

We agree that a range of relevant competencies and backgrounds can make a person suitable to be a care manager, depending on the specific needs of the older people concerned. Given the submissions on this issue, we have decided to recommend that care managers should have qualifications or experience that are suitable to the range of needs of people receiving care. We would expect that for people with very complex clinical needs, care managers should have qualifications or experience as a registered nurse or allied health professional, or some other clinical background.

Lead provider

For people assessed as needing care at home in the future, the older person will—with the assistance of a care finder, if they choose—select a provider, referred to as a 'lead provider', to administer and coordinate their supports and care.[64] This includes coordination of any supports they receive from respite supports, social supports and assistive technology and home modification categories.

Using funding assigned to the older person, a lead provider may arrange for, or permit, third parties to provide direct care services.[65] Regardless of the legal basis used to engage a third party to provide direct care, a person's lead provider is to be responsible for ensuring that high quality and safe care is provided.

Pending the establishment of the care at home category under the new aged care program, the approved provider selected by the older person to administer their Home Care Package funds should be taken to be the lead provider and therefore responsible for ensuring that high quality and safe care is provided.

Choice and control

Mr Robert Fitzgerald AM, NSW Ageing and Disability Commissioner, said that 'the greatest risk that all of us face in the Australian community is when we become invisible and older people tend to become invisible'. He said:

> We deal in the world of people that are slowly losing cognitive capacity. But the assumption has to be, in the first instance, that they have cognitive capacity and that's very important.[66]

Mr Fitzgerald explained the need for 'safeguarding' of people who may be vulnerable to abuse or other risks. He told us that the ability of a person to make or influence decisions on their own behalf is one of the most important parts of safeguarding. He emphasised the importance of ensuring that older people are 'not only at the centre of the service delivery system, but they're an active participant in it'. Mr Fitzgerald explained that often the focus is placed on the approved provider, to the exclusion of participation by the older person. He added that older people need to be given 'the capacity to make decisions on behalf of themselves and to influence decisions made on their behalf'.[67]

Care management should support older people to make choices, in partnership with their provider, about when and where this care is delivered, and what is done each time someone attends their home.

A person may choose to be more or less involved in the week-to-week direction and management of their care. We recommend flexibility in how care management is provided, particularly in the context of home and community aged care. For example:

- A person may wish to have minimal direction and oversight in the management of their care, with their chosen home care provider organising and delivering services in accordance with the assessment process and the care plan established at the start of their relationship. This would not remove the requirement for a relationship-centred approach to the delivery of care.
- A person may wish to exercise a higher degree of choice over who delivers care and when. For example, they may want a specific staff member to shower them each day, or they may want their home care provider to engage a specific person or another provider to deliver an element of their care plan, such as a particular allied health professional who is not employed by their home care provider.

Regardless of the extent to which the older person choses to be involved in their care management, the lead provider is responsible for ensuring the person's needs are being met and that quality and safe care is provided in accordance with the person's care plan.

4.3 Aged care service categories

We recommend the adoption of five service categories in the new aged care program—each of which provides funding for a type of care and supports. These are set out in Figure 1 and discussed further below. The design is intended to simplify the current system and ensure that services build up as people's needs build.

The current system includes 17 Commonwealth Home Support Programme services, 11 forms of respite care, four levels of Home Care Package, and residential aged care. Our recommended system has just five service categories.

Figure 1. Summary of the new aged care program

Service categories	Purpose	Services
Respite supports	To improve the wellbeing of informal carers, increase their capacity to care, and support their social and economic participation.	Respite in the home, in cottages and in purpose-built facilities.
Social supports	To improve social inclusion and community participation for the person's long-term health and wellbeing.	Social activities (alone and in groups) and including centre-based respite, transport (alone and community) and delivered meals.
Assistive technologies and home modifications	To maximise a person's independence to perform tasks or activities of their daily lives and minimise any risk to their safety.	Purchase and installation of goods, aids, equipment and services, including assistive technologies, minor modifications to the home and services to address hoarding and squalor.
Care at home	To support a person's independent living at home and in the community, providing care and support for assessed needs, including for end-of life.	Personal care, clinical, enabling and therapeutic care, and palliative and end-of-life care. Living supports: cleaning, laundry, shopping for groceries, light gardening and home maintenance. Care management.
Care at a residential home	To preserve capacity for a person's dignified living and death in a residential home.	Living supports (if appropriate), personal care, clinical, enabling and therapeutic care, and palliative and end-of-life care. Care management.

The five service categories are designed to operate in a complementary way to meet an older person's needs. Care at home and care at a residential home are alternatives, but otherwise services can, where there is an assessed need, be accessed in more than one category at the same time. An assessment will determine whether a person needs services and will assign an entitlement. Importantly, the services a person receives from each category will vary in intensity in accordance with the person's assessed needs.

The respite supports, social supports and assistive technologies and home modifications categories will be grant funded. Grant funding will support providers to meet the associated fixed and capital costs.[68] It will also allow providers flexibility to respond rapidly to changes in demand and respond quickly and flexibly to people's needs.[69] Current expenditure on these categories should continue, as should annual growth funding. Until a demand-driven system is established, annual growth funding should be aimed at ensuring the categories can meet the growing need for these supports.

4.3.1 Respite supports

A critical element in the sustainability of aged care in many cases is the care, supportive presence, and supervision provided by an informal carer. The failings of the aged care system to provide adequate support to informal carers for respite needs to be rectified.

Recommendation 32: Respite supports category

From 1 July 2022, the Australian Government should implement a respite supports category within the aged care program that:

a. **supports the availability of respite for the carers of older people earlier and more often to maintain their wellbeing and to sustain the caring relationship**

b. **provides a greater range of high quality respite support in people's homes, in cottages and in purpose-built facilities**

c. **provides people with up to 63 days of respite per calendar year**

d. **is grant funded with a potential capital component in areas where supply is inadequate.**

Children, partners and friends of older people who performed caring roles for them have told us about the benefits of caring, of establishing close bonds with the person they care for, as well as building a sense of purpose.[70]

Informal carers have also described to us their feelings of exhaustion, grief and often frustration with the aged care system.[71] Respite care has been made available for short-term or temporary care for an older person, while their informal carer takes a break from their caring responsibilities. That break is designed to allow the carer to attend to their other responsibilities or to sustain their personal wellbeing through leisure, interests and self-care without worrying about who will care for the older person. These breaks should be proactive and preventative, and carers should be able to plan and have them regularly.

We have heard that carers' experience of respite is mixed. Respite does provide a needed break, but quality respite is hard to find. It is difficult to access, conditions imposed upon its use are too restrictive, and it does not adequately support carers.[72]

The need for respite is most pressing and obvious when it comes to dementia care. The care burden is particularly acute with dementia. That is because of its progressive nature and its effect of the cognition of the older person and the indirect effects of this on the carer, including social isolation.[73] We have heard from informal carers about the difficulties in finding services with the skills to provide respite for people living with dementia.[74] We discuss these issues in more detail in our chapter on informal carers and volunteers.

We recommend the creation of a respite support category. Services available under this category should include residential respite, as well as cottage and flexible respite, such as in home day respite, in home overnight respite, host family day respite, host family overnight respite, mobile respite and innovative respite. Respite supports should be resourced and delivered properly, as a core part of the aged care system rather than as an add-on to other services.

We recommend that funding for respite be brought into one category. This category should be grant funded, offering certainty to approved providers to allow respite and carer supports to be fostered and grown over the coming years. In recent years, the way residential respite services have been funded seems to have provided residential aged care providers with insufficient incentive to provide regular short-term periods of respite and has led to the residential respite program being used for purposes other than the purpose for which it was designed—commonly known as 'try before you buy'.[75] Direct grant agreements should allow arrangements to be tailored to local conditions in a way that should ensure that sufficient respite is available for its intended purpose, and of the duration and regularity needed to meet local needs.

New grant-funded respite services should commence as soon as is practicable, with a view to replacing the current residential respite arrangements when sufficient scale has been attained.

Older people assessed as needing respite should be entitled to up to 63 days of respite each year, in line with present arrangements, and assessors should have the ability to approve further days if needed. The conditions of the grant agreements under which respite is provided should ensure that a person's quota of respite may be used in the blocks of time they choose, whether one weekend a fortnight or more sporadically, and that approved providers are not to impose any requirements about minimum blocks of time.

Respite has a dual purpose. It is meant to provide relief for the carer as well as improved outcomes for the person receiving care. It is essential that the respite supports category is sufficiently funded to achieve these outcomes.

Current respite offerings lack any additional measures of reablement. It is critical that rehabilitation and reablement services be made available while an older person is receiving respite to help them manage more independently when they return home. The current system has no incentives for approved providers of residential aged care to offer flexible forms of respite or to undertake reablement measures when an older person enters residential respite. In fact, there are many financial disincentives to do so. These should be removed as part of the approach to respite supports that we recommend.

We recommend that respite support be provided in addition to any care at home entitlement conferred on an older person by their Home Care Package. This will ensure that access to respite will not diminish the money available for the provision of ongoing supports and care for the person receiving care. Respite should be a widespread and standard service offered to all older people and their carers for its intended purpose.

Aged care homes or cottages should be established to facilitate access to meaningful activities with a restorative focus, and include, if appropriate, the provision of services such as physiotherapists and speech therapists. And the new category for respite should be developed with local communities and build on the resources of the Carer Gateway, operated by the Australian Department of Social Services.

The Australian Department of Social Services also plays a role in allowing carers to access emergency respite services through the Integrated Carer Support Service. This should continue alongside changes to the aged care program.

4.3.2 Social supports

The aged care system needs to emphasise personal, social and community connections, as well as clinical care.[76] Social supports and care are not substitutable. Both are important to ensure an older person's health and wellbeing. Older people should have access to both.

Recommendation 33: Social supports category

From 1 July 2022, the Australian Government should implement a social supports category within the aged care program that:

a. **provides supports that reduce and prevent social isolation and loneliness among older people**

b. **can be coordinated to the greatest practicable extent in each location with services and activities provided by local government, community organisations and business designed to enhance the wellbeing of older people**

c. **includes centre-based day care and the social support, delivered meals and transport service types from the Commonwealth Home Support Programme**

d. **is grant funded.**

Our research has shown that older people place high value on belonging and a sense of community, and that they particularly value and prefer in-person interactions.[77]

Funded social activities can provide a supportive social environment for older people who feel isolated from activities, due to age or financial circumstances. Social activities can serve as a forum for information-sharing. They help older people remain active, healthy and engaged, and they can prevent premature entry into residential aged care.[78] Dr David Panter, Chief Executive Officer of aged care provider ECH Incorporated, advised us to put more emphasis on the social aspects of aged care. Dr Panter explained that ECH Incorporated was seeing increased numbers of older clients with mild mental health issues due to their social isolation, emphasising that the social element is the glue that helps people continue to live independently at home.[79]

We agree. With the impacts of COVID-19 still being felt in our communities, we are keenly aware of how social isolation can affect older people's health and wellbeing.

Mr Fitzgerald told us that there needs to be formal services concentrated in this space. And he also cautioned that Australia cannot afford all the social supports needed to minimise risk for older people. He encouraged the re-engagement of the community in supporting older people.[80]

We recognise that social supports contribute to the social fabric of our communities. Mr Paul Sadler, Chief Executive Officer of Presbyterian Aged Care, stated that these services provide 'social capital' to the aged care system.[81] With a low marginal cost, these services support volunteer participation and social connection between the aged care system and local communities.

Commissioner Briggs notes that these services are as important to older peoples' health and wellbeing as the other, more clinically-focused services in the aged care system.[82] Research conducted for us by Ipsos on community attitudes to ageing and aged care noted that:

> Older people are keen not to be 'a burden' on others, specifically their children. At the same time they are aware that loneliness is a significant issue and they need to remain social engaged, physically active and mentally stimulated.[83]

Research conducted by COTA Australia similarly noted the importance that people place on being supported to maintain social relationships and connections with the community.[84] These activities also benefit carers and the caring relationship indirectly, by giving carers short, regular and planned breaks.[85] It will be important to harness the social supports offered already and build inclusion and participation into social support services.

There is opportunity to increase social cohesion by pooling funding with local and State Governments to co-commission and integrate aged care social supports with broader community initiatives.[86]

We want people living at home or in a residential aged care home to be able to use social supports if they are assessed as needing it. The positive benefits experienced by older people in continuing to interact with their established social networks and communities should continue to be available to all older people.

To achieve this, we recommend the creation of a new category in the aged care program: social supports. Services available under this category should include social activities (both group and individual), transport (individual and community), delivered meals (at home and centre-based) and centre-based day care.

Social supports should be provided in addition to any care at home or residential care entitlement.

We recommend this category of social support services be grant funded because they:

- have substantial infrastructure and capital costs—for example, in transport fleets or centres[87]
- are often voluntary-managed and community-based organisations, with high numbers of all volunteers[88]
- can provide some innovative benefits when offered in combination.[89]

These services provide more than just happiness and individual benefit. They build social cohesion and benefit the broader community. This broader community benefit would be lost if these services were funded separately through individualised funding.

Grant funding will provide certainty to providers currently delivering social supports under the current Commonwealth Home Support Programme as well as the Home Care Packages Program.

4.3.3 Assistive technology and home modifications

Ageing brings changes in functioning that can impact on people's ability and capacity to live independently. Small adjustments, new appliances, technologies or minor alterations to the home can enhance older people's independence, mobility and quality of life.[90]

Commissioner Briggs observes that Australia lacks a mature approach to assistive technology and home modification supports, which is a missed opportunity to promote enablement and support independence and wellbeing. Commissioner Pagone agrees that there is substantial room for improvement in the assistive technology and home modifications support in the aged care sector.

Recommendation 34: Assistive technology and home modifications category

From 1 July 2022, the Australian Government should implement an assistive technology and home modifications category within the aged care program that:

a. provides goods, aids, equipment and services that promote a level of independence in daily living tasks and reduces risks to living safely at home

b. includes the assistive technology, home modifications and hoarding and squalor service types from the Commonwealth Home Support Programme

c. is grant funded.

There are practical supports that the aged care program can fund to help people live safely in their own homes, such as a non-slip shower mat, a grab rail on the wall next to the toilet or over the front steps, or a hearing aid. They can also support older people to remain independent by reducing the need for physical care.[91]

But for the presence of an inexpensive grab rail or rubber shower mat, an older person would not be occupying an expensive public hospital bed, recovering from a fractured hip and running the risk of contracting pneumonia or a superbug infection.[92]

If the availability and benefits of those supports were known to older people earlier, they might be encouraged to make decisions to adapt the home, or to try new equipment or technologies, enabling them to remain at home without mishap. The earlier people use these supports, the more likely they are to embrace them.[93]

There is a need for clarification of roles between the States and Territories and the Australian Government in this area. As an example, the Commonwealth Home Support Programme Manual states:

> The CHSP [Commonwealth Home Support Programme] is not designed to replace existing state managed schemes which provide medical aids and equipment (e.g. Medical Aids Subsidy Scheme). CHSP service providers are encouraged to access these state and territory aids and equipment programs where appropriate.[94]

In its submission to us, the Assistive Technology for All Alliance described how State-based aids and equipment programs currently fall well short of people's needs.[95] Further, the Commonwealth Home Support Programme only provides funding for basic supports, and older people with higher care needs have to access funding under a Home Care Package—but often Home Care Packages are not assigned promptly.[96]

Very few people in the current aged care system get access to these sort of supports. In 2019–18, just 15,097 people were able to access assistive technologies (2%) and 48,842 people accessed home modifications (6%) under the Commonwealth Home Support Programme. This access across the States and Territories differed markedly, but did not align with the population share of older people. For example, South Australian clients represented nearly half of all assistive technology clients.[97] In the same year, the Home Care Packages Program supported the purchase of a wide range of items consistent with the program's 'consumer directed care' philosophy. The most popular item purchased by volume was a washing machine, closely followed by a television. Compared with data on the types of equipment purchased in 2008, it seems that funds are less likely to be used to purchase typical assistive technologies.[98]

People with disability aged 65 years or older may not have access to the same assistive technologies and supports in the aged care system as they would be entitled to under the National Disability Insurance Scheme. We make a recommendation about that later in this volume.

Another barrier to ageing in place is the state of the home. Hoarding and squalor present safety issues for the older person and any carers entering the home. The aged care system has a role in ensuring the safety of people that will receive aged care, but only limited support is currently made available through the Assistance with Care and Housing sub-program of the Commonwealth Home Support Programme.[99] Ms Fiona York, Housing for the Aged Action Group, expressed concern to us that 'issues like squalor and hoarding are increasing but there are no specialist training and resources provided to address this high need group'.[100]

We recommend the creation of a new category in the aged care program: assistive technologies and home modifications category. Services available under this category should include: goods, equipment and assistive technologies; hearing services; vision services; home modifications; and hoarding and squalor services. Technology is evolving quickly and these services should continue to develop and be innovative. Services should, for example, include deployment and management of sensors and related technologies to enable a 'smart home' environment and the provision of personal devices to facilitate social inclusion, communication with friends and family and diversional therapies.

Where a person is assessed as needing assistive technology and home modifications, they should have access to this in addition to any care at home entitlement conferred on them by their Home Care Package. Older people who reside in a residential care setting will, subject to assessment of need, be entitled to access applicable goods and services in this category, such as vision or hearing services and other assistive technologies, but not home modifications.

Over the next three years, the Australian Government should align this category within the aged care program with the National Disability Insurance Scheme assistive technology guidance.[101] The alignment should provide clarity on policy objectives, service offerings and Australian Government investment in this category. It should also support national guidelines and standards for assistive technology and home modifications. It should drive research into:

- the extent of demand and need for the supports
- the outcomes and cost-effectiveness of the supports
- new technologies
- evidence-based policy analysis and policy alternatives to the current patchwork of supports, including consideration of shared purchasing arrangements between States and Territories and the Australian Government

If available early, assistive technologies and home modifications may reduce the need for more intensive support services in coming years and slow the rates of admission to residential care.[102] We recommend that this category of goods and services be grant funded, for ease of administration and to ensure they are available in all areas.

4.3.4 Care at home

There has been a constant theme in both the direct evidence and the expert and other evidence we have received—people want to remain at home.[103] Recent reports by Flinders University and Ipsos commissioned and published by us also supports this conclusion.[104]

For older people to remain safely in their homes, they must have access to aged care that meets their assessed needs. Care at home should support older people who live at home to preserve and restore capacity for independent and dignified living to the greatest extent and prevent inappropriate admission to long-term residential care.

We recommend a category of care at home. This category would combine the Commonwealth Home Support Programme and the Home Care Packages Program, other than the service types that have been identified in the three other categories recommended above (respite supports, social supports, and assistive technology and home modifications).

Recommendation 35: Care at home category

The System Governor should be in a position to commence payment of subsidies for service provision within a new care at home category by 1 July 2024. This category should be developed and iteratively refined in consultation with the aged care sector and older people. The starting point for this consultation and refinement process should be that this category:

a. **supports older people living at home to preserve and restore capacity for independent and dignified living to the greatest extent and prevents inappropriate admission to long-term residential care**

b. **offers episodic or ongoing care from low needs (for example, one hour of domestic assistance per week) to high needs (for example, multiple hours of personal care and nursing care)**

c. **provides a form of entitlement (such as, for example, a budget) based on assessed needs which allows for a coordinated and integrated range of care and supports across the following domains:**

    i. **care management**

    ii. **living supports, including cleaning, laundry, preparation of meals, shopping for groceries, gardening and home maintenance**

    iii. **personal, clinical, enabling and therapeutic care, including nursing care, allied health care and restorative care interventions**

    iv. **palliative and end-of-life care**

d. requires a lead provider to be chosen by the older person. The lead provider will:

i. be responsible for ensuring that services are delivered to address the assessed needs

ii. monitor the status of people receiving care and adjust the nature and intensity of the care to meet the person's needs

iii. seek a reassessment if an increased need persists beyond three months.

Based on assessed need, an entitlement to care at home would result in the assignment of a personalised budget reflecting the individual's assessed needs or an amount based on a particular casemix classification.

The care at home category in the new aged care system would provide for a coordinated and integrated range of care and supports across the following domains:

- care management
- living supports: cleaning, laundry, preparation of meals, shopping for groceries, gardening and home maintenance
- personal, clinical, enabling and therapeutic care: nursing care, allied health care and restorative care interventions
- palliative and end-of-life care.

As people age, completing day-to-day tasks like cleaning, shopping and laundry can become daunting, difficult or downright impossible. Independent living supports can represent a person's first step in asking for help.[105] Often, this is because living supports are seen as a more socially acceptable form of aged care.[106] The need for help with household chores and property maintenance are, after health care, the main things older people will admit they need.[107] These supports represent an opportunity for care managers to build trust—trust in the aged care services, in the system, and in the provider. That trust means older people feel comfortable to ask for more personal forms of help as and when they need it. Ms Rosemary Milkins PSM, who gave evidence about caring for her mother, said:

> So, if you start small, accepting some form of help that someone offers, it means that this journey you travel can grow naturally. It's like travelling on a pathway; it just opens out more as time goes by.[108]

Personal and clinical care describes the range of services that provide assistance with self-care tasks. These include help to shower, get dressed, use the bathroom, get around and be mobile, prepare and eat meals, and take medicines. These services work in partnership with the older person and their carer to progressively improve, maintain and monitor the person's independence and capacity to live safely at home and participate in community

activities. Assistance is provided in a manner which promotes skills development, capacity-building and independence.[109]

Before settling the details of the administrative and funding arrangements for the care at home category, or finalising the scope of this category, the System Governor should complete its work on the optimal design for the integration of the Commonwealth Home Support Programme and Home Care Package Program.[110] The most recent report of this work provides preliminary support for a model of scalable or 'proportionate' assessment, with classification and funding dependent on a triage or 'screening' process during assessment.[111] Options then would include people being 'classified and funded using only service events', receiving a more complex assessment that would result in classification of the person to a particular level of funding entitlement.[112]

This should include a study to ascertain the need characteristics, service usage patterns and resource requirements of people who access care at home. In light of this study, the System Governor should develop a classification system with distinct classes of need within categories based on clinically meaningful differences in service usage patterns and resource requirements. The study should address whether individualised budgets, casemix funding levels, or some other mechanism for funding, such as direct grants, are appropriate. It should identify whether different funding mechanisms should be used for certain service types or different needs classifications.

In conducting this work, the System Governor should consult with the aged care sector and older people who use the relevant services, and should conduct any trials it deems necessary.

Personal care, alongside living supports, plays a major role in care at home. Many older people who currently access home support and home care get help from these services.[113] Older people value this support and care.

Palliative and end-of-life care should also form part of the care at home category. These types of care should not be restricted to 'end-of-life' or the last days or weeks of life. Palliative care and discussions about dying need to become core business in aged care so that people and their families and carers feel empowered to be active participants in their end-of-life decisions. Continuous community education and awareness are essential to mobilise appropriate use of palliative care and normalise discussions about dying.

Good care at the end of a person's life is coordinated and multidisciplinary. The current level of coordination must be improved. Effective strategies include the use of case conferencing and team discussions. People who are dying often need a well qualified and authoritative health professional to act as an advocate for them to get the care they need.[114]

The level of care delivered in the new care at home category would increase as people's health and personal care needs increase and respond to the level of vulnerability each older person experiences. Professor Deborah Parker, Chair, Ageing Policy Chapter, Australian College of Nursing and Professor of Aged Care (Dementia), University of Technology Sydney, said that in Australia:

> we also have about 23 per cent of people on home care packages, where death is recorded as the discharge reason, have also stayed for less than six months. So I think we just have to be careful around envisaging that people in this care stream are stable, they're long-term stayers, where we have time to be able to put in a plan. They're complex, they're dynamic and so the services need to be wrapped around very quickly for many people.[115]

Perhaps the most important element of the new approach to care at home will be regular review and flexibility in implementation and refinement of service delivery elements, especially the use of allied health services.

Allied health in the home and community

Throughout the course of our inquiry, multiple witnesses described the importance of maintaining mobility and functionality and the crucial role of allied health in achieving this.[116] Maintenance of a person's functionality helps to sustain their independence and quality of life.[117]

Recommendation 36: Care at home to include allied health care

1. From 1 July 2023, the System Governor should ensure care at home includes a level of allied health care appropriate to each person's needs.
2. From 1 July 2024, System Governor should:
    a. ensure that the assessment process for eligibility for care at home identifies any allied health care that an older person needs to restore their physical and mental health to the highest level possible (and maintain it at that level for as long as possible) to maximise their independence and autonomy
    b. ensure that the funding assigned to the older person following the assessment includes an amount to meet any identified need for allied health care, whether episodic or ongoing. This allocation must be spent on allied health care and be consistent with practice guidelines developed by the System Governor
    c. require the older person's lead home care provider to:
        i. be responsible for ensuring that these services are delivered
        ii. monitor the status of people receiving care and adjust the nature and intensity of the care provided to meet their needs
        iii. seek a new aged care assessment if an increased need persists beyond three months
    d. reimburse the provider for the cost of any additional allied health care needed by the older person through an adjusted Home Care Package, without the need for a new aged care assessment, for a period of up to three months, and undertake a new aged care assessment if the need for additional services persists beyond three months.

Many people who receive aged care services do not have sufficient access to allied health services and are missing out on the many benefits that those services can provide.[118] While much of the evidence we heard related to people living in residential aged care, witnesses described similar considerations affecting people receiving aged care services at home.

In 2018–19, only 2% of total Home Care Package funding was spent on allied health.[119] In the same period, those receiving a Level 4 Home Care Package used approximately 1% of their total hours of care a fortnight on allied health services.[120] This low rate of usage amongst people receiving Home Care Packages is concerning. Dr Nicholas Hartland PSM, First Assistant Secretary In Home Aged Care Division, Australian Department of Health, acknowledged that, ideally, more people would access allied health (and nursing) services through their Home Care Package, particularly those at the higher acuity level.[121]

There is a need for a change in culture in the aged care sector, to view allied health services as valuable rather than a burden on funding. Ms Claire Hewat, Chief Executive Officer of Allied Health Professions Australia, told us that:

> systemically, allied health has to be seen as a priority. It has not been. And that is not necessarily a criticism of individual aged care providers or anything like—a lot of it is about the system and the funding system. And I think the most important thing is that the funding system addresses that holistic approach to care, and it starts right at the beginning from that first assessment, whether you're in community or going into a residential aged care facility, that that assessment needs to be comprehensive.[122]

We agree. The aged care system must support the delivery of allied health care in a way that is person-centred and focuses on the whole person, their goals and quality of life.[123] It must focus on wellness, prevention, reablement and rehabilitation and extend beyond physical health to a multidimensional view of wellbeing.[124] It is crucial that allied health services are recognised when conducting an assessment of a person's care needs, and that the person's aged care entitlement adequately reflects that need. Services should be delivered through multidisciplinary teams and collaborative care arrangements, which are flexible and responsive to changing needs, including the ability to reduce and increase services as required.

4.3.5 Residential care

In the future, residential care must meet the full range of older people's physical, emotional, mental and spiritual needs. It must provide care that preserves each person's capacity for dignified living to the greatest extent possible in their circumstances, and enables each older person to have what they consider to be a good death.

Recommendation 37: Residential care category

1. From 1 July 2024, the System Governor should implement a category within the new aged care program for residential care that:
    a. provides older people with:
        i. goods, aids, equipment and services to meet daily living needs
        ii. accommodation
        iii. care and support to preserve and, where possible, restore capacity for meaningful and dignified living in a safe and caring environment
    b. ensures care is available for people who can no longer live at home due to their frailty, vulnerability or behavioural and psychological symptoms of dementia, or other reasons
    c. provides integrated and high quality and safe care based on assessed needs, which allows for personalised care, regular engagement, and a coordinated and integrated range of supports across the following domains:
        i. care management
        ii. social supports, including support for psychological, cultural and (if applicable) spiritual wellbeing
        iii. personal, clinical, enabling, therapeutic care and support, including nursing care and allied health care
        iv. palliative and end-of-life care.

Residential aged care is described by the Australian Government as '24-hour care and accommodation for older people who are unable to continue living independently in their own homes, and need assistance with everyday tasks'.[125] The exact nature of the care and accommodation to be provided is detailed in Schedule 1 to the *Quality of Care Principles 2014* (Cth).[126] That Schedule specifies the care and services that approved providers must provide to any resident who needs them.[127] It is a complex picture, from hotel-like services to clinical and medical care to social supports. Some services a person can be asked to pay for, others depend on the person's classification. In all, the services are meant to be matched to people's care needs.[128]

The residential aged care setting has changed over the years. People now enter residential facilities later in their lives. Consequently, many more are frail or have chronic or complex health conditions.[129] Increasingly, new entrants to residential aged care have neurological conditions that result in such things as disorders of memory, understanding, behaviour, motor and sensory function, mobility and balance.[130]

Associate Professor Edward Strivens, President of the Australian and New Zealand Society for Geriatric Medicine, estimated that about 50% of people living in residential aged care have been diagnosed with dementia, compared with around 10% of the older Australian population.[131] This is consistent with the work of the Australian Institute of Health and Welfare, which reported about 53% of the 183,000 people who were living in residential aged care on 30 June 2019 had a diagnosis of dementia.[132] These very high levels of dementia have implications for the needs of the people entering care and for the providers who are paid to care for them.

Care provided to older people in residential care in the coming years will also need to accommodate more complex, severe and subacute care needs. The proposed new residential care category provides older people with accommodation, goods and services to meet their daily living needs, and care and support to preserve and, where possible, restore capacity for meaningful and dignified living in a safe and caring environment. It should also provide for a good death. Services should be organised around the older person so the person can access the kinds of care and support services they want and need. The older person should be supported to be themselves and, to the fullest extent possible, live the way they wish. The resulting environment should be one that is caring, vibrant and inclusive.

We note that many of the features of care delivery in residential aged care are influenced by funding—and funding aimed at tasks rather than a person's care needs. This is in large part due to the tool used to classify people in residential care: the Aged Care Funding Instrument. As the former Secretary of the Australian Department of Health, Ms Glenys Beauchamp, said:

> The current residential care funding tool, the ACFI [Aged Care Funding Instrument], in broad terms funds care tasks, rather than care needs. This prescriptive therapy regime may influence the types of care delivered by providers and as such, adversely influence their delivery of other innovative and contemporary best practice treatments. The ACFI also does not provide an incentive for restorative care / reablement as provider payments increase or decrease in tandem with a resident's care needs.[133]

Ms Beauchamp also said that these issues would be addressed if the tool were replaced—for example, by the proposed Australian National Aged Care Classification.[134] The former Chair of the Aged Care Financing Authority, Mr Michael Callaghan AM PSM, agreed that a casemix-adjusted funding model such as Australian National Aged Care Classification would be better placed to deal with variables such as provider location and the specific populations they serve.[135]

Our Recommendation 120, in Chapters 17 and 21, says that, by 1 July 2022, the Australian Government should fund approved providers to deliver residential aged care through a casemix classification system, such as the Australian National Aged Care Classification (AN-ACC) model.

Allied health in residential care

The prescriptive nature of the Aged Care Funding Instrument means that allied health practitioners are not funded to deliver interventions that are the most appropriate and evidence-based.[136] A particular complaint about the operation of the Aged Care Funding Instrument is that it is reactive and does not incentivise or support a preventative care approach.[137] Many witnesses referred to the vital role of allied health care in preventing physical and cognitive decline, in addition to providing restorative short-term care in response to acute events.[138]

Recommendation 38: Residential aged care to include allied health care

To ensure residential aged care includes a level of allied health care appropriate to each person's needs, the System Governor should, by no later than 1 July 2024:

a. require providers to have arrangements with allied health professionals to provide services to people receiving care as required by their assessment or care plan — **Commissioner Pagone**

b. require approved providers to: — **Commissioner Briggs**

   i. employ, or otherwise retain, at least one of each of the following allied health professionals: an oral health practitioner, a mental health practitioner, a podiatrist, a physiotherapist, an occupational therapist, a pharmacist, a speech pathologist, a dietitian, an exercise physiologist, and a music or art therapist

   ii. have arrangements with optometrists and audiologists to provide services as required to people receiving care

c. provide funding to approved providers for the engagement of allied health professionals through a blended funding model, including:

   i. a capped base payment per resident designed to cover about half of the costs of establishing ongoing engagement of allied health professionals

   ii. an activity based payment for each item of direct care provided

   with the Pricing Authority determining the quantum of funding for the base payment and the level of activity based payments, including by taking into account the extra costs of providing services in regional, rural and remote areas

d. **ensure that providers provide allied health services to residents in accordance with their individual care plans through the strict monitoring of the level of allied health services that are actually delivered, including the collection and review of data on:**

   i. **the number of full-time equivalent allied health professionals delivering services**

   ii. **the number of current allied health assessments**

   iii. **the volume of service provision, and**

   iv. **expenditure on allied health services.**

During the assessment process, we expect the assessors to work closely with the person entering residential care, their families and nominated representatives to ensure the full range of their needs and preferences are taken into account. This includes any allied health care needs. Because a person's care needs can, and will, change over time, their condition should be reassessed any time there is a change in their circumstances.

Item 3.11 of Schedule 1 of the Quality of Care Principles requires approved providers to make available 'therapy services, such as, recreational, speech therapy, podiatry, occupational, and physiotherapy services' to all who need them, as long as the services are not 'long-term rehabilitation services required following, for example, serious illness or injury, surgery or trauma'.[139]

If a person is not assessed as 'high' under one of the three Aged Care Funding Instrument domains, or 'medium' under two domains, they may be charged for the allied health services provided under Item 3.11 of Schedule 1 of the Quality of Care Principles.[140] It is perverse that people are charged for services that may avoid or delay deterioration in their health, but services are provided for free once they have deteriorated.

People in aged care may fund their own allied health services, but many people cannot afford to do this. The Australian Government must ensure increased and appropriate allied health delivery in the residential care setting. Implementation of the proposed Australian National Aged Care Classification (AN-ACC) funding tool may achieve this and it may also encourage innovative models of residential care.[141]

We both agree that access to allied health is critical to wellbeing, but differ in how we think it is best achieved.

Commissioner Briggs considers that allied health in residential care services should be provided in multidisciplinary teams.[142] She also considers that aged care facilities must employ, or otherwise retain, a broad range of allied health practitioners so that older people actually receive the range of allied health services that we heard in evidence and submissions was necessary. The existing laisse faire arrangements have not worked and few services have been delivered. The allied health professionals engaged should include: a podiatrist; a physiotherapist; an occupational therapist; a pharmacist; an oral health practitioner, such as a dental hygienist, dental therapist or oral health therapist; a mental health practitioner, such as a psychologist, a social worker, or an occupational therapist; a speech pathologist; a dietitian; an exercise physiologist; and a music or art therapist.

Commissioner Pagone considers there should be greater flexibility in relation to the arrangements between age care providers and allied health professionals. In his view, it is important that access to allied health services be maximised by much more flexible arrangements than only employment or retainers.

We both consider that there should be more flexible arrangements for smaller providers, Aboriginal and Torres Strait Islander-specific services and services in regional, rural and remote areas. Other forms of engagement of allied health professionals, such as service provision contracts, may be appropriate in these instances. This is provided the goals of multidisciplinary care, associated case coordination, and care planning are in place, and that regular contact occurs with residents, staff members and family. The use of telehealth and an increased role for allied health assistants may also assist.

It is well established why some of these allied health professionals should be engaged by residential care providers. Poor foot care can reduce mobility, which in turn can cause falls and pressure injuries. Wound and pressure injuries on feet can lead to ulcerations and amputation. Podiatry services in aged care focus on ‘alleviating foot pain to enhance quality of life, wound and pressure injury management to decrease the risk of complications such as ulceration and amputations, and footwear assessment / recommendation / fitting to assist with falls prevention pressure injuries’.[143] Malnutrition rates in residential aged care are estimated to be 22–50% and dietitians can prevent and manage malnutrition.[144] Physiotherapy, occupational therapy and exercise physiologists can increase physical capacity and mobility, which in turn reduces falls and injuries.[145] Speech pathologists can assist with swallowing, eating, drinking and communication problems.[146]

In the approach recommended by Commissioner Briggs, multidisciplinary teams should also include non-dispensing pharmacists, mental health practitioners and oral health practitioners. We both agree about the importance for there to be access to these allied health professionals. People in residential care take a median of 11 different medicines.[147] Problems with medication use and management are common in residential care.[148] Pharmacists embedded in residential care services can improve the use of medicines. There are high rates of mental health conditions in residential care, particularly depression, anxiety, adjustment disorders and suicide ideation.[149] It is clear there needs to be consistent and ongoing support for people with mental health conditions in residential care. Older people in residential care also have poor oral health. This can be improved with regular assessments, timely referrals and preventative dental and oral health services delivered in the residential service.

Funding of allied health in residential care

Commissioner Pagone considers that the funding for allied health is best achieved as part of casemix finding, which is considered in his funding chapter.

Commissioner Briggs listened to the evidence of providers and allied health workers about ways to fund allied health in residential care. She found that a blended funding model is the best way to fund allied health in residential aged care. This is a combination of a capped base payment and an activity based payment. The capped base payment should be a set amount per resident and designed to cover the cost of establishing the ongoing engagement of allied health professionals as well as the costs of activities that are not easily captured by activity based funding. It would better support the ancillary benefits of having these professionals as part of the service, including increasing the capacity of other staff members in the facility, encouraging collaborations and case management between professionals, developing care plans, taking a holistic view of older people's health, and working with families and carers. The activity based funding would be for direct service provision to the resident. Activity based funding increases service provision, something sorely lacking when it comes to allied health in residential aged care.

The new Pricing Authority should establish funding levels for both base and activity funding. There should be strict accountability measures for the use of this allied health funding. These accountability measures should be established by the Australian Government, in consultation with allied health professionals and aged care providers. They could include the use of clinical indicators and outcome measures to review progress and report the effects of allied health interventions.[150]

Some witnesses expressed concerns about directly funding residential care providers because of the providers' current approach to minimising service provision.[151] Current funding arrangements do not have a separate funding stream for allied health, other than the increment to the Aged Care Funding Instrument—which is contingent on delivering particular kinds of 'pain management'. There has not been any consistent or sustained monitoring of compliance. In a constrained funding environment, services which are not monitored are likely the first to be cut by providers. A separate stream of funding, with an element of activity based funding, and careful compliance monitoring, will minimise the risk of providers underservicing residents.

The presence of multidisciplinary allied health teams will also assist to lift the general standards of care because their professional obligations are to provide patient care and they can act as advocates for residents and provide a professional community of practice. Most importantly, these teams will help to shift the focus of aged care to wellbeing and reablement.

4.4 Challenges of transition and implementation

In 2018–19, 840,984 people received Commonwealth Home Support Programme services, compared to 106,707 people who accessed a Home Care Package as at 30 June 2019.[152] These figures illustrate to us the magnitude of the task of integrating the Commonwealth Home Support Programme and Home Care Package programs into a single suite of service arrangements.

Integration of these programs will involve migrating a large number of people to arrangements for assessment, funding and service delivery that are likely to be administratively more complex than the current arrangements that apply under the Commonwealth Home Support Programme.

Before the removal of population-based caps on the availability of subsidies, it will be necessary to ensure that there is a sufficient supply of medical and health practitioners, personal care and other aged care workers with relevant skills and qualifications. It will also be necessary to ensure that the capabilities are in place to ensure that high standards of quality and safety are met. These considerations necessitate a cautious, phased and flexible approach to implementation by an administrative unit which should commence implementation of the recommendations, and then (if established) by the System Governor, closely monitored by the Inspector-General of Aged Care.

4.4.1 Interim measures to clear the home care waiting list

In the Interim Report, Commissioners Tracey and Briggs described at length the effect on people of the lengthy waiting list for Home Care Packages.[153] The effect of the lengthy wait is profound—there is a clear danger of declining function, inappropriate hospitalisation, carer burnout, premature admission to a residential facility or even death. The waiting list must be addressed urgently.

Recommendation 39: Meeting preferences to age in place

The Australian Government should clear the Home Care Package waiting list, otherwise known as the National Prioritisation System, by:

a. immediately increasing the Home Care Packages available and allocating a package to all people on the waiting list that do not yet have a package or do not yet have a package at the level they have been approved for (as set out in their letter from the Aged Care Assessment Team / Service). The package allocated should be at the level the person was approved for (Level 1, 2, 3 or 4). This must be completed by 31 December 2021

b. keeping the waiting list clear by allocating a Home Care Package at the approved level to any new entrants to the waiting list within one month of the date of their assessment. This must occur between 1 January 2022 and 1 July 2024

c. publicly reporting, each quarter, the status of the waiting list, showing progress in clearing the waiting list as set out in paragraphs a. and b. above, at a national, State or Territory, and regional level. This report should include reasons for delay in clearing the waiting list and actions being taken to address the delay. This must occur every quarter from 31 March 2021 to 1 July 2024

d. pending the establishment of the care finder workforce, the Government should immediately establish a short-term program to link people allocated a Home Care Package with appropriate providers and to encourage the expansion of the home care sector. The 50-day requirement to accept a Home Care Package should be increased to 150 days.

The Australian Government currently funds aged care subject to financial controls based on rationing of aged care residential places and Home Care Packages to a fixed proportion of the population. This creates waiting lists and means people miss out on care they need. This must change because older people needing care do not have the luxury of time to wait for care to be delivered. In the 12 months to June 2018, 16,076 people died while waiting for a Home Care Package.[154]

Wait times for the assignment of Home Care Packages have been unacceptably long for several years. By 2018, the mean wait time was up to 22 months for a Level 4 Home Care Package.[155] Commissioners Tracey and Briggs provided an estimate of waiting times for people entering the Home Care Package Program by package level in 2019 in the Interim Report.[156] According to the most recent estimate of wait times published by the Australian Government, the estimated waiting time for people entering the Home Care Package Program at any level has not improved over the 12-month period from 30 June 2019 to 30 June 2020.

Recently, the Australian Government announced the release of additional Home Care Packages: $1.6 billion over four years from 2020–21 for the release of an additional 23,000 Home Care Packages across all package levels.[157] From November 2020, this provides for: 5000 Level 1 Home Care Packages; 8000 Level 2 Home Care Packages; 8000 Level 3 Home Care Packages and 2000 Level 4 Home Care Packages.[158]

However, Australian Government announcements in relation to additional Home Care Packages have not kept pace with the demand reflected in the national waiting list.[159]

As at 30 June 2020, the number of people waiting to access a Home Care Package at their approved level was 102,081. Of those people waiting, 40,744 had been offered an interim Home Care Package at a lower level while they wait for a package at their approved level and there were 61,337 people waiting without a package of any kind.[160]

We have heard about the practise of assigning an 'interim'-level Home Care Package while the person who has been assessed as needing care waits for a package at their approved level.[161] Ms Raelene Ellis said that despite being assessed as needing a Level 4 package, her mother had to wait just over 14 months to receive it. During those 14 months, her mother's health deteriorated dramatically, and they 'still only received 4 hours of support a week'.[162]

We consider that a person who receives an entitlement to aged care should receive that entitlement within one month of their assessment. We have heard time and again of the distress caused to older people and their families by waiting to access aged care services. This must stop. The Australian Government must publicly report on their progress to clear the waiting list by the end of 2021, including providing detailed information in relation to any delay in achieving this measure.

4.4.2 Transition to care at home

An important element of the new program design is that it should transition as quickly as practicable to a point where the availability of subsidies is no longer subject to population-based rationing, and where all older people who are assessed as needing aged care receive it, funded to the level required to provide high quality and safe care as assessed.

Commissioner Pagone is concerned that the transition to care at home does not become an unintended mechanism for the Australian Government to reduce its expenditure on the care needed by older people. Care at home is to be provided for the genuine improvement of care to older people, rather than because it might involve less expenditure. As a practical measure, it will be necessary for the Government to expedite the work of the Aged Care Workforce Planning Division outlined in the workforce chapter of this volume, in tandem with the increase of supply of Home Care Packages. The key challenge lies in the careful transition of present arrangements for aged care in the community and the home. These considerations necessitate a cautious, phased and flexible approach to implementation.

Recommendation 40: Transition to care at home

1. The Australian Government should commence the transition to the care at home category by ensuring:
    a. from 1 July 2022, any older person that is accessing the Home Care Packages Program can also access supports from the new respite or social support grant categories. These supports should be in addition to the Home Care Package and not be paid for from Home Care Package funds. This should also apply to the assistive technology and home modifications category, but a short assessment should be undertaken to determine the needs of older people for this category
    b. from 1 December 2023, all older people who are assessed for aged care in their home, should be assessed for a Home Care Package level as well as the equivalent classification in the new care at home category
    c. between 1 July 2024 and 1 July 2025, any older people who are still accessing the Home Care Packages Program (and do not yet have a care at home classification) should be assessed for a care at home classification, so long as the classification does not disadvantage the person (for example, it does not offer lower funding than they had been receiving under the Home Care Packages Program).
2. To support this transition, the Australian Government should increase the assessment workforce between 1 July 2023 and 1 July 2025.

Consistent with Recommendation 39, by the end of 2021, the current waiting list for Home Care Packages should be cleared. This will result in a further 102,000 older people receiving packages, including about 41,000 moving from an interim package to a package at a level that matches their assessed need.[163] Then, by 1 July 2024, the maximum value of a new care at home bundle will be increased. People assessed as needing care should all be receiving that care to the determined level.

To manage carefully the transition to a larger number of people receiving care at home, and receiving care at home for higher care needs, the Australian Government must take a stepwise approach.

The first step is that older people using Home Care Packages should have access to the new categories of social support, respite and assistive technologies and home modifications. Once these new grant categories are in place, from 1 July 2022, older people accessing Home Care Packages should automatically be approved to access these services in addition to their package. That access should not require reassessment and it should not mean providers of the grant categories can charge from the package. It will be over and above the package. This recognises the importance of using the package funding for care needs and not having to make choices between important care and social or respite supports.

Access to assistive technology and home modifications, however, does require reassessment. This should be a short assessment, focused on restorative and reabling outcomes for the older person. Again, any supports accessed should be in addition to the package and not be charged to the package funds.

As the comprehensive assessment tool for the new care at home category is developed, and in the lead up to implementation on 1 July 2024, the Australian Government should commence using the tool in tandem with the existing assessment tool. From at least 1 December 2023, the new tool should be used for all people seeking a new aged care assessment, alongside the existing tool. The results from both assessments should show the Home Care Package level and the equivalent classification for care at home. This means that during the transition older people will be assessed under both the old system and the new system: a dual assessment. As the new system takes effect, older people can access care at home to their assessed level.

In the first year of operation of the new aged care program, all people with a Home Care Package at that point who have not received a dual assessment should be reassessed with the new assessment tool. This will mean that during 2024–25, approximately 80,000 people with a package will need reassessment.[164] This estimate is based on the median length of time on a package being three years.[165] It is also based on dual assessment being undertaken prior to the new assessment process taking effect.

If the reassessment of older people results in higher needs and higher associated funding, they should be supported to transfer to these arrangements. If a reassessment results in lower assessed needs and lower associated funding, the older person should continue to receive their current Home Care Package so that they are not disadvantaged by the transfer.

To manage the dual assessment process and the reassessment of older people receiving Home Care Packages, the Australian Government should fund an increase in the assessment workforce for a two-year period. This includes the new care finders which will form a significant and important part of that assessment workforce.

Upon implementation of these transition steps, the Australian Government should be in a position to minimise disruption whilst transforming the aged care program.

4.5 Removal of population-based restrictions on subsidies

Older people should have a universal entitlement to high quality and safe aged care in accordance with their need.

Currently, there are population-based limits on the availability of subsidies, based upon the quotas imposed in the Aged Care Provision Ratio. The new aged care program must be based on assessed need and not rationed. We recommend that the Aged Care Provision Ratio as a tool for limiting and apportioning subsidies be removed.

Recommendation 41: Planning based on need, not rationed

By 1 July 2024, the System Governor should replace the Aged Care Provision Ratio with a new planning regime which:

a. **supports a funding allocation that is sufficient to meet people's entitlements for their assessed need**

b. **provides for demand-driven access to aged care based on assessed need**

c. **funds cost-effective enabling care in the interests of people who need such care**

d. **collects data to monitor outputs and outcomes, and**

e. **aligns planning boundaries for Aged Care Planning Regions with boundaries based on Primary Health Network regions so that aged care planning is aligned with primary health care and hospital planning.**

Funding should be based on the costs of providing high quality and safe care on the basis of assessed need and should not be influenced by the Australian Government's fiscal policies, or be limited to past spending levels. An important element in achieving this goal is for an independent pricing process to determine the levels of funding for particular service types and bundles of services.

4.5.1 New planning measures

We are not confident that capacity currently exists to supply all the services that should be funded under a needs-based system. It will be necessary for supply-side capacity to be assessed and, where necessary, grown, so that aged care services are available when and where they are needed, once subsidy quotas are relaxed. This necessitates detailed planning.

We recommend that the Australian Government should develop and implement a new planning regime, by 1 July 2024, to replace the current Aged Care Provision Ratio. The System Governor should replace the current planning arrangements with planning undertaken at the local level. In doing so, the System Governor should ensure:

- an adequate coverage of services to meet the population needs for major city, rural, regional and remote Australia
- an adequately diverse mix and adequate number of providers to enable older people seeking services to exercise an informed choice, where possible, between available providers
- the capacity and capability of new and existing providers to deliver more aged care services
- the continuity of service for older people.

In Chapter 2, we recommend that the System Governor provide proactive system governance of the new aged care system. This will involve adopting a planning approach that reliably estimates and tracks demand, takes action to develop supply to meet that demand and undertakes planning and allocation on a local basis.

Measuring unmet demand

The National Prioritisation System has provided an insight into unmet demand for Home Care Packages at the national level, by aggregating information about all people who are currently waiting for an assignment of a package at the level which they have been assessed as needing. It is clear that many older people are waiting months or even years to access their package.[166] Revising this rationed system and correcting the assessment process will be the first steps required to clear the waiting list and gain a better understanding of the demand to age at home.

There is no equivalent estimate of demand for the Commonwealth Home Support Programme. However, there is at least some evidence of unmet demand in home support. Providers report needing to turn people away, particularly for respite and transport supports.[167]

Mr David Hallinan, Australian Department of Health, suggested that, ideally, aged care planning should take account of what services are available and what the needs of the population are and will be in the future.[168] He said that the Australian and State and Territory Governments should share data about the different types of services across Australia and potentially establish service level benchmarks or standards for particular areas.[169] We agree.

The move to a needs based system—sometimes called a demand-driven system—requires the System Governor to have a clear understanding of what demand will be. One study found that some 80% of Australians used an aged care program at some stage before their death.[170] Assessing the demand for aged care must be a key priority.

The assessment process will determine a person's needs and their eligibility for aged care services. The assessment workforce, supported by the assessment framework and tools available to them, are therefore critical to implementing the new aged care program's demand-driven approach. They are the gatekeepers for the program. A structure of developing useful metrics for measuring care needs will only benefit the aged care system long-term. This must start with an appropriately designed assessment tool.[171]

For example, one existing indicator of unmet demand, or unmet need, is the number of hospital patient days used by people who are eligible and waiting for residential aged care. The Productivity Commission has cautioned against undue reliance on this data. Nonetheless, its *Report on Government Services 2020* explains that the number of hospital patient days can be an indirect measure of unmet demand in residential aged care because hospitals are 'geared towards shorter periods of acute care' and the needs of older people for 'maintenance care can be better met in residential aged care services than hospitals'.[172] In 2017–18, major cities and inner regional areas experienced 7.1 and 7.8 hospital patient days per 1000 patients respectively. In contrast, outer regional, remote,

and very remote areas had much higher rates ranging from 24 to 39 hospital patient days per 1000 patients.[173] While hospital patient days are not a perfect measure, this stark contrast between major cities and inner regional locations, on the one hand, and outer regional and remote areas locations, on the other, gives some indication that demand for residential aged care is not being properly met in remote areas of Australia. Together with more data and metrics such as this, we can paint a clearer picture of what and where care is needed in Australia.

Supply to meet the demand

While monitoring demand is critical, delivering a demand-driven program means that aged care services need to be available for older people when and where they need them. There will need to be capacity to supply services of the kind needed, at the scale needed, in the places where they are needed. Through the transition to a needs-based and demand-driven program, the System Governor will need to develop a basis for predicting and monitoring supply-side capacity.

Commissioner Pagone does not think it would be prudent to convert the program to a needs-based and demand-driven program until there is a reasonable basis for prediction that sufficient supply side capacity either exists or is developing and will shortly be available to provide the services in question. Commissioner Briggs disagrees. She notes that the Australian Government has been very slow to reduce the home care waiting list despite the attention it received in the Interim Report. She believes that any issues with the availability of services require urgent attention by the Australian Department of Health and Aged Care to ensure that they do not delay access to care for older people. She considers that the System Governor should provide strong, active management of the system to ensure capacity either exists or is developing and will shortly be available to provide the services in question.

Over recent years, there have been challenges associated with establishing new programs or implementing changes to existing programs that involve large amounts of funding.[174] It will be vital that the System Governor adequately plan for, and guard against, these types of issues arising in the transition to the new aged care program. We discuss the role that leadership, provider governance, and capability play in the quality of care older people receive in various parts of this report. These will be particularly critical factors in managing the transition.

The Australian Government has been described as the head of the 'supply chain' in the aged care program.[175] We consider that it has a responsibility to develop or stimulate supply of services. It will be inadequate, in our view, for the Government to rely on a market response to the availability of subsidies, even once the Aged Care Provision Ratio has been relaxed. In our view, the future System Governor should continuously monitor where unmet demand occurs or is likely to occur, evaluate whether supply in an area is developing that can meet that demand, and assess whether augmentation of providers and the local workforce is needed. All this information should be released publicly. Doing so should help stimulate a quick market response to ensure delivery of the necessary additional services.

Consistent data releases could help providers understand what products and services need to be supplied and where they need to be supplied, and to make business decisions about where to offer aged care. In 2020, the Australian Department of Social Services released an analytic tool that provides up-to-date forecasts of the National Disability Insurance Scheme service demand for each postcode across Australia.[176] The demand map assists National Disability Insurance Scheme providers to make decisions on where to grow their business. It also provides useful information to National Disability Insurance Scheme clients on expected spending and the types of supports available in their local areas. The National Disability Insurance Agency also releases quarterly 'Market Position Statements' that share information about the emerging marketplace so providers understand areas of expected demand growth and the characteristics of markets around Australia.[177] Aged care would benefit greatly from a system that provides similar information to this at both the demand (older people) and supply (approved provider) levels of care.

Local system management

Shifting from a rationed system to a needs-based and demand-driven system will involve a shift from a centralised top-down to a localised bottom-up approach to system management. There will remain a role for centralised coordination through the provision of standard data, tools and information, and consistent assessment of needs. However, ascertaining unmet need and evaluation and stimulation of supply-side capacity must be undertaken at the regional and local level. This allows for comprehensive needs assessments and profiles, providing a granularity that is not possible in a broad centralised approach. The planning process needs to involve local consultation with the community, the aged care sector and other stakeholder groups to provide a qualitative element and ensure that pictures of demand and supply are truly reflective of local need.

To ensure consistency in planning across the systems relevant to aged care, we also recommend a shift in the planning region used. The aged care planning regions are only used in one realm: aged care. Primary Health Network regions, however, are used in the primary care system, and directly map to local hospital networks. The Carer Gateway service areas also align with Primary Health Network regions. Aligning regions supports integration across aged care, health and social services. We recommend that, to build a better and more consistent picture of aged care and its interacting systems, the aged care sector should adopt boundaries based on Primary Health Network regions.

4.6 Existing service arrangements to remain

Over recent years there has been a move towards integrated care models in a variety of health and human service settings.

The report we commissioned from the National Ageing Research Institute states that integrated care 'refers to strategies aimed at overcoming fragmentation between different services and sectors as a way of improving the health and wellbeing of clients, client satisfaction with services, and the efficiency and long-term sustainability of health and aged care systems'.[178] Integrated care can include the integration of care across systems, such as aged care, health care, social care, community services and accommodation options. It requires care providers to centre their care around a person's needs, and deliver that care in a cohesive, comprehensive, and empowering way.[179]

The Productivity Commission's *Shifting the Dial* review found that integrated care can lead to 'gains in health outcomes for patients, improvements in the patient experience of care, reductions in costs, and improved job satisfaction for clinicians'. However, it said, due to 'funding, governance, linkages and attitudes' in the health system, a more coordinated approach in Australia has been 'elusive'.[180]

There are currently two programs in the aged care system that integrate care across the aged and health care system. They are centred on a person's needs. We recommend that they continue to operate as separate programs. They are:

- Multi-Purpose Services, which provide integrated health and aged care services to communities in areas that cannot support both a separate residential aged care facility and a hospital. They are jointly funded by the Australian Government and the States and Territories in rural and remote areas. The program enables flexible use of funding, infrastructure and service delivery to improve access to a mix of health and aged care services that meet community needs and improve quality of care.[181]
- Transition Care, which provides short-term care seeking to optimise the functioning and independence of older people after a hospital stay. The program is jointly funded by the Australian Government and the State and Territory Governments. It is goal-oriented, time-limited and therapy-focused, and provides a package of allied health, nursing and personal care services.[182]

These programs have evolved over many years in response to structural and/or demographic requirements. They demonstrate the Australian Government and the States and Territories working well together.

We also recommend that the Australian Department of Veterans' Affairs dedicated entry-level community care programs should continue. Under the current arrangements, veterans can access aged care services where eligible, providing there is no duplication of services.

In addition, services for Aboriginal and Torres Strait Islander people currently provided through the National Aboriginal and Torres Strait Islander Flexible Aged Care Program, widely known as NATSIFACP, should continue to be available for an extended period. We outline our reasons for this approach in Chapter 7: Aged Care for Aboriginal and Torres Strait Islander People.

4.7 Conclusion

The Australian aged care system has been the subject of numerous major inquiries and reviews over the last two decades. These reviews and inquiries have pointed to recurring issues within the current aged care programs, including:

- the difficulty people have in understanding and navigating the aged care system
- 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
- weaknesses in the delivery of services aimed at maintaining healthy functioning, such as physiotherapy, nutrition advice, speech pathology, oral health services and podiatry
- the need for additional support for people with particular needs, including those with dementia, those at the end of their life, those with mental illness, people with disability and those experiencing homelessness.

These same issues have arisen in this inquiry. There is clear consensus that things need to change.

There should be one aged care program, with one set of eligibility criteria, one assessment process and one entitlement to the supports and care that meet people's needs.

The recommendations we have made for this integrated aged care program design match the key areas in aged care that can make a difference to people's lives. They will deliver a greater continuum of support and care to older people and give them more control over that support.

Our recommendations for a new aged care program will require a strong and active System Governor. The System Governor must guide all components and people within the system to achieve transformation of the aged care program, while listening and iterating so that the transformation is fit for purpose and place both now and into the future.

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5. Informal Carers and Volunteers

5.1 Informal carers

Family, friends and community are a crucial part of the aged care system. They are integral to the wellbeing of older people, and are essential to efforts to try to ensure that older people receive high quality and safe care. They nurture, they support, they care, they advocate and they speak up when something is not right. They are the unsung heros.

Many older people want to stay in their own homes for as long as possible. They want to have care and support in their own homes, not in a residential aged care setting. Many family members and friends undertake significant carer-related responsibilities to make that possible. The future aged care program should ensure that the family members and friends who provide this care to older people are supported to look after their own health and wellbeing. It should offer training, skills and knowledge development, counselling and other support.

Not everyone who provides care will identify themselves as a carer. For many people, caring responsibilities are a natural continuation of a pre-existing relationship. We call family members and friends who provide care 'informal carers' to draw a distinction between them and people who are employed or engaged to provide aged care services. A primary informal carer is the person who provides the most informal assistance to a person needing care and support.

The value of informal carers to the sustainability of the aged care system is difficult to overstate, but their work is largely invisible. From the number of informal carers, the economic value they contribute and the important care and support they provide, there is no doubt the aged care system depends on the contribution of informal carers.

In economic terms, the contribution of those people providing unpaid care in Australia is enormous. The replacement value of unpaid care across the total carer population in 2020 has been estimated to be nearly $80 billion.[1]

In 2018, there were 2.65 million carers in Australia. Of these, 428,500 primary carers provided care to someone aged 65 years or older.[2] Seven out of 10 primary carers were women.[3] A 2013 report estimated that between 25% and 35% of informal carers were from culturally and linguistically diverse backgrounds.[4]

The Australian Government pays the carer payment and carer allowance to informal carers who spend a considerable amount of time providing informal care. The Australian Department of Social Services reports that 270,694 people aged over 65 years received assistance from people in receipt of the carer payment in June 2020. They account for about 40% of the total number of people who receive informal care from a person in receipt of the carer payment.[5] It is estimated that in 2018–19, the Australian Government spent around $3.4 billion on carer payments, carer allowances and carer supplements for informal carers of people receiving care aged 65 years and over.[6]

The Australian Government also supports informal carers through information, referral services and the provision of respite care. In 2018–19, the Australian Government spent $383 million on respite in aged care homes—respite subsidy and supplement—and $267.9 million on respite in the Commonwealth Home Support Programme. Some 65,523 older people and their informal carers were assisted with residential respite.[7]

In 2018, the three most common reasons primary carers gave for taking on a caring role were:

- a sense of family responsibility (70.1%, up from 66.9% in 2015)
- emotional obligation (46.6%, up from 44.2% in 2015)
- an ability to provide better care than anyone else (46.4%, down from 50.3% in 2015).

Among those who were primary carers to someone aged 65 years or over, 35.1% said that no other friends or family were available to provide care. A total of 28.8% of primary carers of people aged under 65 years cited this as a reason.[8]

Older people receive informal care from a number of sources: 46.7% receive informal care from a partner, 29.6% from a daughter, 23.7 % from a son, 14.3% from a more distant female relative or friend, and 17.8% from a more distant male relative or friend.[9]

Being an informal carer for an ageing family member or friend can bring great personal rewards and satisfaction.[10] It is often a choice many people make willingly.[11] Ms Nicole Dunn, an informal carer for her grandmother, said that:

> There were a lot of benefits that I got. It really brought my grandmother and I closer together in terms of our relationship, just the silly little things you do day to day that you get to see and you get to experience in caring for someone, and that's, you know, something I look back and I treasure. I'm really proud of being a carer for her, and it's given me a different outlook on life so I really appreciate the little things in life and I'm, you know, very lucky that—that at my age I can really realise what's truly important and it's not the materialistic things, it's the time that you have with people.[12]

Ms Rosemary Milkins PSM, who cared for her mother, told us:

> it is a great privilege to care for people and I think in our society today we diminish that. We care for our children and we see that as a marvellous thing to do. I don't see why it can't be like that for old people…[13]

However, the caring role is so constant, and so physically and mentally demanding, that it can often lead to detrimental effects on the health, wellbeing and financial security of the informal carer.

The caring role taken on by informal carers frequently impacts on their employment and working lives.[14] Many informal carers need to make changes to their working arrangements, including reducing hours of paid employment or levels of responsibility and taking time off work to care. The financial position and career development of informal carers can be compromised.[15] Commissioner Briggs notes that some informal carers need to delay retirement in order to make up for lost earnings. Informal carers' other relationships, particularly their family responsibilities and their wider social circle, also suffer. Their emotional needs can remain unfulfilled.

These long-term consequences have a disproportionate impact on women because of the greater number of women taking on this role. Women often take time out of the labour market to care for children and again, later in life, to care for older parents. Ms Catherine Thomson, Research Fellow at the Social Policy Research Centre at University of New South Wales, described women of this age as 'the sandwich generation'.[16]

It is clear to us that the caring role can have a profound impact on the lives of informal carers. Recognising the importance of informal carers to the people they care for and in the aged care system more broadly, the Australian Government should ensure there is proper support for informal carers. The current aged care system fails to do this. It tends to provide reactive, inadequate and piecemeal support to informal carers. Often, it does not provide even these supports until the strain on a caring relationship has already reached crisis point. [17]

Recommendation 42: Support for informal carers

The Australian Government should improve services and support for informal carers by:

- **a. linking My Aged Care and the Carer Gateway by 1 July 2022, so that informal carers need only use one system to secure respite care and the full range of information, training and support services available on both sites**
- **b. on and from 1 July 2022:**
  - **i. enabling direct referral and information sharing for informal carers between My Aged Care, care finders, assessment services and the Carer Gateway**
  - **ii. providing accurate and up-to-date information on My Aged Care about the range of supports locally available to informal carers, including training, education, counselling, respite, income support, and, access to the Carers Hub network (once established)**

c. on and from 1 July 2023:

   i. requiring My Aged Care, care finders and assessment services to identify the primary informal carer when assessing a person for aged care

   ii. enabling care finders to refer the primary informal carer to assessment services for assessment for, and access to, formal respite care and other supports available

   iii. establishing and funding a community-based Carers Hub network.

5.1.1 Informal carers do not feel supported

There is evidence that informal carers do not feel supported.[18] Mr Don Laity from the Mildura Carers Hub, who has cared for his mother, mother-in-law and father-in-law, said that 'isolation is part of the deal' and that 'stress has a huge emotional cost to the carer. It builds up and very quietly drags the carer down'.[19] Ms Rosemary Cameron described not knowing what path to take in the aftermath of her husband Don's diagnosis of Lewy body dementia. She said that:

> there was no referrals, there was no pamphlets, there wasn't anything to help me to know. You're out the front door....But there was really nothing to know where to head. I had no idea what to do from there.[20]

Ms Cameron simply took her husband home and did her best to care for him as his disease progressed.

Ms Dunn described her priorities in this way: 'I didn't consider my own life choices. So it meant that if my social life was to be impacted, so be it. If work was impacted, so be it. Even if my own health was impacted, so be it.'[21]

Mr George Akl described the lasting impact of caring for his father, who had Lewy body dementia:

> I have no regrets about the time spent with my father, but it did take a significant toll on my life. It was traumatic to experience his decline so intimately and the time pressures set me back significantly, socially and economically. It was like falling down stairs—once you take the first step you can't walk away from it. I am still recovering from the trauma of the isolation and stress.[22]

According to Ms Thompson, people often seek support at a time of crisis. She said it is often that 'as a result of some sort of crisis and them not being able to manage, and being quite desperate and then going on the internet and trying to find help that way'.[23]

Ms Elaine Gregory said that when she took on a caring role for her mother, the assessment team provided no information to her and did not refer her to any other agencies. She said, 'there's sort of no support out there at that stage…it would have helped me a lot to know which way to go'.[24] Ms Holt explained that she did not seek any support:

> because I thought the support you got was the time that Mum was away at day care, or when you got the two hours a week, that that was your support, and that was all directed at Mum's needs that…None of it was actually saying, we could give you this, or you could have this service.[25]

The system should be working the other way. Early investment in, and support for, informal carers helps to maintain the capacity of carers to support older people. Informal carers may help prevent decline in older people, which may delay or avoid older people's entry into the formal aged care system—saving government costs. More fundamentally, early intervention should provide support to those who need it, when it is needed and ideally before a crisis develops.

5.1.2 My Aged Care and Carer Gateway

Informal carers described the difficulties they faced when attempting to access information about support services.[26] In December 2015, the Australian Department of Social Services launched the Carer Gateway, which now comprises a national telephone service, website and an interactive service finder.[27] Its purpose is to 'provide a recognisable source of clear, consistent and reliable information to help carers navigate the system of support and services'.[28] The Carer Gateway provides information, resources and practical advice, including on local supports such as respite, how carers can look after themselves, financial and legal considerations, and what to do in a crisis.[29]

The Carer Gateway was the first stage in the implementation of the Integrated Carer Support Service. The second stage was to work with the aged care sector to co-design a new integrated system of carer-specific supports and services that would be better positioned to support Australia's carers into the future.[30] This work is complete and an Australia-wide network of service providers is being established to provide career support planning, tailored financial packages, in-person counselling, in-person peer support, in-person coaching, and emergency respite care.[31] The objective of this integrated service is to 'improve carer wellbeing, increase their capacity and support their participation, socially and economically'.[32]

With a few exceptions, the alignment of the existing carer support services under the Integrated Carer Support Service, coupled with the introduction of Carer Gateway, was intended to provide a single pathway and nationally identifiable place for all informal carers to go to for information, support and service in their own right.[33]

The principal public source of information about the aged care system is the Australian Department of Health's My Aged Care service. However, there is no interoperability between My Aged Care and the Carer Gateway. This means that data and information cannot be shared. Carers are left to match availability of respite via My Aged Care with the availability of carer support services and training via the Carer Gateway.[34] This can be a barrier to accessing necessary supports.

Dr Lyn Phillipson, a social researcher at the University of Wollongong with a focus on the health and social wellbeing of vulnerable community members, said that the separation of the Carer Gateway from My Aged Care entrenches a division of programs that fails to recognise the interdependency of the needs of the informal carer with the older person they support.[35] Dr Phillipson put it succinctly: 'the needs of one can't be seen without… looking through the lens of the other as well'.[36] Commissioner Briggs is concerned by Dr Phillipson's evidence that both the Carer Gateway and My Aged Care:

> rely on having easy access to online information or via a phone helpline. Neither have physical shopfronts or supports for people to assist with navigation—this is despite the known preference of older people for personal sources for their information.[37]

An example of the practical problems this separation causes is when informal carers are left trying to access support services such as counselling or education. To access those supports, the informal carer often must leave the house of the person receiving care. They need to use the Carer Gateway to arrange their own support and they also have to use My Aged Care to arrange corresponding respite care for the person they are caring for. This can be a barrier to informal carers accessing necessary supports.[38] The requirement to access supports from online systems or telephone helplines can also be a barrier.[39]

We recommend the linking of My Aged Care and the Carer Gateway so that a primary informal carer need only work with one system to secure respite care for themselves and the person for whom they provide care, as well as to access information, training, counselling and other support services to help them fulfil their caring role.

We also recommend that My Aged Care have accurate and up-to-date information on the range of supports locally available for informal carers, including training, education, counselling, income support and access to the Carers Hub network, once it has been established.

Single assessments

Informal carers are required to undertake separate intake and assessment processes if they are seeking supports for themselves as well as for the person they care for. Informal carers described the administrative burden of having to provide the same information to a number of different services and government agencies. Commissioner Briggs is concerned that people like Ms Barbara McPhee AM, an informal carer for her mother, are 'often handed from one department to another to another having spent maybe three-quarters of an hour on the phone only to find that nobody could help us anyway'.[40]

Ms Dorothy Holt described the aged care assessment process as having 'very little interest' in what it was like for her to look after her mother.[41] Ms Danijela Hlis, who cared for her brother-in-law and her mother, suggested that informal carer needs should be considered more comprehensively during aged care assessments.[42] We agree and have made Recommendation 28 to that effect in Chapter 4.

We consider that any assessment of an informal carer's needs must include supports that reflect the specific needs of Aboriginal and Torres Strait Islander people and of culturally and linguistically diverse communities.[43]

Respite

Respite or respite care for informal carers is when someone else temporarily takes care of the person the informal carer usually cares for. The primary purpose of respite is to give an informal carer or the person receiving care a short-term break from the usual care arrangement.[44]

High quality respite is an important and highly valued support service for informal carers.[45] There has been compelling evidence that as a result of poor quality, inflexible and inappropriate respite, informal carers felt significant stress and that this could be detrimental to the health of the person receiving care.[46]

Respite is meant to be an opportunity for both the informal carer and the older person to take a break. We received evidence that respite is frequently used as a stepping stone into permanent residential aged care rather than as the opportunity for more frequent, short-term respite which can benefit the informal carer and the older person alike.[47] Witnesses gave evidence that the current system does not always provide respite and other supports that are accessible.[48]

Ms Sue Elderton, Chief Executive Officer of Carers Australia, described respite as 'probably one of the most underdone areas of aged care'.[49] A 2015 survey of Disability, Ageing and Carers reported that 58.9% of primary carers had not received assistance from organised services in the previous six months, 35.1% were not satisfied or were unsure about their satisfaction with what was available to them, and 25.4% were unaware of the range of services available. A total of 86.2% of carers had never used respite.[50]

Dr Phillipson gave evidence that for over 15 years, informal carers of people living with dementia have identified respite as a key unmet need. She said that negative experiences of information seeking, and negative outcomes associated with, respite created additional stress for informal carers and resulted in delays in the use of respite or a reluctance to use respite services at all.[51] This difficulty is particularly acute for informal carers in regional, rural or remote areas.[52]

Quality respite has been shown to improve informal carers' emotional wellbeing and physical health, providing time for self-care, enhancing autonomy and independence, and offering a period of enhanced freedom or choice of diversity in activity.[53] Respite may also present an opportunity to improve on the condition of the person receiving care through reablement measures, and not just act as a step towards permanent residential aged care.[54] Respite services should also include culturally appropriate respite options for people from culturally and linguistically diverse backgrounds.[55]

Commissioner Briggs considers that current offerings of respite lack any additional measures of reablement. She heard that this is because there are insufficient incentives for approved providers of residential aged care to offer flexible forms of respite or to undertake reablement measures when an older person enters residential respite. For approved providers, not only is the entry of an individual for respite as administratively burdensome as for a new permanent resident, but the subsidy available to them for residential respite has not kept pace with increases in resident acuity. Commissioner Briggs considers that the subsidy is now so low that providers may consider it a disincentive to provide respite. Instead of an incentive to offer respite, an approved provider has an incentive to maximise the use of allocated places for people in permanent residential care, to attract greater revenue and avoid 'onboarding' costs of frequently admitting people seeking respite.[56]

We make recommendations elsewhere in this report (Recommendations 15, 16, 25, 32, 40, 53, 117 and 126 in Chapters 3, 4, 7 and 17) about changes to the way respite care is accessed and funded. We expect these recommendations to result in a substantial increase in the spread and availability of respite. Here, our recommendations are directed at securing better integration of digital supports provided by My Aged Care and the Carer Gateway and ensuring that accurate and up-to-date information on respite services is available to support informal carers gain better access to respite.

5.1.3 How can support for informal carers be improved?

A supportive and preventative approach, where carers get help early in their caring role to increase their skills and reduce the strain of caring, is required to support informal carers more appropriately. This approach must be supported by access to regular and flexible high quality respite. Other supports might include building capacity through education and training in areas including the administering of medicines, manual handling, and using aids and medical devices.[57]

Accessing support services early in the caring role is critical to supporting the wellbeing of the informal carer and increasing the sustainability of the caring relationship.[58]

Carers hubs

There are benefits of shared spaces where informal carers can come together, such as the Mildura Carers Hub and the Home and Community Care Centre in Bidyadanga.[59] Community-based carers hubs can be an important way for informal carers to access information and advice.[60] They enable carers to talk comfortably about the challenges they face and to find practical solutions and ideas for support available locally that they might otherwise not know about. Promoting these local hubs should be part of providing early support to informal carers. Counselling and participation in support groups can reduce stress and help with the feelings of isolation that many informal carers experience. Ms Cameron said she:

> felt immense release when I first attended the Woodend Lifestyle Carers Group because I could discuss issues I was dealing with, and by also listening to others, I felt that I was not the only one to go through this'.[61]

Community-based carers hubs are well placed to provide culturally appropriate support for informal carers. The Home and Community Care Centre in Bidyadanga, an Aboriginal community approximately 200kms north of Broome, provides care and support to people who speak five different languages. Despite these challenges, the centre has 'become an integral part of it [the Bidyadanga community] in just four years of operation'.[62]

We recommend the Australian Government support and fund a community-based carers hub network. Some concern has been expressed about potential duplication between carer hubs and the Carer Gateway.[63] While there are some similarities, we are satisfied that the carers hubs can provide effective practical support in local communities. We consider the two approaches will complement each other and maximise the supports available to informal carers.

Evolving needs

The needs of a person receiving aged care will evolve, as will the role of family and friends. Not all informal carer relationships may be readily apparent at the stage of initial assessment and not all carers will identify as carers. Care finders should have a role in relation to the identification of informal carers. Care finders should be able to refer new informal carers to assessment services for assessment for, and access to, formal respite care. Where appropriate, informal carer support might be sourced from the provider who supports the person receiving care.[64]

Throughout their experience of caring for an older person, informal carers need to develop new skills to manage the physical and emotional toll of supporting the person to live at home. If a person moves into residential aged care, their informal carer(s) will need to develop new skills and ways to support this transition. The aged care system needs to ensure that opportunities for continuous learning are available to informal carers.

Providing early and enhanced support for the wellbeing of informal carers will improve the sustainability of the caring relationship for the benefit of the carer, the person receiving care and the aged care system.

Carer's leave

The National Employment Standards are created by the *Fair Work Act 2009* (Cth). They set minimum standards for the employment of most Australian employees. The minimum standards relate to 10 matters, including maximum weekly hours and different types of leave such as annual leave, sick leave and personal / carer's leave.

There are currently no provisions in the National Employment Standards for an employee to take extended unpaid leave for the purpose of caring for an older family member or close friend. Currently, the National Employment Standards provide for:

- full-time or part-time employees to take 10 days of paid carer's leave for each year of employment[65]
- all employees, including casual employees, to take two days of unpaid carer's leave.[66]

Carer's leave is available to allow an employee to provide care or support to a member of the employee's immediate family, or a member of the employee's household, who requires care or support because of a personal illness or injury, or because of an unexpected emergency affecting the member.[67]

Certain employees have a legal right to request flexible working arrangements if they are a carer. However, employers can refuse requests for flexible working arrangements on reasonable business grounds.[68]

Research commissioned by us examined the approach in other countries, where there are more generous leave provisions for informal carers. It shows that a number of countries have paid leave schemes. For example:

- in Austria, up to three months of paid leave, at 55% of usual income, is available to care for people with severe care needs
- in Japan, paid carer's leave is allowed for up to 93 days per family member
- in Poland, there is a scheme for paid leave for up to 60 days per year, paid at 80% of salary
- in Germany and Ireland, up to two years paid leave is available.[69]

In addition, there are countries that provide for extended unpaid leave, with a right to return to work. For example:

- in Germany, care-givers can also take six months unpaid leave for care without endangering their job (small employers exempt). An interest-free loan is available to provide support during the period of leave
- in Spain, long-term leave can be taken for up to three years
- in Hungary, people are entitled to take up to two years unpaid leave.[70]

We accept that flexibility in work arrangements has the potential to relieve some of the impacts that informal carers experience.[71] Carers NSW supported a proposal that there be an investigation of extending the National Employment Standards to provide for two years' unpaid carer's leave. They submitted that such a proposal 'offers a unique solution to enduring issues around securing flexible work or using paid carer's leave (which is taken from an employee's sick leave balance)'.[72]

Professor Andrew Stewart, who is John Bray Professor of Law at the University of Adelaide, told us that one option may be to amend the Fair Work Act to extend an entitlement to leave to care for an older family member, on the same basis that employees are currently entitled to leave to care for a newborn or newly adopted child.[73]

A change of this kind would have economy-wide impacts and would require careful evaluation. However, the increase to the ageing population as the baby boomer generation enters care, combined with the preference of older people to remain living at home, means that the role of informal carers is likely to increase in importance in the future. The increasing prevalence of dementia in the population means that there will likely be a reduction in the number of informal carers. Ms Elderton identified the factors which influence these trends as:

- the increasing number of women—the traditional providers of family care to older people—in employment
- the number of families requiring two incomes to support themselves
- families having children later in life than has traditionally been the case, making it harder to care for older parents at the same time as young children
- the rising rate of relationship breakdown and divorces later in life, which impacts on the availability of partners to provide care.[74]

Increasing levels of home-based care, along with increases in the support for those who provide informal care to those living at home, will have societal and economic benefits. We encourage the Australian Government to consider the potential costs and benefits of leave entitlements for workers who provide care to older people.

Commissioner Pagone can see some merit in the Australian Government considering the potential costs and benefits of improving leave arrangements for those employees providing care to older people. Commissioner Briggs goes further, recommending a formal study to determine the impact of unpaid carer's leave on people receiving care, informal carers, employers and the broader economy. This would provide a sound basis to make decisions regarding carer's leave provisions, including the costs and benefits of improving leave arrangements.

Recommendation 43: Examination of Leave for Informal Carers

Commissioner Briggs

1. **By 30 September 2022, the Australian Government should examine the potential impact of amending the National Employment Standards under Part 2-2 of the *Fair Work Act 2009* (Cth) to provide for an additional entitlement to unpaid carer's leave.**
2. **The results of this investigation should be made public by 31 December 2022.**

5.2 Volunteers

Along with informal carers, volunteers are an integral part of the aged care system. Data reveals that the majority of volunteers in residential aged care facilities and in home care provide social support as well as support for planned group activities and companionship.[75] Volunteers also help with domestic activities, respite care, home maintenance, gardening, transport, shopping, appointments and meal preparation. This data is consistent with evidence and submissions during our inquiry.[76]

The 2016 National Aged Care Workforce Census and Survey reported that 83% of residential facilities and 51% of home care and home support outlets use volunteers. The survey found a total of 23,537 volunteers provided 114,847 hours of service to residential aged care facilities in a designated fortnight in 2016. Home care and home support outlets used a total of 44,879 volunteers, who provided 206,531 hours of service in the designated fortnight.[77]

While we accept there may be overlap between people who identify as informal carers and those who identify as volunteers, it is clear that volunteers provide essential aged care services.[78] Meals on Wheels Australia has suggested that the numbers of people volunteering in aged care may actually be much higher than the survey results suggest. Meals on Wheels Australia alone has approximately 76,000 registered active volunteers across Australia.[79]

Volunteers can provide important connections for older people from diverse backgrounds. We heard about the importance of volunteers who spoke the same language as older people from culturally and linguistically diverse backgrounds. This is particularly important for older people living with dementia who may have lost the ability to communicate in the English language.[80] Ms Samantha Edmonds, Managing Director of Ageing with Pride, described the importance of LGBTI volunteers. Ms Edmonds stated that this role was essential for LGBTI people receiving aged care, to reduce isolation and maintain connection to their LGBTI identity and communities.[81]

A number of submissions made the point that providers should not be able to use volunteers instead of maintaining appropriate staffing levels and skills mix of the paid workforce.[82] We agree with these submissions.

Nonetheless, we consider that approved providers of aged care services should increase their support for volunteering and volunteers so that older people can remain engaged with more people from their local community and so that there is another set of eyes regularly visiting them and observing their circumstances. As Dr Lisa Trigg, Assistant Director of Research, Data and Intelligence at Social Care Wales, stated, 'the easiest hands-off regulation is when you have lots of people coming in and out every day'.[83]

It should be a condition of approval, and continuing approval, that where a provider operates a volunteer program, it must assign a staff member to the role of volunteer coordination. Providers must also provide induction and regular ongoing training to volunteers in caring for and supporting older people, diversity and inclusion, complaints management, and reporting reasonably suspected abuse or neglect.[84] Good supervision and follow-up of volunteers will also be important, as will the capacity to assess a volunteer's ongoing suitability to be a volunteer.[85]

5.2.1 Community Visitors Scheme

The aged care Community Visitors Scheme is an Australian Government scheme that encourages, and relies on, volunteers. The Community Visitors Scheme arranges visits by volunteers to older people who use aged care services. The volunteers provide companionship and friendship. This service is free to users and has been funded by the Australian Government since 1992.[86]

The Community Visitors Scheme provides funding to organisations known as 'auspices'. Auspices recruit, train and support volunteers, conduct police checks, match volunteers to older people receiving aged care, and support relationships between volunteers and the people they visit.[87] The auspices are not typically approved providers. Community visitors are not advocates and there is a separately funded National Aged Care Advocacy Program for that role.

In August 2016, the Australian Department of Health reviewed the Community Visitors Scheme. The review identified areas for improvement, while noting that the scheme 'is seen as a long-running and highly successful scheme that brings substantial benefits to both visitors and consumers alike'.[88] The review identified a lack of awareness as a key barrier to full use of the scheme. The review also recommended that the scheme's eligibility criteria be broadened to include people receiving support from the Commonwealth Home Support Programme.[89] This point was also raised in submissions.[90]

The Australian Government should rename the Community Visitors Scheme as the 'Aged Care Volunteer Visitors Scheme' and promote the scheme to increase awareness and participation. The Government should provide additional funding to the scheme so that it can extend support to older people receiving aged care who are at risk of social isolation, as described by Mr Laity and other witnesses.[91]

We recommend that the existing Community Visitors Scheme in aged care should be equipped to provide extended support for older people receiving aged care who are at risk of social isolation. There is also a need to promote the work of this scheme and to attract and build an increased volunteer base.

More broadly, Commissioner Briggs considers that approved providers of aged care could do more to support volunteers in their work. They should support volunteers to understand what they can do, and how they can raise any concerns if they witness or suspect neglect or abuse of older people receiving aged care.

Commissioner Briggs notes that volunteers bring the community to aged care, whether in a residential care setting or in a person's home. Volunteering can also bring immense rewards for volunteers, whether they are a younger person developing skills while making a contribution or an older person giving back to the community. Volunteers can create social connectedness—both for the volunteer and the person receiving care—and it is difficult to quantify the value of that.

Various official visitors schemes, also known as community visitors schemes, exist in all States and Territories and have operated in Australia since about 1843, when they were introduced to have an oversight function in respect of mental health facilities.[92] Official visitors, or community visitors, are typically tasked with oversight and monitoring of conditions in institutional settings.

There is no official visitors scheme that has a safeguarding role in the aged care system. The New South Wales Ageing and Disability Commissioner, Mr Robert Fitzgerald AM, and Ms Katherine McKenzie, Director of Operations at the New South Wales Ageing and Disability Commission, raised the possibility of an official visitors scheme in aged care that would extend to both social connection and safeguarding measures.[93] That would depart from the nature of the current Community Visitors Scheme, which is based on social connection rather than oversight and safety. We consider that it is essential to preserve and enhance the existing scheme as a means to maintain the social connection of older people. We make recommendations to enhance the safeguarding function of the Quality Regulator elsewhere in our report.

Recommendation 44: Volunteers and Aged Care Volunteer Visitors Scheme

From 1 July 2021, the Australian Government should promote volunteers and volunteering in aged care to support older people to live a meaningful and dignified life and supplement the support and care provided to them through the aged care system, whether in their own home or in a residential care home, by:

a. increasing the funding to the Volunteer Grants under the Families and Communities Program – Volunteer Grants Activity in 2021–22 to support organisations and community groups to recruit, train and support volunteers who provide assistance to older people

b. requiring, as a condition of approval and continuing approval of all approved providers, that all aged care services which use volunteers to deliver in-house coordinated and supervised volunteer programs must:

    i. assign the role of volunteer coordination to a designated staff member

    ii. provide induction training to volunteers and regular ongoing training to volunteers in caring for and supporting older people, complaints management and the reporting of reasonably suspected abuse or neglect

    iii. retain evidence of provision of such training

c. providing additional funding, and expanding the Community Visitors Scheme and changing its name to the Aged Care Volunteer Visitors Scheme, to provide extended support for older people receiving aged care who are at risk of social isolation.

5.3 Conclusion

Informal carers and volunteers play a vital role in providing care, social interaction, community involvement and maintaining relationships, often under extremely difficult circumstances. They enable people to remain living at home and brighten the days of those in residential care. Commissioner Briggs believes that social and community connections are very important to older people. This is even more so when people are vulnerable, live alone or find it hard to get out and about. Some older people may go days, weeks or even months without visitors. People entering residential aged care can lose their connection to the local community, which may have been home for decades.

Commissioner Briggs notes that the contribution made by informal carers and volunteers through formal organisations, as well as less formal mechanisms, is of tremendous value to the Australian Government and the broader community. Family, friends and volunteers are key connectors between aged care and the community, and they play a vital role in enriching and protecting the lives of older people.

Informal carers often perform their caring role at significant personal cost. Wherever possible, the needs of informal carers must be recognised and met. However, not every older person has family and friends who are available to assist them. A structured and dedicated volunteer visiting service, prioritising people who may otherwise be isolated, can help to address this critical need.

Volunteers and informal carers are the fabric of our society and are part of the solution in keeping our older population safe and connected. We must ensure that they are recognised and supported, with training, knowledge, financial assistance where required and protections for those who wish to continue working.

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6. Aged Care Accommodation

6.1 Introduction

The place where an older person lives affects their sense of security and quality of life. Accommodation that is well designed to meet people's needs can improve their lives and their wellbeing. The more familiar and secure their accommodation, the happier they are likely to be. But people's needs change over their lives. They may need to reduce accommodation costs or maintenance and upkeep as their circumstances change. They may need to find more stable and suitable housing. Ideally, people should plan ahead for their changing needs, but often they do not.

People's accommodation should, where possible, cater to their changing needs. Accommodation with accessible and dementia-friendly design features will allow older people to remain in familiar surroundings if they become frail or develop symptoms of dementia. Accommodation located close to shops and other amenities is not only convenient but may also help people maintain social engagement with the local community.

Most older people in Australia choose to remain at home as they age.[1] Of the approximately 1.3 million people who received aged care services in 2018–19, around one million received care in their home.[2]

Older people who are at risk of not having secure and accessible accommodation are especially at risk of not being able to receive aged care services in their homes or to age in place.[3] People who live in insecure housing, whose housing options are unaffordable, or who have no control over their housing environment often cannot make modifications to improve accessibility and, therefore, maintain their physical independence. Special attention should be paid to their needs, including integration of the aged care and affordable housing programs. There should be an increase in aged care support for people in insecure housing who want to remain living in the community.

It will not always be possible for older people to remain living at home. Some people will find it necessary or desirable to move into residential aged care to receive the support and care that they need.[4] The built environment in which residential aged care is provided must be suitable to meet the particular needs of people receiving that care. In this chapter, we make recommendations to ensure that this will be the case in the future aged care system.

Commissioner Briggs notes that, over the last 20 years, there has been significant capital investment in upgrading existing residential facilities and constructing new facilities.[5] She considers that the facilities that have been constructed often have not reflected residents' preferences for smaller-scale facilities or the increasingly clear evidence that lower-density congregate living arrangements generally promote better quality care.

Commissioner Briggs recognises that an expansion of accommodation has been necessary, and welcomes the increasing availability of private rooms and other facilities. But she considers that the available funding does not always meet the needs of the people who have to live in this newer accommodation. She refers to research that she and Commissioner Pagone commissioned that shows residents rate their life satisfaction higher when they live in facilities that have fewer numbers of beds.[6] Residents surveyed for that research were also asked about their living space: 36% of these residents 'rarely' or only 'sometimes' felt at home in their own room, and 28% could not or could only 'sometimes' access outside areas or gardens.[7] Commissioner Briggs observes that the aged care sector has nonetheless continued to build large-scale facilities while the availability of smaller homes has fallen. In June 2019, less than 1% of operational places were available in facilities of 1–20 places and almost 80% were located in larger facilities of over 60 places.[8]

For Commissioner Briggs, greater diversity in the scale and design of residential aged care accommodation, including an expansion in the availability of small-scale accommodation, is a necessary precondition for long-term and sustainable improvements in the quality and safety of aged care and for older people's quality of life. She urges the Australian Government to explore opportunities to develop more suitable long-term aged care accommodation. She considers that practical steps to encourage the growth of small group, home-like models of aged care offer the potential to meet the growing demand for services that could improve quality of life, better meet people's preferences, and provide safer and more sensitive living arrangements for the most vulnerable citizens.

6.2 Residential aged care accommodation for the future

We both consider that, in general, residential aged care services should transition progressively away from large institutional design settings.[9] Accessible and dementia-friendly design should be the norm for new or substantially refurbished residential aged care buildings. Appropriate design of residential aged care buildings, as outlined in this chapter, must complement and support an effective operational model of care delivery.[10]

6.2.1 Appropriate design

There is a need for greater awareness and consistency of standards for accessible and dementia-friendly design in residential aged care. The Australian Government should develop and publish a comprehensive set of national aged care design principles and guidelines for residential aged care.[11]

Accessible design guidelines, such as the Livable Housing Design Guidelines, provide useful guidance for design and construction of houses and apartments. However, they were not developed with residential aged care in mind and do not apply in that setting.[12] They do not specifically provide for people who are physically frail. They also do not refer to dementia-friendly design principles.

With over half of all people in residential aged care living with dementia, the physical environment of residential aged care should be designed to meet their particular needs.[13] People living with dementia are particularly sensitive to their environment because dementia can change the way they perceive their surroundings.[14] Either the built environment can be supportive, familiar and therapeutic—even serving as a prosthetic for various changes in cognition caused by dementia—or it can be a barrier to independent functioning and a high quality of life.[15] The design of residential aged care buildings should consider the needs of residents, including those with 'cognitive impairments, memory loss, confusion, wandering, over/under stimulation and reduced judgement'.[16] There is considerable academic literature on design principles for people living with dementia.[17]

In broad terms, the evidence before us is that good design in residential aged care, particularly for people living with dementia, usually involves smaller, lower-density congregate living arrangements rather than larger, more institutional settings.[18] Smaller, lower-density congregate living arrangements generally promote better quality of life for everyone.[19] Large, noisy institutional environments can worsen the adverse consequences of dementia.[20]

Commissioner Briggs observes that large, noisy institutional environments can make people, whether living with dementia or not, feel ill at ease and insecure, and these environments can be confusing and uncomfortable for guests. She found that it was not uncommon to be told during visits to aged care facilities and in community meetings that large institutions were not appropriate for older people and, in a number of cases, that aged care facilities were the last remaining form of institution in Australia (other than prisons), were often located away from shops and services, and were no longer considered suitable for older people. Commissioner Pagone, on the other hand, sees value in allowing innovative facilities in which size is not limited. He saw some large facilities built with an eye to complementary uses, allowing for more complex care needs when required and blending other benefits. In his view, what is needed is attention to design and planning.

Despite the existence of a number of dementia-friendly design resources in Australia, including guidance materials from Dementia Australia and Dementia Training Australia, there is no indication that any of them have been adopted nationally.[21] Although there is some variation between those different resources, there is also considerable overlap in the core principles of dementia-friendly design. As research in, and understanding of, dementia continues to develop, the characteristics of dementia-friendly design will continue to evolve.

Many aspects of dementia-friendly design are beneficial for everyone and not just for people living with dementia.[22] As Dr Stephen Judd, now former Chief Executive of aged care provider HammondCare, stated:

> If you have ever been stuck in a large, confusing airport or shopping centre then you will know why good design is important. When an environment is not intuitive, it becomes disabling. For a person with dementia, the need for good design is even more important.[23]

Recommendation 45: Improving the design of aged care accommodation

The Australian Government should guide the design of the best and most appropriate residential aged care accommodation for older people by:

a. developing and publishing by 1 July 2022 a comprehensive set of National Aged Care Design Principles and Guidelines on accessible and dementia-friendly design for residential aged care, which should be:

   i. capable of application to 'small household' models of accommodation as well as to enablement and respite accommodation settings

   ii. amended from time to time as necessary to reflect contemporary best practice

b. implementing by no later than 1 July 2023 a program to promote adoption of these National Aged Care Design Principles and Guidelines in design and construction of residential aged care buildings, which should include:

   i. industry education, including sharing of best practice models

   ii. financial incentives, whether by increased accommodation supplements or capital grants or other measures or a combination of such measures, for residential aged care buildings that comply with the Guidelines

c. advancing to the National Federation Reform Council by 1 July 2025 a proposal for any amendments to Class 9c of the *National Construction Code* to reflect accessible and dementia-friendly design standards for new residential aged care buildings, or those proposed to be substantially refurbished, according to specifications informed by the National Aged Care Design Principles and Guidelines.

6.2.2 National Aged Care Design Principles and Guidelines

The National Aged Care Design Principles and Guidelines should permit some flexibility for different circumstances.[24] From time to time, the National Aged Care Design Principles and Guidelines should be reviewed and amended, as necessary, to reflect contemporary best practice. They should be voluntary.

The Australian Government should actively promote and encourage approved providers, builders, architects and others to adopt and apply the National Aged Care Design Principles and Guidelines. This might be done through measures including publicising best practice models to demonstrate what adoption and application of the Principles and Guidelines will look like.

Financial incentives, whether by increased accommodation supplements or capital grants or other measures, should be paid to approved providers that can demonstrate that their residential aged care buildings adopt the National Aged Care Design Principles and Guidelines.[25]

If, however, accessible and dementia-friendly design principles remain voluntary for an indefinite time, there is a very real risk that, without more active measures, their adoption and application will not be sufficiently widespread. Class 9c of the *National Construction Code* sets out building specifications for residential aged care buildings. We have heard that those building specifications may work against the adoption of innovative models of residential aged care, such as small household models of care. Adjunct Professor Stephen Cornelissen, Group Chief Executive Officer of aged care provider, Mercy Health, explained that, when refurbishing an aged care facility to provide for a small household model of care, Mercy Health had been required by the *National Construction Code* to install industrial grease traps for three domestic-style kitchens designed for a maximum of 10 residents. Professor Cornelissen described this obligation as 'completely unnecessary'.[26] It is clear that unnecessary requirements may deter approved providers from adopting innovative designs.

The Australian Government should advance a proposal to the National Federation Reform Council, by no later than 1 July 2025, for any amendments to Class 9c of the *National Construction Code* deemed necessary to reflect accessible and dementia-friendly design standards for new residential aged care buildings, or those proposed to be substantially refurbished, according to specifications informed by the National Aged Care Design Principles and Guidelines. Any amendments to those specifications should allow for flexibility and innovation in the design of residential aged care buildings.

6.2.3 Small household design

At Sydney Hearing 1, Mr Glenn Rees, Chair of Alzheimer's Disease International, described residential aged care in this country in the following terms:

> Australia has a fairly institutional provision, it seems to me, of aged care, even though as a country we've probably known since…the early 1990s what good design looks like.[27]

The average size of residential aged care facilities has increased in recent years. In 2008, 39% of facilities had over 60 places; by 2019, 60% of facilities had over 60 places. During that same period, the proportion of facilities with 40 places or fewer fell from 32% to 20%. The proportion of the smallest facilities with 20 or fewer places fell from 7% in 2008 to under 5% in 2019.[28] Mr Grant Corderoy, Senior Partner, Consulting and Aged & Community Services Division at StewartBrown, told us that the 'financial sweet spot' for providers of residential aged care involves facilities, often multi-storey, with between 60 and 90 places.[29]

What is not known is the proportion of larger aged care facilities that have been physically configured or reconfigured to adopt small household models of care. Professor Cornelissen said that although Mercy Health regarded small household models of accommodation as preferable to more institutional settings, only two of its 35 aged facilities had been purpose built for the adoption of a small household model of care. Another four had been 'refurbished…in varying forms' to accommodate that model, and two others were 'larger variations of that theme with 15 beds or the like'.[30] Professor Cornelissen estimated that, even with 'all the capital in the world', Mercy Health would not complete such a reconfiguration of its existing aged care facilities for eight years and, without access to unlimited capital, 'it could be quite a while' before that could be achieved.[31]

Creating 'familiar households' facilitates the provision of person-centred care.[32] We have heard that for residential aged care, there is significant benefit to a domestic setting instead of a traditional institutional model.[33] Despite considerable evidence about the benefits of 'small household' models, there is no single definition of what such a model is.[34] However, there are some common characteristics.

Small household models usually involve housing eight to 10 people receiving aged care services, and sometimes up to 16 people, within a home-like environment. Common features of small household models include 'a focus on domestic, homelike, familiar or normalised environment with medical equipment hidden'.[35] Regular staff are employed and they do not wear uniforms. Residents are able to choose the structure of their day and are given the opportunity to engage in domestic or regular duties such as food preparation.[36] Smaller-scale housing can be constructed as standalone facilities or operate in cottage-like clusters as part of a larger development.[37]

We have heard that the small household model provides a 'significant advantage' over traditional institutional residential aged care.[38] For instance, Dr Judd described institutional environments as inflexible, hierarchical and disabling for people receiving care.[39] He stated

that ‘small, domestic, and familiar residential aged care environments that can both provide high quality aged care and escalate to public health services where needed’ are best suited to achieving the goals of residential aged care.[40]

While acknowledging these views, Commissioner Pagone sees merit both in large developments as well as small developments. He considers that in large developments, providing they are well designed, there can be efficiencies of scale, improved capacity to recognise diversity and ability to have clusters of different types of activities at the facility.

Commissioner Pagone was impressed by the effort he saw by many in the sector to develop new, novel, innovative and appropriate accommodation for residential care. There is some accommodation which still has the feel of an institution rather than a home, and some which bears the signs of makeshift conversion of properties designed for other purposes being modified and compromised. It was clear from the site visits to a number of places of a growing awareness of the need for accommodation to be a home for those in residence and for design to maximise opportunities and choice.

Commissioner Pagone considers that a lesson of the site visits was the benefit of diversity and options. It was instructive to see how different types of well-designed accommodation could be to provide a home with the diverse care needs that the residents frequently had. Commissioner Pagone was pleased to note the actual construction of new facilities putting into practice the lessons learned from previous experience. In Montrose, Melbourne, for example, it was possible to see side by side two facilities where the provider had constructed a new building next to an old one that was being decommissioned. The latter (earlier in time) had the feel of an outmoded institutional location in what looked like a building converted from a different use. The new building had been specifically designed for the purpose of aged care, including for people living with dementia, and built upon architectural principles specifically intended to maximise care.

There will, no doubt, be more lessons to be learned as time passes and when what is new today becomes old. For Commissioner Pagone, however, one lesson is that diversity and options are important. What is good for one may not be for another. Small-scale accommodation is not for everyone and in some cases minimises options that large-scale construction may allow.

In Sydney, Commissioner Pagone visited two remarkably different sites: one was small and had the feel of a well-appointed home, the other was large and had the feel of a luxury hotel. Each had its benefits and each had its place in an aged care system such as that in Australia. He would not want to express a preference for one model over the other because choices of those kinds are for those who create spaces to attract those who are to live in them, and for those who choose to do so.

Commissioner Briggs considers that residential aged care needs to offer appropriately scaled accommodation to better meet older people’s needs. The dominant model for residential care in Australia is large-scale congregate living facilities. The term ‘residential aged care facilities’ accurately describes the depersonalised, industrial-scale environments in which most older people who need high level care are asked to live.

Commissioner Briggs notes that as the system governor and funding authority, the Australian Government has a role in influencing the scale of residential accommodation, which it should embrace to achieve higher quality aged care.

Commissioner Briggs draws attention to increasing interest overseas and in Australia in providing care in small group or home-like facilities, to improve quality of life for residents. Examples of this include the Green House project in the United States or European group living homes. These homes typically provide housing for a small number of residents per living unit—generally 12 to 16 people—and have an allocation of staff to living units, better access to outdoors and a greater emphasis on developing relationships and maximising independence. The US Veterans' Health Administration is committed to the use of the 'Small House Model' of care in all of its facility-based settings, including Community Living Centres and State Veterans Homes.[41] The US Veterans' Health Administration has issued a Small House Model Design Guide as a guide to the standards for the planning and design of facilities. The Small House Model Design Guide states that:

> While comprehensive data on outcomes is limited, the currently available evidence suggests that implementation of the Small House (SH) Model leads to better resident outcomes and higher resident satisfaction at comparable or lower overall cost.[42]

In the same vein, Commissioner Briggs notes that academic research in Australia and overseas has shown that people living in 'home-like' clustered models of care have better quality of life, better consumer-rated quality of care, lower hospitalisation rates and lower emergency department presentation rates compared to those in standard care.[43] There are also reports of decreased physical and chemical restraint use for residents of these homes as well as improved functioning and mood.[44] In a study for us by the University of Queensland, higher quality in residential aged care facilities was found to be highly correlated with smaller size.[45] That study found that residential aged care facilities fell into three broad quality levels:

- Facilities in the best level had a lower use of high-risk medicines, did not fail to meet accreditation standards, received a lower number of issues and complaints, and had a relatively higher customer experience rating score. This best quality group comprised 41% of facilities with 1–15 places, 26% of those with 16–30 places, 17% of those with 31–60 places, 5% of those with 61–120 places, 2% of those with 121–200 places, and 0% of those with more than 200 places.
- The worst quality level had lower customer experience ratings, failed to comply with accreditation standards more often, and received a higher number of complaints and issues. This worst quality group comprised 21% of facilities with more than 200 places, 17% of those with 121–200 places, 12% of those with 61–120 places, 8% of those with 31–60 places, 6% of those with 16–30 places, and 0% of those with 1–15 places.[46]

Commissioner Briggs was impressed by the results of a survey conducted for the Royal Commission by the National Ageing Research Institute, which showed that:

- residents in facilities with 0–60 places rated their general life satisfaction significantly higher than those living in facilities with 61–100 places and those living in facilities with more than 100 places

- residents living in facilities with 61–100 places rated quality of care significantly lower than residents living in facilities with 0–60 places or more than 100 places
- the total number of concerns per resident was higher in facilities with 61–100 places and in facilities with more than 100 places, compared to residents living in facilities with fewer than 60 places.[47]

We agree that the small household model is one way that residential aged care can adopt dementia-friendly and accessible design principles. Without wishing to limit innovation, we consider that residential aged care providers should be encouraged to adopt small household models, paired with appropriate relationship-based care staffing arrangements.

At the same time, Commissioner Pagone considers that there may be other ways, in addition to the small household model, to provide appropriate accommodation for those who need residential aged care. The focus of planning appropriate accommodation should always be on providing the best option to meet the needs of those to be accommodated. It would, therefore, be wrong to substitute the current or outmoded prescriptions with other rigid prescriptions. But the small household model is clearly established as among the models which need to be available and which require more, and immediate, attention.

Commissioner Briggs believes that small home or household models of design are the best option for future residential aged care and, in the absence of government action to steer the sector toward smaller-scale accommodation, providers and developers will continue to build larger facilities. She considers that strong leadership and appropriate financial incentives will be required to encourage the construction of more appropriate residential aged care accommodation.

While acknowledging that providers and developers are discouraged from building smaller homes because of higher upfront capital costs per resident, Commissioner Briggs points out that smaller homes can generate longer-term welfare improvements and cost savings for the sector as a whole. A recent study suggested that providing residential aged care in a clustered domestic model requires an approximate 17% increase in capital establishment costs, including floor area, but significantly lower operating costs.[48] On the other hand, operating costs can be higher in very large facilities (over 100 places), especially as the acuity of the care needs of residents increases.[49] The balance of these factors appears to be that smaller homes can be moderately more expensive to operate in terms of 'bed-days' or per resident, as reflected in the empirical work undertaken for us by the University of Queensland, which showed statistical evidence that larger facilities have slightly lower average costs. However, if quality of care is taken into account, there are likely to be significant savings to the Australian Government because higher quality of care has been found to be associated with lower adverse events, hospitalisations and health outcomes by residents, leading to a lower call on health and care services by the people living in those small homes, over time.[50] Importantly, Dr Judd stated that 'the cost of delivering care to residents in small domestic environments is approximately $13,000 less per resident per year when compared with more traditional residential aged care homes'.[51]

Commissioner Briggs considers that rapid growth and development in the area of small home or household models of design would provide significant benefits for older people

and deliver much needed improvements in the quality of aged care. She recommends that such growth should be supported by a significant increase in the amount of the current capital grants fund provided under the *Aged Care Act 1997* (Cth)—an increase to at least $1 billion each year, with annual indexation, when fully phased in. The increased amount of capital grants funding should continue for at least 10 years to prepare for the next generation of those needing residential aged care. The level of increased funding reflects the high cost of capital replacement and the high level of unmet demand for refurbished or new places. The additional grants should be only made available to support small home or household models of design, or other innovative models that are the subject of emerging evidence.

We both consider that the Australian Government should support the building or upgrading of residential aged care facilities, including to provide small-scale congregate living which facilitates the small household model of care. One way it should provide support is through capital grants for projects of this kind. The Australian Government should give priority to projects for premises for people who have particular needs, are financially disadvantaged, or live outside of a major city or in a location where there is a demonstrated need for additional residential aged care services. It should also give priority to projects that will meet the needs of people living with dementia.[52]

Recommendation 46: Capital grants for 'small household' models of accommodation

1. From 1 January 2022, the Australian Government should provide additional capital grants for building or upgrading residential aged care facilities to provide small-scale congregate living.
2. The amount of annual grant funding should be increased to $300 million in 2021–22, $600 million in 2022–23 and $1 billion in 2023–24, and should be indexed for inflation in subsequent years. **Commissioner Briggs**
3. Priority for these capital grants should be given to approved providers whose premises have or will have a majority of aged care residents who are (within the meaning of section 7 of the *Grant Principles 2014* (Cth)) in one or more of the following categories:
    a. low-means care recipients, supported residents, concessional residents or assisted residents
    b. people with special needs
    c. people who live in a location where there is a demonstrated need for additional residential care services
    d. people who do not live in a major city.
4. The capital grants program for building or upgrading residential aged care facilities to provide small-scale congregate living should continue after the introduction of the new Act.

There may well be other ways in which the Australian Government could support the building or upgrading of residential aged care facilities to provide small-scale congregate living. The Australian Government should consider other measures, such as financing, funding, commissioning, policy direction or regulation. One change could require pricing for the provision of residential aged care to account properly for the costs associated with small household models of accommodation and care. Commissioner Briggs also refers to the possibility of setting differential accommodation supplements for facilities based on small household or other innovative models. Other measures might involve consideration of changes to use of Refundable Accommodation Deposits by approved providers of residential aged care. We consider Refundable Accommodation Deposits in greater detail elsewhere in our report.

The size of the task of ensuring appropriate accommodation for those who need residential aged care should not daunt the Australian Government from seeking to address it. We note that in 1994, more than half of all nursing home residents (51%) lived in rooms with three or more beds and 12% of residents lived in rooms with five or more beds.[53] At that time, 13% of the nursing homes did not meet fire authority standards, 11% did not meet health authority standards, and 75% did not meet Australian Design Standard AS1428 for access and mobility.[54] The Aged Care Act introduced building certification requirements. Compliance with those certification requirements was not mandatory for approved providers. Providers were, however, only able to access certain additional funds, such as accommodation subsidies, if their residential aged care buildings complied with the requirements. Within 10 years, by 2006, the average number of beds per room had reduced to 1.19—with 95% of all bedrooms built between 1999 and 2006 having only one bed.[55]

In 2019, the Aged Care Financing Authority estimated that the combined total investment for new and rebuilt residential care places over the next decade under the current policies would be about $56 billion.[56] It is imperative that this investment be directed towards the aged care of the future and not to the creation of more institutions.

6.3 Secure accommodation for changing needs

There is a distinct need for coordinated intergovernmental policy, planning and action relating to housing and accommodation for Australia's ageing population.[57] As a matter of priority, governments should work together to increase accessible housing, including private rental housing and social and affordable housing, for the ageing population. Given the focus of our Terms of Reference on the delivery of aged care services, however, these general accommodation issues are not the subject of any particular recommendations by us. They nonetheless warrant an urgent call for government action to improve access to accessible housing.

By planning ahead, people give themselves the best chance of growing old at home and, if they so choose, of dying there. Planning ahead means that a person experiencing a major life event, such as serious illness or injury, may not be compelled, at short notice and at great emotional and financial cost, to leave a longstanding and cherished home to move into other accommodation. It means that a person may be able to receive aged care services at home for longer.

Access to accommodation in which people can age and, as necessary, receive aged care services needs to be improved. That is so regardless of whether the accommodation is owner-occupied, privately rented, social and affordable housing, or residential aged care. Older people living in unsuitable housing face greater risk of falls, injury and immobility, and the prospect of unanticipated or premature entry into residential aged care.[58]

At present, the majority of older people in Australia own their own homes or are paying them off.[59] Many are reluctant to move when it becomes apparent that smaller or more modern accommodation might better suit their needs.[60] It is therefore important that barriers to the adoption of innovative, well-designed housing models and downsizing should be reduced.[61] One example of innovative housing is cohousing, which can provide for affordable downsizing with ongoing financial independence and social connections.[62] Cohousing communities require a great deal of initiative and planning, often taking years to establish. The National Ageing Research Institute highlighted that there may be challenges in obtaining finance for these projects and they are more likely to be successful if supported by government grants.[63] Dr Brendan Radford, Manager of Policy and Advocacy, National Seniors Australia, told us that people would consider moving to more accessible, suitable accommodation earlier if there were more housing options within their local community that suited their needs, such as single-storey low-maintenance housing. He considered that there are currently not enough of these options available.[64]

The Australian Housing and Urban Research Institute has projected that, in the future, fewer older people will be home owners and more of them will be private renters.[65] The Australian Housing and Urban Research Institute anticipates that by 2031, over 200,000 older private housing tenants will need assistance with daily living activities and will rely on landlords to permit home modifications.[66] Measures to increase the supply of accessible private rental housing, such as government-funded occupancy supplements and planning concessions, should be explored by all governments.[67]

In addition, some older people depend upon social and affordable housing, the supply of which has historically not met demand.[68] It is not enough to acknowledge that more accessible social and affordable housing for older people is needed. State and Territory Governments need to do more to provide much more of that housing. In mid-November 2020, the Victorian Government announced that it would invest $5.3 billion to construct 12,000 new public and community housing homes throughout Victoria.[69] That is a promising development. Those new homes should adopt accessible design principles. At least some of them should be suitable for older people's needs.

More generally, the design of much existing social housing does not conform to accessibility standards.[70] More investment in, and construction of, well-designed, age-appropriate social and affordable housing is required.[71] This will help to prevent people having to move into residential aged care prematurely to access accommodation suitable for their care needs.[72]

The issue of homelessness and ageing in place was raised in Melbourne Hearing 2. Ms Fiona York, Chief Executive Officer of the Housing for the Aged Action Group, told us that there is an assumption with ageing in place that everyone owns their own home or has safe housing. The ability to provide aged care in the home becomes problematic when housing is inappropriate, insecure or unaffordable.[73]

People who are ageing and experiencing homelessness or who are at risk of homelessness require support to engage with services. They often present with premature ageing, a background of trauma, and mental health conditions.[74] The number of people aged 55 years and over who accessed Specialist Homelessness Services in Australia increased by 39.6% between 2013–14 and 2017–18. More than half (57.3%) of these people were women. Older people aged 75 years or over were the fastest growing age cohort within the overall homeless population, increasing by 76.5% in the five years to 2017–18.[75]

The Commonwealth Home Support Programme includes a specialist sub-program, Assistance with Care and Housing. The aim of the sub-program is to support people who experience, or are at risk of, homelessness to access appropriate and sustainable housing linked to community care and other support services. The sub-program targets frail older people and prematurely aged people who are financially disadvantaged. It funds providers to link clients to housing through assessment referrals, financial / legal advocacy, and boarding / squatting services. In 2017–18, 5990 people used the Assistance with Care and Housing sub-program, which was delivered by 61 providers.[76]

There has been no formal evaluation of the Assistance with Care and Housing sub-program since 1996. However, we have heard that it provides significant support to its target groups and that it needs to be expanded, including the limited funding that it provides for hoarding and squalor services.[77]

We note that there is currently no discernible connection between the Australian Government aged care program and any Australian Government or State or Territory Government housing program. This must change. We urge that the National Cabinet Reform Committee on Ageing and Older Australians, which we have recommended be established (Recommendation 4), should work with housing ministers on options to provide for more integrated solutions to the housing and care needs of older people who are homeless or at risk of homelessness.

Endnotes

1 Exhibit 19-1, Sydney Hearing 3, general tender bundle, tab 9, RCD.9999.0410.0253 at 0347; Exhibit 2-86, Adelaide Hearing 2, Statement of Hjalmar Swerissen, WIT.0085.0001.0001 at 0003 [14]; Exhibit 1-9, Adelaide Hearing 1, Statement of Paul Versteege, WIT.0009.0001.0001 at 0005 [28]–[29].

2 Aged Care Financing Authority, *Eighth report on the Funding and Financing of the Aged Care Industry,* 2020, p 11 (Exhibit 20-1, Sydney Hearing 4, general tender bundle, tab 7, CTH.1000.0004.9017).

3 Transcript, Melbourne Hearing 2, Fiona York, 7 October 2019 at T5337.26–34.

4 See, for example, Exhibit 19-8, Sydney Hearing 3, Statement of Stephen Cornelissen, WIT.0777.0001.0001 at 0005 [25]; Exhibit 21-18, Sydney Hearing 5, Statement of Nicolas Mersiades, RCD.9999.0319.0001 at 0006 [40]–[41].

5 Australian Bureau of Statistics, *8731.0 Building Approvals, Australia,* 2020, Table 51: Value of Non-residential Building Approved, By Sector, Original—Australia, https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/8731.0Jul%202020?OpenDocument, viewed 9 January 2021.

6 National Ageing Research Institute, *Inside the system: Aged care residents' perspectives*, A report for the Royal Commission into Aged Care Quality and Safety, Research Report 13, 2020, pp 32–33.

7 National Ageing Research Institute, *Inside the system: Aged care residents' perspectives*, A report for the Royal Commission into Aged Care Quality and Safety, 2020, Research Report 13, pp 7–8.

8 Productivity Commission, *Report on government services 2020, F Community Services, 14 Aged care services,* 2020, Operational places, occupancy rates and size and distribution of residential aged care services [Table 14A.13], https://www.pc.gov.au/research/ongoing/report-on-government-services/2020/community-services/aged-care-services, viewed 9 January 2021.

9 Exhibit 19-1, Sydney Hearing 3, general tender bundle, tab 29, RCD.9999.0410.0001 at 0008; Transcript, Sydney Hearing 3, Robert Pahor, 14 August 2020 at T8804.1–14; Transcript, Sydney Hearing 3, Stephen Cornelissen, 14 August 2020 at T8796.1–24.

10 Transcript, Sydney Hearing 3, Stephen Cornelissen, 14 August 2020 at T8792.31–32.

11 See, for example, Transcript, Sydney Hearing 3, Robert Pahor, 14 August 2020 at T8791.7–18; Transcript, Sydney Hearing 3, Frank Weits, 14 August 2020 at T8794.23–27; Transcript, Sydney Hearing 3, Stephen Cornelissen, 14 August 2020 at T8792.22–26.

12 Exhibit 19-1, Sydney Hearing 3, general tender bundle, tab 21, RCD.9999.0408.0001 at 0015.

13 Australian Institute of Health and Welfare, *Australia's Health 2020 data insights*, 2020, p 211.

14 Exhibit 19-1, Sydney Hearing 3, general tender bundle, tab 32, RCD.9999.0410.0117.

15 MP Calkins, 'From research to application: Supportive and therapeutic environments for people living with dementia', *Gerontologist,* 2018, Vol 58, S1, p S114.

16 Exhibit 19-1, Sydney Hearing 3, general tender bundle, tab 30, RCD.9999.0409.0408.

17 See, for example, MP Calkins, 'From research to application: Supportive and therapeutic environments for people living with dementia', *Gerontologist,* 2018, Vol 58, S1, pp S115–S116; MO'Malley et al., 'Decreasing spatial disorientation in care-home settings: How psychology can guide the development of dementia friendly design guidelines', *Dementia,* 2017, Vol 16, 3, pp 315–328; R Fleming and K Bennett, *Environmental Design Resources*, 2017 (Exhibit 19-1, Sydney Hearing 3, general tender bundle, tab 32, RCD.9999.0410.0096); SM Dyer et al., 'Clustered domestic residential aged care in Australia: fewer hospitalisations and better quality of life', 2018, Vol 208, 10, *Medical Journal of Australia*, pp 433–438; G Marquardt et al., 'Impact of the design of the built environment on people with dementia: An evidence based review', *Health Environments Research and Design,* 2014, 8; H Chau et al., 'Design Lessons from Three Australian Dementia Support Facilities', *Buildings,* 2018, Vol 8, 5, p 67 (Exhibit 19-1, Sydney Hearing 3, general tender bundle, tab 30, RCD.9999.0409.0001).

18 See, for example, Transcript, Sydney Hearing 3, Frank Weits, 14 August 2020 at T8790.10–20; Transcript, Sydney Hearing 3, Stephen Cornelissen, 14 August 2020 at T8796.1–14; Exhibit 19-1, Sydney Hearing 3, general tender bundle, tab 39, WIT.1367.0001.0001 at 0005 [35]–0006 [36].

19 See, for example, Exhibit 3-45, Sydney Hearing 1, Statement of Tamar Krebs, WIT.0124.0001.0001 at 0004–0005 [22]–[23]; Exhibit 3-84, Sydney Hearing 1, Statement of Kate Swaffer, WIT.0127.0001.0001 at 0030 [229]; Exhibit 3-47, Sydney Hearing 1, Statement of Lucille O'Flaherty, WIT.0122.0001.0001 at 0002 [9]–[10]; Exhibit 19-1, Sydney Hearing 3, general tender bundle, tab 39, WIT.1367.0001.0001 at 0013 [73]–0014 [80].

20 Exhibit 3-68, Sydney Hearing 1, Statement of Stephen Macfarlane, WIT.0125.0001.0001 at 0018 [82].

21 Exhibit 19-1, Sydney Hearing 3, general tender bundle, tab 29, RCD.9999.0410.0001; tab 31, RCD.9999.0410.0094; tab 32, RCD.9999.0410.0096.

22 MP Calkins, 'From research to application: Supportive and therapeutic environments for people living with dementia', *Gerontologist,* 2018, Vol 58, S1, p S116.

23 Exhibit 19-1, Sydney Hearing 3, general tender bundle, tab 39, WIT.1367.0002.0001 at 0008 [46]–[47]. See also Transcript, Sydney Hearing 1**,** Jennifer Lawrence, 14 May 2019 at T1580.3–5.

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7. Aged Care for Aboriginal and Torres Strait Islander People

7.1 Introduction

Aboriginal and Torres Strait Islander people occupy a unique place in what is now known as Australia. They descend from the first inhabitants. Over millennia, they have developed rich and diverse cultures. In contemporary Australia, Elders and older Aboriginal and Torres Strait Islander people are 'cultural knowledge holders'. They provide the 'social glue' within their communities and foster 'other humane qualities such as patience…empathy and communication'.[1] They are often caregivers for children, grandchildren and an extended family, and they may live in multi-generational households. Elders are recognised and honoured for their role in solving public problems, reinforcing culture and beliefs, and holding traditional knowledge about the Australian ecology and environment.[2] They are central to the continuation of Aboriginal and Torres Strait Islander cultures and communities.[3]

Aboriginal and Torres Strait Islander people who require aged care should be embraced by an aged care system that shows respect for their cultures and heritage, and in a manner that responds to that which is important to each individual. This involves recognising both the diversity of the Aboriginal and Torres Strait Islander populations who need aged care and the diversity of locations where that care needs to be delivered—across urban, regional, rural and remote parts of Australia.

In the Royal Commission's Interim Report, Commissioners Tracey and Briggs observed that:

> 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.[4]

Many Aboriginal and Torres Strait Islander people have faced systemic disadvantage throughout their lives and across generations.

In this chapter, we provide a blueprint for significant change to Aboriginal and Torres Strait Islander aged care. One of the key reasons for this change is the projected rapid growth of the Aboriginal and Torres Strait Islander population. The communities' identities, and the diversity among their numbers, is also undergoing a profound change.

The aged care system does not ensure culturally safe care for Aboriginal and Torres Strait Islander people. Unless things change, it will be unable to meet the growth in demand that will accompany the increase in the eligible population.

The existence of a separate flexible aged care program in the form of the National Aboriginal and Torres Strait Islander Flexible Aged Care Program, widely known as NATSIFACP, which sits outside of the *Aged Care Act 1997* (Cth), demonstrates the failings of the existing mainstream system.[5] Our concern is that NATSIFACP has limited coverage, delivering services to very few Aboriginal and Torres Strait Islander people, with places predominantly allocated to remote and very remote settings.

We propose the development of a new approach to aged care for Aboriginal and Torres Strait Islander people, within a single national system that is built on evidence-based planning and that incorporates key aspects of the flexibility afforded by NATSIFACP.

The Institute for Urban Indigenous Health submitted that we should recommend that NATSIFACP be expanded.[6] While we acknowledge the success of NATSIFACP in the limited locations in which it is delivered, we consider that it is important that all Australians are served by a single national system. Aboriginal and Torres Strait Islander people should be able to access the most appropriate provider for them from a range of providers within a single national system governed by legislation rather than having to choose between two systems with different regulatory and approval requirements.

The purpose of the aged care system that we propose is to ensure that older people have the same universal right to receive high quality aged care. Care and support must be safe and timely and must assist older people to live active, self-determined and meaningful lives in safe and caring environments that allow for dignified living. For Aboriginal and Torres Strait Islander people to benefit from these reforms, the mainstream system must meet their specific needs.

To achieve the necessary change, we recommend the appointment of a dedicated Aboriginal and Torres Strait Islander Aged Care Commissioner, so that the sector will be supported, for the first time, by someone with a broad range of responsibilities to ensure that the voices of Aboriginal and Torres Strait Islander people are heard and acted upon in the aged care system. Those responsibilities, which are developed in Recommendations 47 and 49 below, include:

- identifying where and how Aboriginal and Torres Strait Islander people need aged care
- ensuring the aged care sector is engaging with relevant communities
- developing a provider base that draws upon the experience and skill of existing Aboriginal and Torres Strait Islander organisations that wish to become aged care providers.

The aged care system must reflect the fact that for many Aboriginal and Torres Strait Islander people, health is grounded in connection to Country, culture, family and community. Each of these elements is capable of affecting the social, emotional and physical wellbeing of older Aboriginal and Torres Strait Islander people and, in turn, determining their health outcomes.[7]

The aged care system must respond to the reality that in the years and decades ahead, there will be a much greater number of older Aboriginal and Torres Strait Islander people who will need aged care wherever they live. Steps need to be taken now to ensure that their care needs will be met as close as possible to where they live and, where applicable, to their community and Country.

Many Aboriginal and Torres Strait Islander people have a clear preference to plan, run and deliver aged care services for themselves and their communities, wherever they live.[8] This extends not only to the leadership and governance of providers but to the staff who are engaged in the face-to-face delivery of care.

Through the recommendations in this chapter, we seek to expand the role of Aboriginal and Torres Strait Islander communities and populations in determining how their aged care is designed and delivered, and to encourage more Aboriginal and Torres Strait Islander people to work in the aged care sector.

7.2 Population trends

Aboriginal and Torres Strait Islander people who require aged care and assistance with daily living are able to apply for aged care from the age of 50 years because they experience earlier onset of ageing-related conditions and disability compared to the rest of the Australian population.[9] At the Broome Hearing, Professor of Geriatric Medicine at the University of Western Australia, Leon Flicker AO, made the point that Aboriginal and Torres Strait Islander people regularly experience age-related health conditions from the age of 50 years that are not usually seen until 70 years or more in the non-Aboriginal and Torres Strait Islander population.[10]

Aboriginal and Torres Strait Islander people experience the burden of disease at around 2.3 times the rate of the general population.[11] Disabling health conditions that are common in older people, including pain, urinary incontinence, heart disease, type 2 diabetes, renal failure and frailty, affect Aboriginal and Torres Strait Islander people at younger ages.[12]

Long-term health conditions affect almost nine in 10 (88%) Aboriginal and Torres Strait Islander people over the age of 55 years.[13] Dementia is also more prevalent, with one study reporting that 12.4% of Aboriginal and Torres Strait Islander people in the Kimberley region aged 45 years and over were living with dementia, compared to 2.4% of the rest of the Australian population.[14] By any objective measure, they should be receiving proportionately higher levels of aged and health care.

The Australian Bureau of Statistics estimates at 30 June 2016 there were 124,012 Aboriginal and Torres Strait Islander people aged 50 years and older. By 30 June 2020, this population increased to approximately 148,312 people.[15] The age distribution of those aged over 50 years is shown in Table 1.

Table 1: Estimates of the Aboriginal and Torres Strait Islander population eligible for aged care[16]

Age group	50–54	55–59	60–64	65–69	70–74	75–79	80–84	85 +	Total
30 June 2016	37,215	30,361	22,424	15,416	8877	5023	2825	1871	124,012
	30.00%	24.48%	18.08%	12.43%	7.15%	4.05%	2.27%	1.50%	
30 June 2020 (Series A)	40,886	35,020	27,656	19,695	12,713	6840	3440	2062	148,312
	27.56%	23.61%	18.65%	13.46%	8.57%	4.36%	2.32%	1.39%	

Source: Australian Bureau of Statistics, *Projected population*, *Aboriginal and Torres Strait Islander Australians, Australia, state and territories, 2016 to 2031*, 2019.

In 2016, Aboriginal and Torres Strait Islander people comprised around 1.5% of the Australian population aged 50 years and older and around 0.9% of the Australian population aged 65 years or more.[17]

The Australian Bureau of Statistics' Series A projections describe population growth among Aboriginal and Torres Strait Islander people aged 50 years or more as being at a rate faster through to 2031 than for the total Australian population aged 50 years or more. Most of the growth is projected to be in major cities, and inner and outer regional areas. Even stronger growth is projected for Aboriginal and Torres Strait Islander people aged 65 years and over. This age group is projected to increase as a proportion of the Aboriginal and Torres Strait Islander population from 4.3% in 2016 to 8.1% in 2031. The number of Aboriginal and Torres Strait Islander people aged 65 years and over is projected to grow from around 34,000 people to 89,600. The cohort aged 50–64 years is projected to grow from around 90,000 to 122,700 people.[18]

Despite perceptions to the contrary, most Aboriginal and Torres Strait Islander people live in urban areas. Those people comprise the largest group of Aboriginal and Torres Strait Islander people who are likely to need care.[19] Fewer than one in five Aboriginal and Torres Strait Islander people over the age of 50 years live in remote or very remote parts of the country, as Table 2 demonstrates.

Table 2: The estimated distribution of the Aboriginal and Torres Strait Islander population by remoteness, 2016[20]

Age group	50–54	55–59	60–64	65–69	70–74	75–79	80–84	85 +	Total
Major cities	13,185	10,427	7733	5261	2956	1782	991	727	43,062 (34.72%)
Regional	16,381	13,951	10,260	7374	4242	2401	1332	872	56,813 (45.81%)
Remote and Very Remote	7649	5983	4431	2781	1679	840	502	272	24,137 (19.46%)
Total	**37,215**	**30,361**	**22,424**	**15,416**	**8877**	**5023**	**2825**	**1871**	**124,012**

Source: Australian Bureau of Statistics, *Projected population*, *Aboriginal and Torres Strait Islander Australians, Australia, state and territories, 2016 to 2031*, 2019.

7.3 Access to services

Aged care for Aboriginal and Torres Strait Islander people is currently delivered in one of two ways:

- through mainstream programs delivered by approved providers under the Aged Care Act, such as home care, residential care and Multi-Purpose Services
- through flexible specialist programs that sit outside the Aged Care Act, namely the Commonwealth Home Support Programme and NATSIFACP.

In 2017, the Australian National Audit Office reported that as few as 22% of the Aboriginal and Torres Strait Islander people receiving residential aged care services lived in an Aboriginal and Torres Strait Islander-focused residential facility—defined as having at least 30% Aboriginal and Torres Strait Islander residents.[21] In contrast, 61% of Aboriginal and Torres Strait Islander people accessing home care did so from Aboriginal and Torres Strait Islander-focused providers.[22] Evidence suggests that Aboriginal and Torres Strait Islander people living in urban locations have to relocate further away than others to take up aged care.[23] Further, those in very remote locations are often forced to seek care in major cities or regional centres because of their need for primary or secondary health care.[24]

In major cities and inner regional areas, care is delivered mainly by mainstream aged care providers, very few of which have an Aboriginal or Torres Strait Islander focus.[25] In remote and very remote areas, care is provided almost exclusively by government and not-for-profit providers, each working in partnership with Aboriginal community-controlled organisations such as local councils. For-profit providers have virtually no presence.[26] Across Australia, most aged care for Aboriginal and Torres Strait Islander people is delivered though the Commonwealth Home Support Programme, confirming the disadvantage experienced by Aboriginal and Torres Strait Islander people in the allocation of Home Care Packages.[27]

Where there is no provider, there is no institutional care. We have no doubt that informal carers shoulder much of this burden. A lack of care options can be devastating for Aboriginal and Torres Strait Islander people who have to leave their communities and Country to access care in regional or major cities.[28]

For the financial year ended 30 June 2020, Table 3 sets out the population of Aboriginal and Torres Strait Islander people receiving aged care, other than via NATSIFACP.

Table 3: Aboriginal and Torres Strait Islander people using aged care during 2019–2020, by age[29]

	50–64 years	65 years +	50 years and over total
Permanent residential care	469	1920	2389
Residential respite	168	634	802
Level 1 or 2 Home Care Package	477	1287	1764
Level 3 or 4 Home Care Package	641	1589	2230
Commonwealth Home Support Programme	8507	13,284	21,791

Source: Australian Department of Health, *Aged care data snapshot 2020 – third release*, 2020.

Aboriginal and Torres Strait Islander people comprised less than 1% of the people who received permanent residential aged care during 2019–20.[30]

Figures 1 and 2 show the differences in uptake for the age and gender profiles of the residential aged care and home care populations for the Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander populations as at 30 June 2019.

Figure 1: People using residential aged care by Aboriginal and Torres Strait Islander status, age and sex as at 30 June 2019[31]

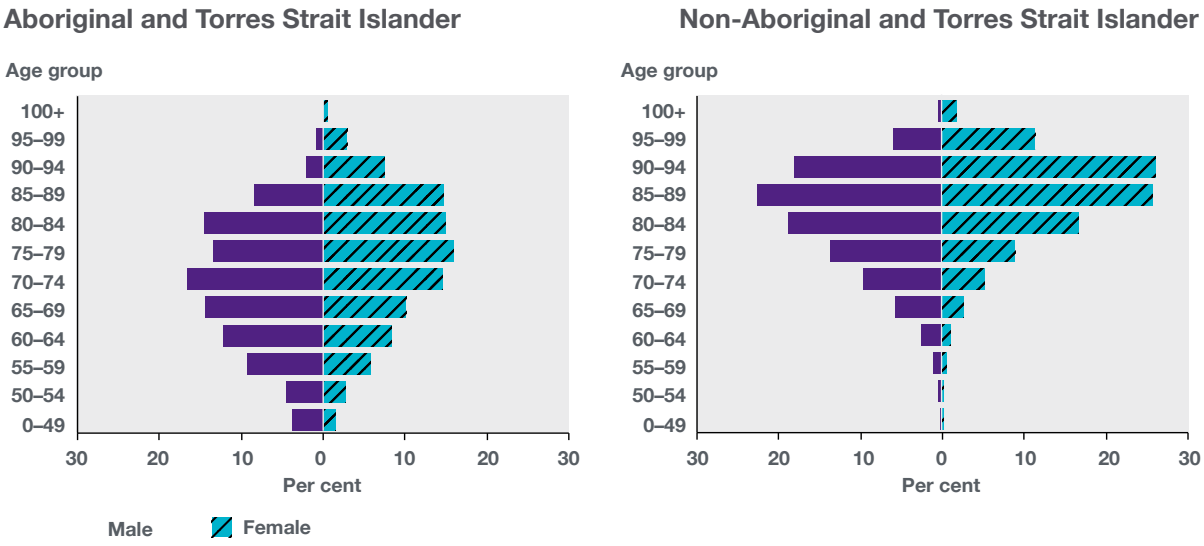

Figure 2: People using home care by Aboriginal and Torres Strait Islander status, age and sex as at 30 June 2019[32]

Source: Australian Department of Health, *Aboriginal and Torres Strait Islander people using aged care*, 2019.

Aboriginal and Torres Strait Islander people also find it difficult to access disability services.[33] In time, the maturation of the National Disability Insurance Scheme will result in the delivery of more appropriate services for Aboriginal and Torres Strait Islander people living with disability. But there is no guarantee that this need can be met in the short to medium term.[34] It follows that Aboriginal and Torres Strait Islander people aged between 50 and 65 years should remain able to access aged care services even though they may have an entitlement under the National Disability Insurance Scheme. Put simply, they should be served by the system that best meet their needs.

7.3.1 NATSIFACP

NATSIFACP is the main aged care policy response to the challenges of Aboriginal and Torres Strait Islander aged care. It has operated since 1994.[35] Through NATSIFACP, service providers are funded by the Australian Government to 'provide flexible, culturally appropriate aged care to Aboriginal and Torres Strait Islander people close to their home and community'.[36] While the program funds both home and residential care, it predominantly operates in remote and very remote areas and only provides services to a small portion of the Aboriginal and Torres Strait Islander population.

Through NATSIFACP, services are block or grant funded on 'an agreed allocation of' high care residential, low care residential and home care places.[37] The great advantage of NATSIFACP is its grant funding. This arrangement provides a set amount of funding to deliver aged care services to an allocated number of aged care places, regardless of whether those places are filled. The Aged Care Funding Instrument does not apply. Services funded in this way have the ability to pool funds, providing additional flexibility. The NATSIFACP model is well suited to providing financial certainty to small-scale, tailored residential and home care services.[38]

NATSIFACP providers are not required to be 'approved providers' under the Aged Care Act. While they do have to meet grant funding criteria, such as financial viability, they do not have to meet the same range of criteria as providers that deliver care under the Aged Care Act. We touch upon this matter in Recommendation 50 below.

However, a significant limitation of NATSIFACP is the small portion of the total aged care services it delivers to Aboriginal and Torres Strait Islander people. As at 30 June 2020, NATSIFACP funded 1264 operational residential and home care places across Australia.[39] Table 4 shows how these places were spread across the country.

Table 4: Total NATSIFACP places by location as at 30 June 2020[40]

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust
Major cities	14	94	24	-	33	-	-	-	**165**
Inner regional	-	44	-	-	-	30	-	-	**74**
Outer regional	13	-	-	-	37	-	-	-	**50**
Remote	-	-	45	15	-	-	-	81	**141**
Very remote	-	-	40	129	115	17	-	533	**834**

Source: Australian Department of Health, *Aged care data snapshot 2020 – third release*, 2020.

The bulk of NATSIFACP places are in remote or very remote locations. In its current form, NATSIFACP cannot meet demand in major cities and regional areas, where 80% of the eligible Aboriginal and Torres Strait Islander population are estimated to live.[41] Mainstream aged care is all that is available to the majority of the Aboriginal and Torres Strait Islander population, and this, without major modification, is unsatisfactory.

It is particularly concerning that Aboriginal and Torres Strait Islander people tend to be more highly represented in 'lower-level care', which is care delivered at homes or in community centres, than in residential aged care services or post-hospital care.[42] Aboriginal and Torres Strait Islander people do not access aged care at rates or at care levels in keeping with the percentage of their population who are aged over 50 years or commensurate with their higher incidence of complex and chronic disease.

The National Advisory Group on Aboriginal and Torres Strait Islander Aged Care paper, *Our Care, Our Way*, supports this view in saying:

> We do know Indigenous Australians eligible for aged care experience higher rates of chronic illness, yet apply for, access and receive appropriate levels of aged care at a much lower rate. This suggests that Indigenous Australians are significantly underrepresented in aged care services, given their rate of need as a population.[43]

Multi-Purpose Services, which are to be found predominantly in outer regional and remote areas, complement the coverage of NATSIFACP. As at 30 June 2019, there were 105 Aboriginal and Torres Strait Islander people receiving permanent residential care in Multi-Purpose Services.[44] At the time of writing, there are 179 Multi-Purpose Services in rural, regional and remote locations, but only one in the Northern Territory.[45]

While Multi-Purpose Services offer another way to provide flexible care in locations with smaller populations, they have not yet been deployed in the Aboriginal and Torres Strait Islander communities that could benefit from them.[46] Even with the expansion that we propose in Recommendation 55, Multi-Purpose Services will not address the needs of Aboriginal and Torres Strait Islander people living in major cities and larger regional centres.

Demographic trends identified in data from the Australian Bureau of Statistics, set out in Table 2, demonstrate that the aged care system will be challenged by an increasing number of older Aboriginal and Torres Strait Islander people needing aged care wherever they live. We are obligated to not only address this but to do so in a way that ensures that the aged care services provided are culturally appropriate, safe and welcoming to older Aboriginal and Torres Strait Islander people.

7.4 Aboriginal and Torres Strait Islander aged care pathway

We propose an aged care system that will provide Aboriginal and Torres Strait Islander people with meaningful choice—that is, choice between mainstream aged care providers with improved cultural capability and awareness, and, under the Aboriginal and Torres Strait Islander aged care pathway within the new system, providers who are predominantly Aboriginal and Torres Strait Islander-run and staffed and whose services are directed to Aboriginal and Torres Strait Islander people.

Recommendation 47: Aboriginal and Torres Strait Islander aged care pathway within the new aged care system

The Australian Government should ensure that the new aged care system makes specific and adequate provision for the diverse and changing needs of Aboriginal and Torres Strait Islander people and that:

a. Aboriginal and Torres Strait Islander people receive culturally respectful and safe, high quality, trauma-informed, needs-based and flexible aged care services regardless of where they live

b. priority is given to existing and new Aboriginal and Torres Strait Islander organisations, including health, disability and social service providers, to cooperate and become providers of integrated aged care services

c. regional service delivery models that promote integrated care are deployed wherever possible

d. there is a focus on providing services within, or close to, Aboriginal and Torres Strait Islander populations while maximising opportunities for people to remain on, and maintain connection with, their Country and communities

e. aged care is available and providers are engaged at the local aged care planning region level on the basis of objectively established need that is determined in consultation with Aboriginal and Torres Strait Islander populations and communities, and recognising that aged care needs and service delivery preferences may vary between locations and population centres

f. older Aboriginal and Torres Strait Islander people are given access to interpreters on at least the same basis as members of culturally and linguistically diverse communities when seeking or obtaining aged care, including health care services.

One object of the new Act that we propose is to provide comprehensively for a system of aged care based on a universal right to high quality, safe and timely support and care to assist older people to live an active, self-determined and meaningful life.[47] Aboriginal and Torres Strait Islander people should be able to obtain the benefits of this right through culturally safe care that is delivered by a single national system that is comprehensive, unified and flexible. It follows that the new aged care system should provide for a single national pathway that is capable of meeting the individual needs of older Aboriginal and Torres Strait Islander people.

Establishing the Aboriginal and Torres Strait Islander aged care pathway necessitates consideration of the role of NATSIFACP in the medium to long term. One option would involve the expansion of NATSIFACP as a separate program to make it more capable of meeting the growing need that we have described. Such an option is favoured by the Institute for Urban Indigenous Health.[48]

A second option involves incorporating, over time, the best features of NATSIFACP within the Aboriginal and Torres Strait Islander aged care pathway of the aged care system. This is what we propose. Both the National Advisory Group for Aboriginal and Torres Strait Islander Aged Care and the Australian Government supported this approach in responses to Counsel Assisting's final submissions.[49]

The second option would, as the National Advisory Group suggests, enable more funding with greater flexibility. This would allow the Australian Government to meet the needs of growing numbers of vulnerable Aboriginal and Torres Strait Islander people in rural, regional and urban areas.[50]

NATSIFACP sits outside of the aged care legislation. This means that it is subject to variability as a result of policy changes. The approach that we recommend moves the Aboriginal and Torres Strait Islander aged care pathway into legislation that has an object of safe and high quality aged care for all Australians. There are other advantages associated with the approach that we propose, namely:

- it will bring NATSIFACP into the aged care system and ensure greater flexibility and cultural safety to the care that is to be provided to the majority of Aboriginal and Torres Strait Islander people
- all Aboriginal and Torres Strait Islander people will benefit from aged care based upon, and informed by, assessments that determine need and connect the person with the appropriate levels of care
- all Aboriginal and Torres Strait Islander people in residential aged care will benefit from providers being subject to the same clinical requirements and triggers for care reviews as providers of mainstream aged care
- providers will be subject to the same approval and regulatory requirements as other aged care services, resulting in greater consistency in the quality of services
- the Aboriginal and Torres Strait Islander pathway will build on NATSIFACP by providing additional benefits such as a dedicated Aboriginal and Torres Strait Islander Aged Care Commissioner to assist providers and to ensure that Aboriginal and Torres Strait Islander people's voices are heard.

In such a system, there should not be any need for programs to sit outside the legislation. The Aboriginal and Torres Strait Islander pathway should, over time, absorb NATSIFACP and incorporate a number of its elements in flexible service arrangements for Aboriginal and Torres Strait Islander people. Incorporating these elements means that the best features of NATSIFACP will not be lost. Instead, they will be enhanced and expanded in conjunction with greater use of Multi-Purpose Services.

The care delivered through the Aboriginal and Torres Strait Islander pathway should have the flexibility to provide the care that all Aboriginal and Torres Strait Islander people need regardless of whether they live in a very remote community or in the largest city. The pathway will ensure the provision of a much greater suite of culturally safe aged care services across the country.

The demographic pressures that we have described above mean that these elements of the national system should be established without delay. The Aboriginal and Torres Strait Islander aged care pathway outlined in Recommendation 47 provides a framework for the single national system to meet this goal.

Effective service provision in this sensitive space should not be disrupted or compromised unnecessarily and will need an adequate period for transition. We recognise that the system that we propose represents a significant shift for some, as observed by Services for Australian Rural and Remote Allied Health:

> Aboriginal and Torres Strait Islander organisations would ideally lead this process but would require considerable resource assistance to enable skills development, training and deployment.[51]

Oversight of the process will be the responsibility of the Aboriginal and Torres Strait Islander Aged Care Commissioner we propose in Recommendation 49.

In response to Counsel Assisting's final submissions, the Institute for Urban Indigenous Health submitted that in regions with fewer than 2000 Aboriginal and Torres Strait Islander older people, regionally-based assessment teams should incorporate at least one Aboriginal and Torres Strait Islander registered nurse. In regions with 2000 or more older Aboriginal and Torres Strait Islander people, the Institute said that there should be Aboriginal and Torres Strait Islander-specific assessment arrangements in place.[52] According to the Institute, there are 13 locations—'8 state/territory capital cities and the 5 major regional urban areas'—with 2000 or more older Aboriginal and Torres Strait Islander people where 50% of older Aboriginal and Torres Strait Islander people live.[53] Ultimately, we see a role for the Aboriginal and Torres Strait Islander Aged Care Commissioner to drive implementation of assessment processes. We otherwise endorse this approach.

In the new aged care system, existing and new Aboriginal and Torres Strait Islander organisations, including health, disability and social service providers, should be supported and given priority to expand into aged care service delivery, whether on their own or in partnership with other organisations.

7.4.1 Embedding cultural safety

The marginalisation, discrimination, disadvantage and racism that many Aboriginal and Torres Strait Islander people experience during their lives can lead to a deep distrust of government and institutions.[54] This distrust has extended to the aged care system. It is apparent to us that many Aboriginal and Torres Strait Islander people will not engage with an aged care system that is not considered to be culturally safe.[55] Without cultural safety, there can be no trust.

Aged care services must be culturally safe for each person receiving care. It follows that cultural safety must be embedded throughout aged care: from initial contact with the system, during assessment, and when an older person receives aged care services at home, in their community or in a residential setting.

The National Aboriginal Community Controlled Health Organisation has explained that cultural safety is critical and 'must be both the starting point and central to any aged care offerings' for Aboriginal and Torres Strait Islander people.[56] The aged care system must reflect the fact that 'culture' means different things to different Aboriginal and Torres Strait Islander people in different communities and locations across the country, and that these matters are likely to develop and change over time.

What constitutes cultural safety requires ongoing reflection and engagement. It depends on the factors that affect each older person, such as location, personal circumstances and history.[57] The National Safety and Quality Health Service Standards User Guide for Aboriginal and Torres Strait Islander Health explains cultural safety as follows:

> Cultural awareness is a basic understanding that there is diversity in cultures across the population. Cultural competency extends beyond individual skills or knowledge to influence the way that a system or services operate across cultures. It is a process that requires ongoing learning. One-off training does not create a culturally competent workforce, but could create cultural awareness. A culturally safe workforce considers power relations, cultural differences and the rights of the patient, and encourages workers to reflect on their own attitudes and beliefs.[58]

We do not assume that connections to culture or Country are uniform for all Aboriginal and Torres Strait Islander people. We also recognise that Aboriginal and Torres Strait Islander cultures are dynamic, not static. The aged care system must recognise and respect this and be capable of flexibility in its responses.

Ms Olga Havnen, a Western Arrernte descendent and Chief Executive Officer of Danila Dilba Health Service in Darwin, described a culturally safe environment as 'one where we feel safe and secure in our identity, culture and community'.[59] People receiving aged care, not care providers, must be the ones to determine whether cultural safety has been achieved.[60]

Culturally safe and trauma-informed care must also be reflected in palliative and end-of-life processes. It must also extend into the period after a person has died to ensure that cultural requirements are met. We consider that additional steps are required to ensure that Aboriginal and Torres Strait Islander people have access to culturally relevant advance care planning processes that help them attain a 'good death' on their own terms. As Ms Havnen explained, advance care planning 'is based on the paradigm of the "individual's choices"' whereas end-of-life processes for most Aboriginal cultures consider the individual and family together, including kinship matters.[61] We recommend that the Australian Government, in conjunction with the States and Territories, establish culturally appropriate advance care directive processes, guidance material and training for aged care providers. These should recognise the diversity of cultural practices and traditions within each State and Territory, and address training and knowledge gaps.

Evidence suggests that obtaining an accurate and culturally safe assessment of an Aboriginal and Torres Strait Islander person into the future will demand:

- Assessments being conducted in person by, wherever possible, Aboriginal or Torres Strait Islander assessors or others who have undertaken training in cultural safety and trauma-informed approaches that have been approved by the Aboriginal and Torres Strait Islander Aged Care Commissioner. Where that is not possible, assessments should be conducted in the presence of care finders who are local Aboriginal and Torres Strait Islander people, culturally trained and familiar with existing Aboriginal and Torres Strait Islander service providers and trusted by the local population.[62]
- The provision of Aboriginal or Torres Strait Islander interpreting services.[63]
- The use of a culturally appropriate assessment tool that does not make assumptions about education, literacy or lifestyle.[64]
- An adequate amount of time, including multiple visits if required, to develop relationships of trust, and to allow for a slower approach where appropriate.[65]
- Taking care to avoid actions that could trigger trauma, such as requiring a person to tell their story multiple times or assuming that all Aboriginal and Torres Strait Islander people have close family or ongoing connections to Country.[66]

The care finders referred to in Recommendation 48 will be particularly valuable for Aboriginal and Torres Strait Islander people. As Professor Flicker explained, navigators are needed for both the aged care and the National Disability Insurance Scheme because they 'are both almost impenetrable systems for Aboriginal people, not only in rural and remote, but also urban centres'.[67] Mr Matthew Moore, from the Institute for Urban Indigenous Health, went further when he described the consequences for Aboriginal and Torres Strait Islander people who do not have this kind of assistance:

> if Aboriginal and Torres Strait Islander people don't have appropriate advocacy and don't have somebody who is accepted and trusted that can provide the information they require to get into the system the barriers are just too many for them and they will walk away from the system.[68]

This cannot be permitted.

Recommendation 48: Cultural safety

1. By 1 July 2022, the Australian Government and the System Governor should:
    a. require all of its employees who are involved in the aged care system, and any care finders who are not its employees, to undertake regular training about cultural safety and trauma-informed service delivery
    b. require all aged care providers which promote their services to Aboriginal and Torres Strait Islander people to:
        i. train their staff in culturally safe and trauma-informed care, and
        ii. demonstrate to the System Governor that they have reached an advanced stage of implementation of the Aboriginal and Torres Strait Islander Action Plan under the Diversity Framework.
2. From 1 July 2023, the System Governor should:
    a. ensure care finders serving Aboriginal and Torres Strait Islander communities are local Aboriginal and Torres Strait Islander people who are culturally trained and familiar with existing Aboriginal and Torres Strait Islander service providers who are trusted by the local population
    b. ensure, wherever possible, that aged care assessments of Aboriginal and Torres Strait Islander people are conducted by assessors who are Aboriginal or Torres Strait Islander people, or others who have undertaken training in cultural safety and trauma-informed approaches
    c. work with State and Territory Governments to establish culturally appropriate advance care directive processes, guidance material and training for aged care providers that account for the diversity of cultural practices and traditions within each State and Territory.
3. From 1 July 2023, the System Governor should require its employees, and any care finders who are not its employees, to undertake regular training about cultural safety and trauma-informed service delivery.

7.5 Aboriginal and Torres Strait Islander Aged Care Commissioner

Delivering broader coverage and greater access to high quality and culturally safe aged care to Aboriginal and Torres Strait Islander people demands a fundamental change in approach. At the outset, it demands leadership and an effective Aboriginal and Torres Strait Islander voice within the system.

For that reason, we propose the establishment of a statutory office within the System Governor—namely, a designated Aboriginal and Torres Strait Islander Commissioner to oversee service delivery of aged care.

Recommendation 49: An Aboriginal and Torres Strait Islander Aged Care Commissioner

1. **By 1 July 2023, there should be within the System Governor a statutory role that involves the ongoing fostering, promotion and development of culturally safe, tailored and flexible aged care services for Aboriginal and Torres Strait Islander people across the country. The person appointed to this role shall be an Aboriginal or Torres Strait Islander person.**
2. **A person should be appointed by 31 December 2021 under interim administrative arrangements to perform relevant functions and exercise relevant powers.**

The principal tasks of the Aboriginal and Torres Strait Islander Aged Care Commissioner should be to identify unmet need, develop strategies to meet that need and provide direction to the System Governor on resource allocation and program delivery. This will require collaboration with Aboriginal and Torres Strait Islander populations, communities and community health organisations about the types of aged care services they require. The Commissioner should work with local and regional aged care infrastructure as well as existing Aboriginal health networks. Consultation and co-design are crucial to this work.

The Aboriginal and Torres Strait Islander Commissioner should also be responsible for gathering data and providing information to the Pricing Authority about the real cost of delivering aged care to Aboriginal and Torres Strait Islander people around Australia. The Commissioner will coordinate, plan and advocate for the strategic expansion of Aboriginal and Torres Strait Islander aged care.

The Commissioner should have direct expertise—preferably a clinical background—in Aboriginal and Torres Strait Islander health and aged care. The Commissioner will need to establish and work with a network of officials located around the country and be capable of travelling to Aboriginal and Torres Strait Islander populations and communities. The Commissioner should have an Aboriginal or Torres Strait Islander background. To the greatest extent possible, staff within the Commissioner's office should be Aboriginal and Torres Strait Islander people drawn from across Australia. This is consistent with the principle that Aboriginal and Torres Strait Islander people should be involved, at all levels, in the planning and delivery of aged care services for their communities.

Other responsibilities of the Aboriginal and Torres Strait Islander Aged Care Commissioner should include:

- facilitating the transitioning of providers who currently operate outside of the Aged Care Act to become registered under the new national system
- encouraging more Aboriginal and Torres Strait Islander organisations to become approved providers, either independently or in partnership or collaboration with existing trusted organisations, as part of a regional, cooperative and integrated model of aged care service delivery
- assessing cultural safety training to ensure it is consistent, high quality and available to provider staff and management, as well as to those who carry out care finder roles, aged care assessment, and provider regulation and compliance activities
- providing technical assistance to Aboriginal and Torres Strait Islander-approved providers so that they develop their technical, clinical, and gerontological skills and governance capabilities
- developing provider capacity in governance, recruitment and business expertise, including education, tools, templates and resources for Aboriginal and Torres Strait Islander approved providers and facilitate Aboriginal and Torres Strait Islander staff to attain the necessary skills and qualifications during transition
- advocating for the aged care needs of Aboriginal and Torres Strait Islander populations across Australia
- keeping people informed about the degree to which the Aboriginal and Torres Strait Islander aged care pathway and other reforms arising from this report are meeting their aged care needs
- collaborating with the Australian Commission on Safety and Quality in Health and Aged Care to develop a national Continuous Quality Improvement Framework for Aboriginal and Torres Strait Islander aged care to complement the existing framework for primary health care and the broader aged care framework that we recommend elsewhere in this report
- developing an evidence base surrounding the capacity of both the aged care system and the National Disability Insurance Scheme to meet the needs of those Aboriginal and Torres Strait Islander people aged under 65 years, and, in the longer term, to commission research to ascertain the appropriate age for Aboriginal and Torres Strait Islander people to receive aged care services
- contributing to the oversight of the 'provider of last resort' model mentioned below, so that where the Commissioner is unable to identify and attract residential and/or home care approved providers in regions where there is identified Aboriginal and Torres Strait Islander aged care need, services are provided under a universal service obligation by negotiation with the relevant State or Territory and/or local governments, where appropriate and available, until another provider can be identified and established
- developing the workforce programs referred to in Recommendation 51.

The Australian Aged Care Commission will not be formally established until 2023 if the Independent Commission model is adopted, but a senior executive role, including the functions described above, should be established within the Australian Department of Health and Aged Care on an interim or transitional basis before the end of 2021. This will allow the necessary work to establish the proposed Aboriginal and Torres Strait Islander aged care pathway to commence while the new system arrangements are being put in place.

7.5.1 Interpreters

Approved providers of the Commonwealth Home Support Programme, Home Care Packages, residential aged care and other programs can access free migrant language interpreters for many of the aged care processes they are required to carry out to meet their responsibilities.[69] These include discussing care needs and preferences, explaining fees and charges, and developing care plans and agreements. There is no similarly available translating service for Aboriginal and Torres Strait Islander languages.

The absence of Aboriginal and Torres Strait Islander language interpreters in aged care is another example of systemic disadvantage faced by Aboriginal and Torres Strait Islander people. In response to Counsel Assisting's final submissions, the Australian Government advised us that a National Indigenous Interpreting Service is being progressed.[70] Development of this service must be prioritised. The barriers to communication that are presented by an absence of Aboriginal and Torres Strait Islander language interpreters are incompatible with a high quality and safe aged care system.

Even with the use of interpreters, the absence of a culturally safe assessment process means that some Aboriginal and Torres Strait Islander people in need of care can be reluctant to disclose the full extent of their needs and miss out on the services and supports they require.[71] The risk is that without cultural safety in assessment, inappropriate levels of care will be approved or Aboriginal and Torres Strait Islanders may stop seeking the care that they need. Like so many other facets of care, time is required for some Aboriginal and Torres Strait Islander people to develop the trust required to disclose significant personal information. Not establishing this level of trust is likely to result in them telling assessors 'what they think they want to hear'.[72]

7.5.2 Interface with the National Disability Insurance Scheme

Aboriginal and Torres Strait Islander people aged between 50 and 65 years who are eligible for both the National Disability Insurance Scheme and aged care, should receive services from the system that best meets their needs and should be able to make real choices about where they live.

Care needs to be taken to ensure that Aboriginal and Torres Strait Islander people who are aged over 50 years but under 65 years, with conditions that affect their ability to function, do not move straight into the aged care system where they may miss out on the full range of National Disability Insurance Scheme assistance that they would otherwise be entitled to. More often than not, this seems to be what happens.

Chapter 11 of this volume concerns younger people in residential aged care. There, we recommend that younger people at risk of entering residential aged care should be referred for assessment by the most appropriate agency. This will mean that Aboriginal and Torres Strait Islander people aged under 65 years who have one or more condition affecting their ability to function, should be assisted by their care finder to apply to the National Disability Insurance Scheme. Referral and assessment of Aboriginal and Torres Strait Islander people should be focused on obtaining the full range of services to which they are entitled. This approach will have the added benefit of assisting the National Disability Insurance Agency to understand the disability needs of Aboriginal and Torres Strait Islander people, wherever they live. The information collected will help the National Disability Insurance Agency target its development of culturally safe disability services and accommodation options.

7.6 Closing the Gap

The National Indigenous Reform Agreement, known as Closing the Gap, commenced in 2008. It included targets aimed at achieving equality for Aboriginal and Torres Strait Islander people in health and life expectancy outcomes within a generation.[73] In July 2020, a new National Agreement on Closing the Gap came into effect.[74] For the first time, representatives from the Coalition of Aboriginal and Torres Strait Islander Peak Organisations were involved in the design and development of a new framework. It is also the first time that all levels of government are parties to the agreement.

There are now four priority reform areas: Formal Partnerships and Shared Decision-Making; Building the Community-Controlled Sector; Transforming Government Organisations; and Shared Access to Data and Information at a Regional Level.

Although there are no aged care-specific targets in the new National Agreement on Closing the Gap, there are many areas that are directly relevant to Aboriginal and Torres Strait Islander aged care. The new National Agreement establishes 16 socioeconomic targets, listed as outcomes. Many of these outcomes, particularly those concerning training, employment, and supporting cultures and languages, align with the recommendations that we make in this chapter.[75]

Outcome one is especially relevant. Its goal is that ‘Aboriginal and Torres Strait Islander people enjoy long and healthy lives’. The outcome sets out indicators to track relevant changes such as ‘rates of accessing / utilisation of health services’. It also sets out areas for improved data development, including ‘a broader measure of access to services compared to need to include availability and distance travelled’ and ‘broader measures of wellbeing’.[76]

We see an undeniable nexus between health, aged care and the quality and length of an older person's life. This relationship is illustrated by Aboriginal and Torres Strait Islander people who, compared with the rest of the population, have higher rates of disability and are more likely to require aged care at a younger age.[77] Being able to access aged care services that assist each person to live as well as possible is an important factor in maintaining a person's health.

We encourage all parties to pay close attention to aged care data, the collection and sharing of which we expect to improve significantly, as the New Agreement on Closing the Gap is further developed and progress is tracked. In particular, the parties should examine the extent to which Aboriginal and Torres Strait Islander people are achieving parity in:

- access to the aged care system
- the number and type of aged care services they are assessed as eligible for
- the extent to which Aboriginal and Torres Strait Islander people obtain aged care services that meet their assessed needs.

The gap between Aboriginal and Torres Strait Islander people and other Australians must be closed. The changes we recommend to aged care will help. But to ensure the promise of high quality, culturally safe aged care is delivered, there must be ongoing monitoring and evaluation of the changes and the data. For as long as Aboriginal and Torres Strait Islander people continue to experience poorer health at earlier ages, the data should show that Aboriginal and Torres Strait Islander people access aged care assistance at higher rates and for higher levels of need than other Australians.

7.6.1 The Stolen Generations

Given the number of members of the Stolen Generations who will need care in the years ahead, cultural safety demands a trauma-informed approach to care. For members of the Stolen Generations, their childhood experiences further compromise their ability to seek services. Recognition of this reality should dictate and inform how such services should be provided.[78]

By 2023, all Stolen Generations survivors will be over the age of 50 years and potentially eligible for aged care services.[79]

Uncle Brian Campbell, a Murri man, spoke frankly about his experiences as a member of the Stolen Generations. He explained that he had missed out on the emotional benefits that come from being a part of a family. The boys' home he was sent to prohibited him from learning about his Aboriginal language or culture.[80] This has had life-long consequences.

> My dad is Aboriginal and my mum is Jewish. I was taken away from them when I was one year old—or going on to one—and I didn't see them until I was 15. I was part of the Stolen Generation, and I have never had that nurturing as a family, and so that's what happens with us. And I think that's the biggest problem I have in life is that I never had that family connection, but I had family connection with my grandfather at 15. He taught me a few of the Aboriginal things I had to learn and from there on I just was here.[81]

Overall, members of the Stolen Generations aged 50 years and over are more likely to be worse off than other Aboriginal and Torres Strait Islander people of the same age, on a range of health and socioeconomic outcomes.[82] They are a particularly vulnerable section of the Australian community.

Members of the Stolen Generations can fear the possibility of residential aged care, dreading 'another removal, being re-institutionalised and reliving their experience of trauma'.[83] The Healing Foundation, a national Aboriginal and Torres Strait Islander organisation that seeks to address ongoing trauma, submitted that the particular needs of the Stolen Generations can only be met by trauma-informed, culturally relevant approaches. Many others agreed.[84]

7.7 Priority for Aboriginal and Torres Strait Islander aged care providers

The Australian Government should enhance the involvement of Aboriginal and Torres Strait Islander people in the planning, running and delivery of aged care services for Aboriginal and Torres Strait Islander people.

There is opportunity to build on the successes achieved in health care, where there are approximately 143 Aboriginal Community Controlled Health Organisations across the country.[85] There is also scope for organisations that already deliver services in complementary or related areas, such as wellbeing and mental health services, to expand into aged care service delivery.

Recommendation 50: Prioritising Aboriginal and Torres Strait Islander organisations as aged care providers

1. The Australian Government should assist Aboriginal and Torres Strait Islander organisations to expand into aged care service delivery, whether on their own or in partnership with other organisations, including with Aboriginal Community Controlled Organisations and existing Aboriginal and Torres Strait Islander providers.
2. The Australian Government and the System Governor should encourage and support additional Aboriginal and Torres Strait Islander aged care providers by flexible approval and regulation of them to ensure:
    a. existing Aboriginal and Torres Strait providers are not disadvantaged and should continue to provide high quality and safe aged care while being assisted to meet the new provider requirements
    b. other organisations that wish to move into aged care to enhance services to Aboriginal and Torres Strait Islander people across Australia are given special consideration.

3. **Flexibility in approval and regulation should extend to such matters as: additional time to meet new requirements; alternative means of demonstrating the necessary capability or requirement; and, in some very limited cases, exemptions. Assistance should include financial assistance for capacity-building.**

The importance of developing links between primary health and aged care is evident in the Australian Government's *National Aboriginal and Torres Strait Islander Health Plan 2013–2023*, a central framework for Aboriginal and Torres Strait Islander health services.[86]

Aboriginal Community Controlled Health Organisations are recognised for their holistic approach to service delivery, with aged care a core component of primary health care functions.[87] These organisations are well positioned to lead the expansion of culturally safe, integrated aged care services for Aboriginal and Torres Strait Islander people across Australia.[88] A small number of these services already provide aged care services.[89] Services that have the trust of the Aboriginal and Torres Strait Islander people they serve, should be prioritised when consideration is being given to assisting expansion into aged care services, particularly where those services are community-controlled. The same priority should extend to services that are delivered to Aboriginal and Torres Strait Islander people by staff members 'who speak their language and understand their culture and their circumstances'.[90]

In fostering additional providers, the Australian Government should provide a degree of flexibility in the approval and regulation of Aboriginal and Torres Strait Islander approved providers. This is to ensure existing Aboriginal and Torres Strait Islander providers are not disadvantaged and that they should be able to continue to provide high quality and safe aged care while being assisted to meet the new provider requirements. We are encouraged by the Australian Government's acknowledgement in response to Counsel Assisting's Final Submissions that:

> As the system reforms, the Commonwealth should continually engage with Aboriginal and Torres Strait Islander providers to ensure they can operate in and take advantage of the reformed environment.[91]

Other Aboriginal and Torres Strait Islander organisations that wish to move into aged care to enhance services to Aboriginal and Torres Strait Islander people across Australia should be given special consideration, including additional time to meet new aged care provider requirements, alternative means of demonstrating the necessary capability or requirement, and, in limited cases, exemptions.

7.8 Employment and training

In the same way that Aboriginal and Torres Strait Islander people prefer to receive care from organisations that have ties to their own local communities, they often have a strong preference for face-to-face care being provided by other Aboriginal and Torres Strait Islander people.[92]

Recommendation 51: Employment and training for Aboriginal and Torres Strait Islander aged care

1. By 1 December 2022, the Australian Government should:
    a. develop a comprehensive national Aboriginal and Torres Strait Islander Aged Care Workforce Plan in consultation with the National Advisory Group for Aboriginal and Torres Strait Islander Aged Care, including:
        i. the refinement of existing Aboriginal and Torres Strait Islander training and employment programs
        ii. targets for the training and employment of Aboriginal and Torres Strait Islander people across the full range of aged care roles
    b. provide the funds necessary to implement the Plan and meet the training and employment targets
    c. work with the State and Territory Governments to implement the Plan, which should include making available vocational educational training facilities, teachers and courses available in urban, rural, regional and remote Australia.
2. In the interim, the Australian Government should ensure, in consultation with the National Advisory Group for Aboriginal and Torres Strait Islander Aged Care, that the existing employment programs and initiatives for Aboriginal and Torres Strait Islanders are aligned to the needs of the aged care sector.

Local Aboriginal and Torres Strait Islander staff are also better placed to meet the language needs of the people they provide aged care services to. This is particularly important for people living with dementia, where knowledge of the local language by people providing care is likely to facilitate communication with previously withdrawn residents.[93]

Cultural safety is most readily provided and trust more readily established, when Aboriginal and Torres Strait Islander people deliver aged care services.[94]

Uncle Brian Campbell put it this way:

> I find them friendly and culturally safe and they understand our needs…they're young and they're still learning but they still respect us as elders and as Aboriginal people. They don't stop learning from us and we don't stop teaching them. So…they actually ask you questions, "Is this going to be all right for you?" and you go yes or no. That's how it is with them.[95]

We have received evidence of best practice in this context:

- almost 80% of the staff at aged care provider Star of the Sea on Thursday Island are recruited from the Torres Strait, including the service manager[96]
- 95% of the staff who deliver centre-based care in the Anangu Pitjantjatjara Yankunytjatjara lands for Aboriginal Community Care in South Australia are local to the area[97]
- in areas of the Kimberley region (WA) serviced by the Kimberley Aged Care Services, 90% of the aged care workers and coordinators in remote locations are Aboriginal people from the communities where they work[98]
- 80% of aged care staff at aged care provider Purple House, in the Northern Territory, are Aboriginal and Torres Strait Islander people.[99]

However, there are significant barriers that work against increased Aboriginal and Torres Strait Islander employment in this sector, including:

- limited access to suitable pre-employment and employment training opportunities[100]
- employers lacking flexibility or cultural awareness to accommodate cultural requirements[101]
- a lack of wraparound support services to help people get and retain a job[102]
- negative perceptions of the aged care sector[103]
- less favourable pay and conditions compared with health sector opportunities.[104]

There is a need to increase the number of Aboriginal and Torres Strait Islander people who are able to fulfil the full range of aged care roles, within providers and also in the broader aged care system, to meet the expected demand for culturally safe and appropriate aged care services.

Against this background, the 2008 report, *A Matter of Care*, by the Aged Care Workforce Strategy Taskforce reported that 'a program to expand the recruitment of Aboriginal and Torres Strait Islander staff into the My Aged Care workforce is vital to support Indigenous consumers who are seeking information to meet cultural safety'.[105]

A Matter of Care did not address how to ensure more Aboriginal and Torres Strait Islander people enter the aged care workforce, but recommended the establishment of an Aged Care Workforce Remote Accord.

In a submission to us, the Aged Care Workforce Remote Accord made the case that remote Aboriginal and Torres Strait Islander communities need a 'workforce that understands the need for cultural sensitivity and respect of traditional law and customs' and highlighted the opportunities for local Aboriginal and Torres Strait Islander people to work in aged care and provide advice on services delivery and design.[106] It also said that more needed to be done to recruit local Aboriginal and Torres Strait Islander people. It explained that 'levels of education and community engagement may not be high, and roles in aged care may be seen as inaccessible'.[107]

Gaps in data mean there is not up-to-date information on the number of Aboriginal and Torres Strait Islander people working in aged care. The most recent data is for 2016 and suggests there were approximately 1800 Aboriginal and Torres Strait Islander people working in direct care roles in residential care, including 10% registered nurses and 7% enrolled nurses. In home care and support, the number of Aboriginal and Torres Strait Islander people working in direct care roles was also around 1800, including 3% registered nurses and 1% enrolled nurses.[108] There is a role for the Aboriginal and Torres Strait Islander Aged Care Commissioner in collating data and feeding this into broader initiatives about training and employment gaps.

Existing Aboriginal and Torres Strait Islander employment programs such as the Indigenous Advancement Strategy and the Tailored Assistance Employment Grants program, both administered by the National Indigenous Australians Agency, are not well targeted at aged care. The Institute for Urban Indigenous Health submitted that the Indigenous Employment Initiative program should be amended to direct the training component to the costs of meeting direct care worker training.[109] Other opportunities to increase Aboriginal and Torres Strait Islander employment in aged care have been missed. For example, the *National Aboriginal and Torres Strait Islander Health Plan 2013–2023* includes measures that concern aged care, but the *National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework (2016–2023)*, which looks to provide a workforce for the Health Plan, does not include such measures.

Plans for the Aboriginal and Torres Strait Islander health workforce should include engagement with aged care services. The Australian Association of Gerontology's Aboriginal and Torres Strait Islander Ageing Advisory Group has called for 'an Aboriginal and Torres Strait Islander aged care workforce training and employment strategy, and for measures to promote recruitment and retention of Aboriginal and Torres Strait Islander aged care employees'.[110] We agree. Later in this chapter, we recommend the preparation of an Aboriginal and Torres Strait Islander Aged Care Workforce Plan.

Evidence suggests that criminal history checks, also known as police checks, can be a barrier to the employment of more Aboriginal and Torres Strait Islander people in aged care. Aboriginal and Torres Strait Islander people are over-represented in the criminal justice system and are disproportionately impacted by statutory fine enforcement regimes that can result in imprisonment.[111] Some Aboriginal and Torres Strait Islander people elect not to apply for jobs in aged care because they are daunted by the police check process, lack the documentation necessary to obtain a police check, or have a sense of shame at even relatively minor convictions.[112] Good providers help Aboriginal and Torres Strait Islander people overcome these barriers. Both Ms Ruth Crawford of Kimberley Aged and Community Services and Mr Graham Aitken, a Yankunytjatjara descendent and the chief executive officer of Aboriginal Community Care SA, gave evidence about the work that they do to assist their potential Aboriginal and Torres Strait Islander staff members to apply for necessary documentation and police checks.[113]

Police checks are currently required for all staff employed by approved providers and providers delivering care under NATSIFACP or the Commonwealth Home Support Programme. We support the retention of 'precluding offences'—that is, offences that preclude a person from working in aged care—particularly those involving murder or sexual assault.[114] Criminal history checks will be a component of the personal care worker registration that we propose in Recommendation 77. But the various aged care programs in existence at present have different thresholds for the kinds of convictions that preclude a person from any employment in aged care. In particular, NATSIFACP precludes people from aged care work on the basis of a broader range of offences. For instance, a driving offence involving the death of a person may preclude someone from working in aged care.[115]

In our view, some convictions should exclude people from aged care employment, but the threshold must be consistent across all of the types of aged care available under the new aged care system. There are instances where providers should be able to exercise discretion and put in place mitigation strategies for other, less serious, convictions. The current NATSIFACP manual focuses on the risk of harm to people receiving aged care and provides instruction on how to weigh up relevant considerations about a person's criminal history.[116] The Aboriginal and Torres Strait Islander Aged Care Commissioner should draft guidance to all aged care providers to assist them to exercise their discretion when employing Aboriginal and Torres Strait Islander people with a criminal record.

7.9 Funding

We propose five funding streams for the Aboriginal and Torres Strait Islander service arrangement:

- home and community care
- residential and respite care
- capital development and expenditure
- provider development
- retaining connection to Country (return to Country).

Aged care providers should be able to pool funding for the first two streams. Allowing funding to be pooled recognises the flexibility that is needed by approved providers to deliver care to Aboriginal and Torres Strait Islander people in the locations where they need care. Pooled funding is particularly important to the financial viability of small-scale services that cannot use economies of scale.[117] Aboriginal and Torres Strait Islander residential and home care providers are most likely to be small-scale, tailored services providers. Mr Aitken described a rare urban NATSIFACP facility run in Adelaide that has only 33 beds as 'one of the larger ones'.[118]

However, it is not enough simply to replicate the level of funding that NATSIFACP presently makes available. The funding must meet the actual costs of delivering care to Aboriginal and Torres Strait Islander people, and in the locations where that care is delivered. As part of its consultation process, the Aboriginal and Torres Strait Islander Aged Care Commissioner will need to assist the Pricing Authority to acquire information about the actual costs of delivering high quality and culturally safe aged care services to Aboriginal and Torres Strait Islander people across Australia. The Pricing Authority will need to carry out costing studies at a more granular level than simply applying a geographic classification system across a region to determine likely costs and current supplements.[119]

Both the Pricing Authority and the Aboriginal and Torres Strait Islander Aged Care Commissioner will need to consider the needs of people at specific locations. These may include the proportion of the Aboriginal and Torres Strait Islander population requiring aged or disability care, geography, weather, cultural practices and requirements, interpreter and translation needs, the prevalence of complex or changed behaviours and rates of dementia, whether there are opportunities to partner with other services in the location or region, the ability to train and retain staff, and the costs of bringing in external staff if they are required for particular roles.

In the *Shifting the Dial 5 Year Productivity Review*, the Productivity Commission pointed to the benefits that longer funding for periods of five years would have for Local Health Network planning and efficacy.[120] In its *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services Productivity Commission Inquiry Report*, the Productivity Commission recommended a default contract length of seven years for family and community services.[121] It recommended default contract terms of 10 years for human services in remote Aboriginal and Torres Strait Islander communities to 'improve the continuity of service provision and contribute to better outcomes'.[122] We agree.

Funding under the Aboriginal and Torres Strait Islander aged care pathway should, in general, be provided for longer terms, with the possibility of grants of up to seven years and not less than three years. This will enable aged care providers to plan effectively, establish and deliver services, train and employ staff, build capacity and partnerships, and acquire the trust of the people they serve through demonstrated effectiveness. It will also necessitate proactive system oversight to manage risks and ensure providers deliver safe and high quality aged care.

There is also a need for a capital development and expenditure stream, which could be made available upon application. This would enable the development and maintenance of the infrastructure needed to deliver aged care, particularly residential aged care, and to establish respite facilities. It may also be necessary to pay for accommodation for staff who have to move to remote locations. This stream could be used to fund or establish physical infrastructure for providers where there is currently unmet need—for example, the 2019 announcement that the Australian Government will fund a much-needed facility at Nhulunbuy, in the Northern Territory, after many years of delay.[123]

The provider development stream—an enhancement to the existing Remote and Aboriginal and Torres Strait Islander Aged Care Service Development Assistance Panel program—should be available on an as-needed basis and provide funding to assist in organisational development as opposed to bricks and mortar. This will establish small regional cooperatives that work through, and in conjunction with, a number of service providers in that region.

Many Aboriginal and Torres Strait Islander people have a connection to Country that is central to their ability to live, age and die well. At the Darwin Hearing, an Aboriginal Elder who had to move 800km away from her community of Numbulwar to access residential aged care in Darwin, said:

> 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.[124]

Uncle Brian Campbell described his connection to Country:

> I felt really comfortable when I walked on Country, and all my spirits come back and haunted me and told me I should've been there ages ago. So that's something what non-Aboriginal people cannot understand, what the spirit does to you, how you feel.[125]

He told us that he would like to return to Country. He said that it will be the 'last place' that he goes.[126]

As noted by the South Australian Lifetime Support Authority:

> the primary concern of people living in remote Aboriginal communities is to continue living within culture on the Lands, close to family, regardless of disability or care arrangements.[127]

This observation was echoed by the words of others.[128] The retaining connection to Country (return to Country) funding stream is intended to provide funding to assist Aboriginal and Torres Strait Islander people who have left Country or their community, to receive aged care services to return to their home or community or to return for visits in circumstances where they are unable to return to Country or their community on an ongoing basis. This stream should also assist the older person to maintain connection to Country and community through the use of technology for communication, and to assist a family member to travel to the older person when the older person is unable to travel themselves.[129]

In response to Counsel Assisting's final submissions, the Australian Government told us that it 'respects the need for cultural safety and connection to country'.[130] True respect of the importance of these matters requires the practical support that we contemplate in our recommendations.

Recommendation 52: Funding cycle

1. The Australian Government should block fund providers under the Aboriginal and Torres Strait Islander aged care pathway (see Recommendation 47) on a three-to seven-year rolling assessment basis.
2. The Pricing Authority should:
    a. set the funding of the Aboriginal and Torres Strait Islander aged care pathway following advice from the Aboriginal and Torres Strait Islander Commissioner, and
    b. annually assess and adjust the block funding on the basis of the actual costs incurred while providing culturally safe and high quality aged care services to Aboriginal and Torres Strait Islander people in the preceding year.

Recommendation 53: Program streams

1. Under the Aboriginal and Torres Strait Islander aged care pathway, the Australian Government and the System Governor should:
    a. provide flexible grant funding streams that are able to be pooled for:
        i. home and community care
        ii. residential and respite care, including transition
    b. establish funding streams under the Aboriginal and Torres Strait Islander aged care pathway that allow Aboriginal and Torres Strait Islander aged care pathway providers to apply for funding for:
        i. capital development and expenditure
        ii. provider development
    c. make funds available, on application, for any residential aged care provider that has Aboriginal and Torres Strait Islander residents who require assistance to retain connection to their Country, including meeting the costs of:
        i. travel to and from Country, as well as the costs of any people needed to provide clinical or other assistance to the resident to make the trip
        ii. a family member travelling to and from the older person at a distant residential facility
        iii. establishing, maintaining and using infrastructure that facilitates connection between the residential facility and communities on Country, such as videoconferencing technology.

7.10 Conclusion

There is an opportunity to bring about real improvements in aged care for Aboriginal and Torres Strait Islander people. The reforms that we propose start with the aged care sector understanding the actual aged care and support needs of older Aboriginal and Torres Strait Islander people, and how to best meet them. Aboriginal and Torres Strait Islander people should have meaningful choices in aged care services and providers. They should be able to access an aged care pathway and assessment services that are sensitive to their needs. There should be equity of access and a commitment to high quality, safe and culturally aware aged care.

In aged care, there should be active partnership with Aboriginal and Torres Strait Islander people through consultation, co-design, building cultural expertise and building regional relationships. New providers will need to be supported to move into aged care, and the Aboriginal and Torres Strait Islander workforce will need to be trained and expanded.

There are significant opportunities for integrated, flexible and innovative aged care services that prioritise the wellbeing of the older Aboriginal and Torres Strait Islander people they serve. While this will take time, the work should commence without delay.

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8. Aged Care in Regional, Rural and Remote Areas

8.1 Introduction

Australia is a large and sparsely settled country. This means that the challenge of delivering services in regional, rural and remote areas is difficult to resolve. We heard evidence about the particular needs of older people in Australia's regional, rural and remote areas and the difficulties they have when trying to access high quality aged care services in their local areas. That evidence has referred to: remoteness; scarcity of local services; greater travel times; higher costs to access and provide services; difficulties recruiting and retaining service providers; and a lack of access to health professionals.[1] The need for high quality and culturally safe aged care for Aboriginal and Torres Strait Islander people living in regional, rural and remote Australia was also identified.

In our report, we use the words 'regional', 'rural' and 'remote' to refer to areas outside major cities.[2] There are around 1.4 million people aged over 65 years living in regional, rural and remote Australia.[3] These people should have better access to aged care than they do. This should be achieved through better planning, costing and funding, and more flexible, integrated service provision.

People living in regional, rural and remote areas experience relative disadvantage in various ways. On average, they have lower incomes, poorer education, and poorer health outcomes, including higher rates of disability, disease and injury.[4] This disadvantage can increase the need for support in older age. In regional, rural and remote areas, older people make up a greater share of the population than elsewhere in Australia.[5] And yet, availability of aged care in regional, rural and remote areas is poor—and it is worsening.[6]

Sue Dunlop

Mrs Sue Dunlop and Mr Phillip Dunlop are a married couple who live on a farm in a small country town three hours from Mudgee, New South Wales. They told us about the challenges they had experienced in finding a provider prepared to travel to their rural property to deliver care. Mrs Dunlop told us, 'I don't want to move. I love having animals around me'. She continued: 'But it is so, so hard when you can't get any help out there'.

Mrs Dunlop was assessed as needing a Level 4 Home Care Package but a Level 4 package was not available. She was assigned a Level 3 package in the interim. But the Dunlops told us that they were not able to find a provider that could offer the full range of services for Mr Dunlop's Level 3 package. The provider told them that they could not offer more services because they had insufficient staff. When

Mrs Dunlop moved to a Level 4 package, nine months later, the level of service she received did not increase.

A dispute arose when, for the first time in two years, the provider charged for 'travel'. Their property is accessible via five kilometres of all-weather gravel or 'dirt' road. They were informed that the new fee covered the cost for Mrs Dunlop's carer to be accompanied by an experienced four-wheel drive driver. The Dunlops continued to have issues with the provider, resulting in the suspension of Mrs Dunlop's home care services. The Dunlops told us that there were no other providers that they could easily turn to and that the interruption to Mrs Dunlop's care left them with virtually no support.[7]

8.2 Planning in regional, rural and remote Australia

Recommendation 54: Ensuring the provision of aged care in regional, rural and remote areas

The System Governor should ensure that older people in regional, rural and remote locations are able to access aged care in their community equitably with other Australians by:

a. **identifying areas where service supply is inadequate, and**

b. **actively responding by planning for, and supplementing services to meet entitlements and needs.**

The aged care system needs precise and comprehensive planning and management. There should be improved analysis of unmet need and future demand, accurate costing of the provision of care in different locations, and increased use of flexible and adaptable funding to supplement gaps in service provision. The System Governor must ascertain, on a regular basis:

- the aged care needs of older people in different geographic areas, including in regional, rural and remote areas
- the services which are required to meet those needs in those areas
- the extent to which, in those areas, services are not available and needs are not being met.

By doing this, the System Governor can prepare a transparent response to unmet need, including increasing service provision and identifying the minimum services that a person living in a particular location can expect to receive.

The management function must rest on a sound understanding of what resources are required and where they are required. The current aged care legislative framework acknowledges the 'special needs' of older people who live in rural or remote areas.[8] At least in relation to allocation of residential aged care places and payment of flexible care subsidies, this framework shows an intention to identify and meet those needs. The evidence before us does not suggest that the intention translates into practical results in any consistent and systemic way.[9] Instead, the evidence shows that specific planning to meet the needs of people in regional, rural and remote Australia is either not happening or, if it is happening, is not working.

Representatives from the Australian Government acknowledged that projections of demand for residential aged care and home care services in regional, rural and remote locations are population-based and do not take into account the high levels of health care needs in a community. They also acknowledged that there were no models to make projections about aged care needs in those locations, and that the Australian Government did not have a 'targeted strategy for providing home care in remote and very remote locations'.[10]

It is imperative that an accurate and detailed audit of local variations in access to aged care be conducted, and then maintained. The Australian Department of Health accepts this. Mr David Hallinan, then Deputy Secretary for Ageing and Aged Care in the Department, told us that ideally aged care planning should take account of what services are available and the needs of the population now and in the future.[11] He said that the Australian and State and Territory Governments should share data about the different types of services across Australia and potentially establish service-level benchmarks or standards for particular areas:

> for aged care, there is some point at which you would need to make judgments about, well, where's the right point to be providing multipurpose service, where's the right point to be providing a market-based solution and at what stage in a planning framework do you apply principles of a market-based solution or principles of a supply-based government contracted or MPS-type [Multi-Purpose Services] solution.
>
> And I think that differs depending on the location and I think it would differ depending on which providers, whether they're government or NGO [non-government organisation] or privately provided services, are embedded and have deep roots in the community. And local community engagement, I think, would be the most important aspect of determining in each circumstance what your best solution is. But I think in all circumstances some level of cooperation between service providers at a minimum would be necessary.[12]

This sharing of data will require the System Governor to evaluate service accessibility and plan strategies to meet deficient access where it occurs, at the local level, supported by a regional network of offices. Specific local knowledge is essential in this evaluative and planning process. The needs of a population and the established services available should inform the type and range of services provided in an area. Determining the level of service provision should be a transparent process so that people know what minimum level of service they can expect to be provided for any given location.

Proper management for provision of aged care services also requires an understanding of the actual costs of providing those services in different areas. It costs more to provide aged care services to a person living in a regional, rural or remote area than it does in a major city.[13] Accurately costing, and funding, the provision of services in regional, rural and remote Australia will attract more providers to these areas by ensuring that they are paid fairly in line with their costs. The Pricing Authority should have responsibility for determining, each year, the costs of service provision in different areas in Australia, including regional, rural and remote areas (see Recommendation 115).[14]

Allocation of funding on a differentiated basis would eliminate the need for the Australian Government to make a separate payment, such as the Viability Supplement, to aged care providers in regional, rural and remote areas.[15] This supplement, despite a number of recent increases, is not working. In its 2020 report, the Aged Care Financing Authority noted that:

> there is a growing number of smaller residential care providers, particularly in regional and remote areas, facing significant financial stress and seeking to leave the industry.[16]

Mr Craig Barke, Chief Executive Officer of UnitingCare Queensland and Chair of the Australian Regional and Remote Community Services Board, said that although UnitingCare Queensland's very remote sites receive a very high level of Viability Supplement, it still needed to 'trim' its costs.[17] Some aged care providers told us that they are currently cross-subsidising their regional, rural and remote services, which receive the Viability Supplement, from their metropolitan services and that this is not sustainable.[18]

This situation is perhaps unsurprising, because the Viability Supplement is not based on an assessment of the actual cost of service provision in regional, rural and remote areas.[19] However, until funding is allocated on the differentiated basis described above, the Viability Supplement should be retained at the level announced on 31 March 2020 and indexed annually (see Recommendation 113).

Wherever possible, older people should have timely access to high quality and safe aged care services to support them to age in their own communities. The aged care system must be flexible and adaptable to provide services for smaller and dispersed populations, and to provide services where there are fewer aged care providers.

The Pricing Authority should also consider the best funding method for aged care in regional, rural and remote areas. Under the National Health Reform Agreement, Australian Government funding for non-metropolitan hospitals with low service activity is calculated using a different methodology to that which is used for mainstream larger public hospital funding. Many smaller public hospitals in regional, rural and remote areas are funded by a combination of block funding and activity based funding.[20] The System Governor should consider pooled funding across service systems, such as with the disability and health sectors.[21]

Adopting flexible funding approaches would recognise the disproportionate impact that the change to individualised funding for Home Care Packages has had on older people in regional, rural and remote areas. Mr Graeme Barden, from the Australian Department of Health, said that the impact of the Home Care Package reforms has been to reduce access to Home Care Packages for people in remote and very remote areas.[22] We heard evidence in support of policies that promote consumer choice in regional, rural and remote areas.[23] Our proposals to improve funding for home care will go some way to addressing these concerns.

Even with improvements to planning, costing and funding for different areas, it may not always be possible to deliver aged care services in an older person's local community. In some communities, the provision of certain aged care services may not be feasible and an older person may have to travel or relocate to receive services that are needed. This is not desirable and should only occur on rare occasions when it is unavoidable. In most cases where there are few or no aged care providers, the System Governor should commission a provider of last resort. This approach must be reflected in aged care planning and in particular for areas where home care services are inadequate.

8.3 Expansion and augmentation of the Multi-Purpose Services Program

Recommendation 55: The Multi-Purpose Services Program

From 1 December 2021, the Australian Government, working together with State and Territory Governments, should maintain and extend the Multi-Purpose Services Program by:

a. establishing new Multi-Purpose Services in accordance with community need as identified by the System Governor, including:

   i. in areas where there is an existing aged care provider, if the System Governor advises that the demographic and market profile justify increased access to aged care services

   ii. in areas where there is not an existing acute health service, but governments agree that a combined aged care and health service would address local needs

b. ensuring that people entering Multi-Purpose Services are subject to the same eligibility and needs assessments as all other people receiving aged care

c. requiring people accessing Multi-Purpose Services to make contributions to the cost of their care and accommodation on the same basis as all other people receiving aged care (with appropriate protections for people currently accessing Multi-Purpose Services)

d. permitting Multi-Purpose Service providers to access all aged care funding programs on the same basis as other aged care providers

e. developing a funding model for Multi-Purpose Services which reflects the changing number and acuity of people receiving care over time while maintaining certainty of funding over the course of a financial year

f. establishing a cost-shared capital grants program to rebuild or refurbish older Multi-Purpose Services to ensure that the infrastructure meets contemporary aged care design standards, particularly to support the care of people living with dementia.

The Multi-Purpose Services Program should be retained and expanded. The program is a longstanding joint initiative between the Australian and State and Territory Governments. One of its primary objectives is to provide integrated health and aged care services for regional, rural and remote communities in both residential aged care and home care settings. The program facilitates the presence of health and aged care services in regions that could not viably support a standalone hospital or residential aged care facility.[24]

The Multi-Purpose Services Program operates under a series of agreements, usually between the Australian Government and a State or Territory Government. The Australian Government provides funding to the approved provider in the form of a flexible care subsidy under the *Aged Care Act 1997* (Cth). Funding is based on the number of 'high care' and 'low care' residential places and the number of home care places allocated to each service.[25] While the 'high care' and 'low care' classification ceased for mainstream residential care in 2014, it continues to be used for the Multi-Purpose Services Program.[26] The service provider 'pools' or combines the aged care subsidy with funding for health care services received from the State or Territory Government.[27] As at 30 June 2020, there were 179 operational Multi-Purpose Services across Australia.[28] They provide for, among other things:

- integrated health, community and aged care in regional, rural and remote communities
- care that is focused on the needs of the local community
- financial viability of providing services in some communities
- the retention of health services in regional, rural and remote locations
- efficient use of scarce resources.[29]

Evidence about the Multi-Purpose Services model is generally positive.[30] A 2019 evaluation commissioned by the Australian Government and conducted by the Centre for Health Economics Research and Evaluation at the University of Technology Sydney identified the high social and economic value of the Multi-Purpose Services Program within regional, rural and remote communities. It found that the program was a 'sound model' of aged care service provision.[31] The authors of the University of Technology Sydney review made a number of recommendations for improvements to the program. The Australian Government has accepted, or at least agreed in principle, to those recommendations.[32]

We recommend that the program should be maintained, but with some significant changes.

There are many small communities in regional, rural and remote Australia that do not have local access to aged care services, and do not have a public hospital or other State or Territory Government health presence. Establishment of Multi-Purpose Services in these locations would produce a number of benefits, including:

- allowing for local provision of aged care services, including home care
- supporting the establishment of health infrastructure for lower-level care after an acute episode in a larger centre
- enabling such infrastructure to support visiting specialists and, potentially, other types of health and community service providers such as disability support services.

The Australian Department of Health, which administers the program, has stated that 'as a rule, new Multi-Purpose Services are not established in towns where other residential aged care services already exist'.[33] However, some existing Multi-Purpose Services operate in the same area as other aged care providers. To the extent that there is such a rule, it should no longer apply.[34] The main concern should be the needs of the local community. If the System Governor identifies a need for increased access to aged care services in a particular area, the existence of a residential aged care service in that area should not prevent the establishment of a Multi-Purpose Service.

Nor should the establishment of new Multi-Purpose Services be limited to locations with existing local hospitals. That historical approach is not warranted. The proper location of new Multi-Purpose Services should be determined by local needs in a particular area and not by arbitrary rules. Meeting those local needs through the establishment of a Multi-Purpose Service should be the subject of consultation between the Australian Government and the relevant State or Territory Government.

Dr Nigel Lyons, Deputy Secretary, Health System Strategy and Planning, New South Wales Ministry of Health, said that joint planning for, and addressing the needs of, each community is vital.[35] In November 2019, he told us that over the previous 'five-plus' years, there had been a move away from consultative arrangements between the Australian Government and the New South Wales Government in their planning for Multi-Purpose Services to a situation where the State Government was considered as 'just another provider' required to apply for places.[36] He said:

> we are so inextricably bound with the Commonwealth around responsibilities for health, aged care, disability, it's important that we work collaboratively in all of these interface areas and we find solutions, particularly when we get into smaller rural communities where it's critical that we find solutions that will work to support those local communities.[37]

The Australian Government has agreed to work with the State Governments to establish a more collaborative governance arrangement for the Multi-Purpose Services Program.[38] They should also work with the Territory Governments. All governments should work together to identify the characteristics of communities that could benefit from an expanded Multi-Purpose Services model.

There is also a need for greater alignment of aged care services provided through the Multi-Purpose Services Program and aged care services provided through the 'mainstream' aged care system. In this context, we see at least three problems.

First, there are inconsistencies between fees and charges paid by people receiving aged care services from Multi-Purpose Services and fees and charges paid by people receiving care from mainstream aged care services. For instance, there is no requirement for Multi-Purpose Services to charge daily care fees or for people entering a Multi-Purpose Service to pay a Refundable Accommodation Deposit or a Daily Accommodation Payment. Multi-Purpose Service providers can determine whether and how much residents are charged for daily care fees and accommodation, including whether to accept a Refundable Accommodation Deposit, up to the limits that apply to residential aged care providers.[39]

People entering a Multi-Purpose Service may currently enjoy a considerable financial advantage compared to those entering other residential aged care facilities.[40] This has the potential to create an inequitable and unfair competitive advantage for Multi-Purpose Services. It can also create inequities between people receiving aged care services in the same area.[41] In the future, people accessing Multi-Purpose Services for residential care should be required to make equivalent financial contributions as others accessing residential aged care. Any change should be made subject to preservation of the rights of existing residents in Multi-Purpose Services.

Second, assessment for entry into aged care is not consistent across Multi-Purpose Services or between the Multi-Purpose Services Program and the mainstream aged care system. In particular, there is no formal requirement for assessment by an Aged Care Assessment Team before a person receives residential aged care or home care from a Multi-Purpose Service.[42] Nor do State and Territory Governments adopt a consistent approach to assessment before a person enters a Multi-Purpose Service.[43] There should be a consistent assessment process for all people entering any type of aged care. A single eligibility and needs assessment will promote equity of access, improved assessment of need and better data capture.

Third, the Australian Government's funding contribution to Multi-Purpose Services is different from its funding contribution to other aged care services. Funding for a Multi-Purpose Service is 'calculated according to a determined number of high care and low care residential places and home care places'.[44] Funding is provided in the form of a flexible care subsidy under the Aged Care Act. Under the *Aged Care (Subsidy, Fees and Payments) Determination 2014* (Cth), the amount of funding is determined for each allocated place, adjusted for factors such as care status—high, low or home care—and the remoteness, size and resident mix of the Multi-Purpose Service.[45]

Under this approach, funding is fixed and not contingent on occupancy. This may provide 'administrative simplicity and reasonable funding certainty'.[46] It does not, however, reflect the actual cost of providing care because the funding does not respond to changes in acuity of those needing care, or numbers of people actually receiving care.[47] Evidence suggests that Australian Government funding for Multi-Purpose Services has failed to keep pace with need and with equivalent mainstream aged care funding arrangements.[48]

Pooled block funding is one of the factors that sets Multi-Purpose Services apart from mainstream aged care. The University of Technology Sydney review highlighted that the certainty resulting from pooled block funding had helped to respond to economies of scope and scale, and avoided market failure that can arise where there are factors such as fluctuating demand, unpredictable revenue, minimum staffing levels and high fixed costs.[49]

The authors of the University of Technology Sydney review recommended that research be undertaken into developing an Australian Government funding contribution model for aged care services in Multi-Purpose Services which, among other things, reflects prevailing acuity and numbers of aged care residents while maintaining medium-term certainty, administrative simplicity and the effectiveness of the pooled funding arrangements. The authors also said that the funding research should consider concerns about adequate care funding for both residential and home care acuity and address the issue of delivering Home Care Package Program services and Commonwealth Home Support Programme services in small isolated communities.[50] The Australian Government has agreed in principle to this recommendation.[51]

Through pooled funding, Multi-Purpose Services can provide innovative, flexible and integrated health and aged care services to local communities in regional, rural and remote areas. Pooled funding also facilitates efficient use of limited physical and human resources while improving the scope of options for service delivery and the approach may be applicable to other types of health and community services in these areas.[52] Integrated service provision is particularly important in regional, rural and remote Australia.[53] It should be easier for non-government organisations to access this flexible funding so as to provide integrated services.

The Pricing Authority should develop the new funding model for Multi-Purpose Services.

Although the Multi-Purpose Services Program is a practical example of the benefits of integrated service provision, many existing buildings that house Multi-Purpose Services are outdated and need improvements.[54] The absence of dementia-specific facilities is a barrier to older people continuing to live in their own community.[55]

The authors of the University of Technology Sydney review found that a large number of Multi-Purpose Services had difficulty accessing funds to upgrade their facilities.[56] Under the Multi-Purpose Services Program, the Australian Government is not required to provide capital funding to improve infrastructure.[57] Multi-Purpose Services are not eligible to apply for Australian Government capital funds for new or renovated infrastructure.[58] In contrast, mainstream aged care providers in regional, rural and remote areas are able to access infrastructure grants provided by the Australian Government, allocated through the annual Aged Care Approval Round.

Representatives of both the Australian Government and some State and Territory Governments supported the need for this discrepancy to be resolved by the Australian Government and State and Territory Governments agreeing on a systematic capital grants program for Multi-Purpose Services.[59] The Australian Government has agreed in principle to review its approach to funding accommodation and infrastructure in Multi-Purpose Services.[60] The Australian and State and Territory Governments should contribute together to the cost of ensuring that Multi-Purpose Services infrastructure is fit for purpose and conducive to the provision of high quality aged care services.

8.4 Conclusion

People in regional, rural and remote Australia have limited access to aged care services compared with the rest of Australia, for both residential and home care. The changes we recommend in this chapter and elsewhere in this report will result in increased, fairer and more flexible service provision in regional, rural and remote Australia. In the new aged care system we recommend, the System Governor will systematically monitor the need for aged care services and plan how best to meet it.

In the new system, older people and their carers will know what level of services they can expect in any given area. The Pricing Authority will accurately calculate the cost of aged care services in any area on an annual basis. Aged care providers will be funded based on this costing, which will result in increased funding for regional, rural and remote providers and people receiving care. Providers will be able to use their funding flexibly to meet the needs of people in regional, rural and remote places. On the rare occasions when providers select not to provide services in some locations, the Australian Government should ensure that there is a default care provider, particularly for areas where home care services are inadequate. In the exceptional instances when there is no provider at all in a particular location, this should be transparent and publicised.

Endnotes

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9. Better Access to Health Care

9.1 Introduction

People using aged care should have access to and receive high quality health care that meets their high level of need. Like all people in Australia, they should be able to see a general practitioner when they need to. General practitioners should be able to spend the time needed to deal with the person's health problems and to work with others, including allied health professionals, to provide coordinated care that focuses on reablement, maintenance and prevention.

When the health problems of people receiving aged care are complex or acute, they should be able to access and receive specialist care. They should also be able to have their specific health care needs met, such as their oral and dental care needs and their mental health care needs. They should be taking the right medications, and the fewest necessary, to avoid overuse, adverse drug interactions and debilitating side effects.

However, as we set out in Volume 2 of this report, people receiving aged care miss out on getting proper access to adequate health care all too often.

The health care needs of people receiving aged care are, on average, greater and more complex than those of the general population.[1] Those complex needs regularly require a coordinated multidisciplinary response that involves various people across both the health and aged care systems. Higher levels of frailty and acuity also mean that it is difficult for some people receiving aged care, particularly those living in residential care, to travel to access health care services. There must be access to outreach heath care services for people who need them.

Any breakdown in the relationship or meeting point or 'interface' between the aged care and health care systems is likely to have significant, and adverse, impacts on the health of people receiving aged care.[2] The respective roles of the health and aged care systems in delivering health care to people receiving aged care must be clearly defined, well understood, and effectively carried out.

The interface between the aged care and health care systems is complicated by Australia's federal system of government. The National Health Reform Agreement between the Australian and State and Territory Governments outlines respective responsibilities for the funding and delivery of health care and aged care in Australia.[3] The Australian Government is responsible for the funding of large primary care programs, including the Medicare Benefits Schedule and the Pharmaceutical Benefits Scheme. The Australian Government is also responsible for the 'planning, funding, policy, management and delivery of the national aged care system', which covers the delivery of basic home care through to residential aged care. State and Territory Governments are responsible for the system management of public hospitals. The Australian Government and the State and Territory Governments are jointly responsible for the funding of public hospitals. The Australian Government subsidises the provision of private medical services and, to a very limited extent, some allied health services which are usually funded by individuals, supported in some cases by private health insurance. [4]

In the words of the National Health and Hospitals Reform Commission in 2009:

> The historical legacy of Federation and its divided responsibilities for the continuum of health and aged care has created tensions, inconsistencies and misalignment of reward and effort. This interplay of Commonwealth-state financial arrangements for health and aged care has created perverse incentives which allow allocative inefficiencies to become entrenched. Patient care is often driven by funding flows rather than clinical best practice.[5]

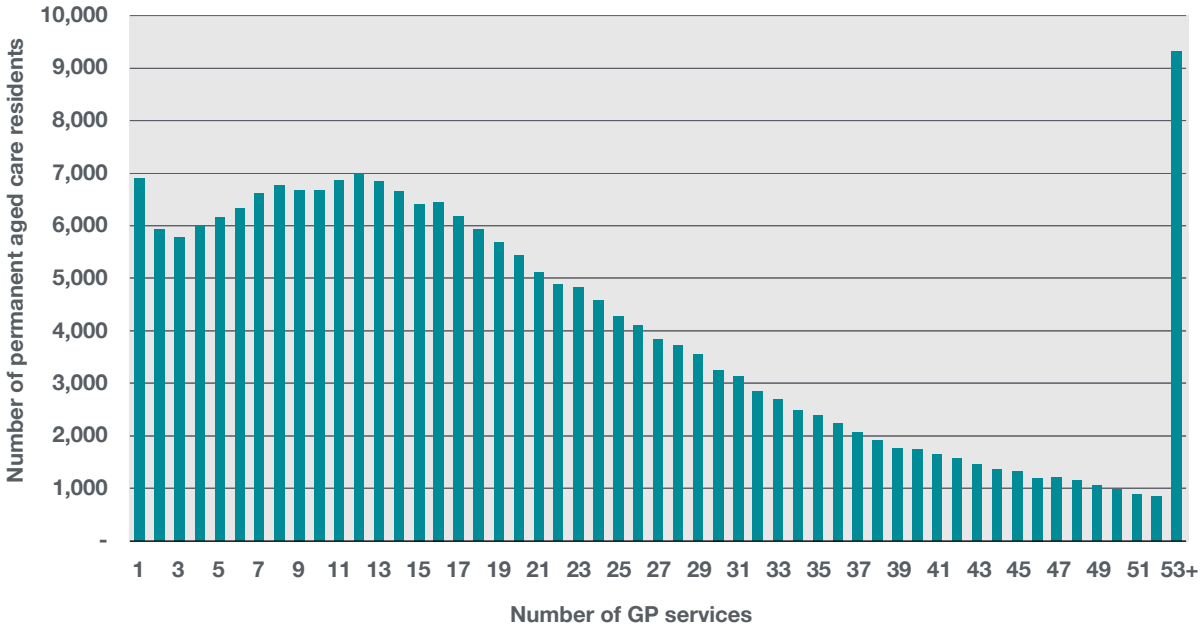
More needs to be done by all those involved in health and aged care to make older people's needs a priority.

9.2 A new primary health care model

People receiving aged care should receive high quality health care that meets their needs. They should have better access to general practitioners.

Australian Institute of Health and Welfare data suggest that almost everyone receiving aged care sees a general practitioner, and does so relatively often.[6] Commissioner Briggs notes that while this data shows that on average people living in residential care receive a general practitioner service once a fortnight, the average is skewed by a large number of residents receiving visits at least once a week.[7] As indicated in Figure 1, many residents see a general practitioner less than once a month. However, without data about the nature and extent of the health care needs of those people, we cannot conclude that the level of service provision by general practitioners actually meets those needs.

Figure 1. Distribution of general practitioner services by permanent aged care residents, 2016–17



Source: Exhibit 14-1, Canberra Hearing, general tender bundle, tab 65, RCD.9999.0280.0025 at 0031.

Witnesses, including people receiving aged care, their families, and staff of approved providers, have stated to us that the level of service provision is not adequate to meet the needs of people receiving aged care.[8]

Some general practitioners do attend residential aged care and do provide exceptional care.[9] However, we heard too often from aged care residents, their families, and aged care staff about poor access to general practitioners.[10] This included:

- general practitioners not performing home visits, including in residential aged care
- limited choice of general practitioners willing to attend aged care services
- difficulty accessing after-hours services
- long wait times for general practitioners to attend
- poor-quality locum services
- general practitioners reacting to poor health, rather than maintaining good health and wellbeing.

On the basis of that evidence, we infer that primary health care practitioners are either not visiting people receiving aged care at their residences, or not visiting enough, or not spending adequate time with them to provide the care required.

We are concerned that access to general practitioners will continue to be a challenge for people living in residential aged care, unless something significant is done to fix it.

We are concerned by survey results from the Australian Medical Association, which indicate that one in three general practitioners are intending to stop taking on new patients in residential aged care, to reduce visits, or to stop visiting residential aged care facilities altogether.[11] The Australian Medical Association identified inadequate Medicare Benefits Schedule fees and increasing unpaid work as major reasons for general practitioners intending to decrease or cease visits to residential aged care.[12] Associate Professor Mark Morgan, a general practitioner and representative of the Royal Australian College of General Practitioners, said that while some general practitioners are continuing to visit residential aged care, this is a 'fragile situation and it wouldn't take a lot to collapse it'.[13]

Commissioner Briggs considers that part of the problem is the way in which general practitioners are funded, and the amount that they are funded. Commissioner Pagone agrees that the funding of general practitioners for people in aged care is insufficient and agrees that consideration should also be given to how they are funded. Associate Professor Morgan noted that it costs a general practitioner money to leave their surgery.[14] Dr Troye Wallett, a general practitioner and Aged Care Consultant at GenWise Healthcare, recounted his experience of a colleague wishing to specialise in aged care general practice but finding it was not financially viable to do so.[15]

The existing fee-for-service remuneration model includes the following measures to facilitate access to general practitioners by people receiving aged care:

- rebates for attendances at residential aged care facilities for general practitioners applying under the Medicare Benefits Schedule, including a 'flag fall' rebate of $56.75 in addition to a standard attendance rebate
- bulk billing incentives for primary health care services provided to people holding a concession card
- the General Practitioner Aged Care Access Incentive payment under the Practice Incentive Program.[16]

These measures at these amounts have not proven to be sufficient for the type and amount of care needed by people receiving aged care.[17] Witnesses identified a number of problems with the type of care provided under the current fee-for-service model.[18] They told us that it creates an incentive for:

- care that responds or reacts to an episode of ill health, rather than encouraging care that proactively attempts to reduce the risk of ill health
- care that is episodic, rather than based on an established long-term relationship
- care that is provided directly to the patient only, without communication with family and the aged care service
- time-limited consultations, which may not allow for the time needed to communicate effectively with people with reduced cognitive ability, and
- care delivered by general practitioners individually, rather than in collaboration with other health practitioners as part of a multidisciplinary team.

The current fee-for-service model has long been considered by some as 'in conflict with the proactive, coordinated and ongoing team based approaches that are needed to support the prevention and optimal management of chronic and complex conditions'.[19] This is particularly the case for the kind of complex care often needed by older people accessing aged care.

Recommendation 56: A new primary care model to improve access

1. Commencing by no later than 1 January 2024, the Australian Government should trial for six to ten years a new voluntary primary care model for people receiving aged care. — **Commissioner Pagone**

2. Commencing by no later than 1 January 2024, the Australian Government should implement a new voluntary primary care model for people receiving aged care. — **Commissioner Briggs**

3. The new primary care model would have the following characteristics:
   a. general practices may, if they choose, apply to the Australian Government to become accredited aged care general practices
   b. the initial accreditation criteria would be:
      i. accreditation with the Royal Australian College of General Practitioners
      ii. participation in after-hours cooperative arrangements, and
      iii. use of My Health Record
   c. over time, as aged care general practices mature, the accreditation requirements could be strengthened
   d. each accredited aged care general practice would enrol people receiving residential care or personal care at home who choose to be enrolled with that practice
   e. each accredited aged care general practice would receive an annual capitation payment for every enrolled person, based on the person's level of assessed need
   f. an accredited aged care general practice would agree with each enrolled person and the person's aged care provider on how care will be provided, including by any use of telehealth services and nurse practitioners

g. the accredited aged care general practice would be required to:

   i. meet the primary health care needs of each enrolled older person (including through any cooperative arrangements with other general practices to provide after-hours care if required)

   ii. use My Health Record in conjunction with aged care providers

   iii. initiate and take part in regular medication management reviews

   iv. prepare an 'Aged Care Plan' (in collaboration with a geriatrician and the aged care provider and others) for each enrolled person

   v. accept any person who wishes to enrol with it (subject to geography) to avoid practices accepting only patients with less complex care needs, and

   vi. report on performance against a range of performance indicators, including immunisation rates and prescribing rates

h. the capitation payment would be reduced by the value of benefits paid when an enrolled person sees a general practitioner in another practice.

4. The Australian Government should undertake a thorough evaluation of the new primary care model, including any trial, in 2030 and make appropriate adjustments to the model at that time.

We recommend consideration of a new primary care model to encourage the provision of holistic, coordinated and proactive health care for the growing complexity of the needs of people receiving aged care.

Commissioner Pagone recommends that, to determine whether it is viable to adopt a different model to improve access to health care for people receiving aged care, a model should be trialled for a period of six to ten years and then thoroughly reviewed. Commissioner Pagone considers that a trial of the model is necessary to ensure that what may ultimately be implemented is the best for older people.

Commissioner Briggs considers that the fee-for-service general practitioner funding model has its place, but it is now time to adopt a new primary care model for people using aged care that is more likely to enable people to receive health care proportionate to, and consistent with, their needs. Commissioner Briggs does not consider that a trial is necessary as the new model is fit for purpose and can be adjusted over time if further enhancements emerge through the experience of operating the new model. She also notes that the current fee-for-service model will remain in place, operating alongside the new model. Commissioner Briggs recommends that the model should be implemented and thoroughly reviewed for enhancements after a period of six to ten years. She thinks that this is the best way to guarantee that the health care needs of older people receiving aged care will be met fully and fairly.

The proposed new primary health care model is a capitation model with patient enrolment that would include the following features:

- general practices could apply to the Australian Government to become accredited aged care general practices
- each accredited aged care general practice would enrol people receiving residential care or personal care at home who choose to be enrolled with that practice
- each accredited aged care general practice would receive an annual capitation payment for every enrolled person, based on the person's level of assessed need
- the accredited aged care general practice would be required:
    - to meet the primary health care needs of each enrolled older person (including through any cooperative arrangements with other general practices to provide after-hours care if required)
    - to use My Health Record in conjunction with aged care providers
    - to initiate and take part in regular medication management reviews
    - to prepare an 'Aged Care Plan' (in collaboration with a geriatrician and the aged care provider if there is one) for each enrolled person
    - to accept, subject to geography, any person who wishes to enrol with the practice, to avoid only patients with less complex care needs being accepted
    - to report on performance against a range of performance indicators, including immunisation rates and prescribing rates
- the capitation payment would be reduced by the value of benefits paid when an enrolled person sees a general practitioner in another practice.

This funding model is proposed for people receiving residential care and people receiving personal care at home such as clinical and allied health care, nursing services and assistance with activities of daily living. These people often have highly complex and long-term health care needs. The existing fee-for-service model is primarily designed for the general population who have 'short-term' health care needs and can easily navigate the health care system and attend at a general practitioner's clinic.[20] A capitation model may be better suited to the needs of people receiving aged care than the fee-for-service model.[21] Capitation may possibly encourage greater collaboration, continuity and prevention in the provision of care.[22]

The Australian Government was intending to introduce a voluntary patient enrolment model for people with chronic conditions in July 2020, although this has been postponed.[23] This model would have adopted, at least in part, a form of capitation. The model would have remunerated general practitioners $36 for each patient upon enrolment, and quarterly payments of $30 thereafter. General practitioners would still have used the standard fee-for-service billing against Medicare Benefit Schedule items for patient services.[24]

The extra capitated funding in this particular model was intended to compensate general practitioners for services that currently are not reimbursed through the fee-for-service funding model. Such services include: accessing repeat prescriptions; referrals without a face-to-face appointment; follow-up and monitoring via telephone and email; and inclusion of patients in recall and reminder systems for preventative health and chronic disease care.[25] However, the additional payments appear to be too low.[26] They are unlikely to be sufficient to promote a proactive preventative care model with regular rounds, reviews and comprehensive care plans. In essence, this model would have been a continuation of the fee-for-service status quo with some minor capitation payments added on.

The Australian Government is also trialling a Health Care Homes model with general practices and Aboriginal Community Controlled Health Services for enrolled people with chronic and complex conditions. Funding is through a combination of risk-adjusted base funding and fee-for-service. While this is not available to aged care residents, lessons can be learnt from this trial. These lessons include that there needs to be sufficient funding levels, consultation, and time for implementation of reforms to primary health care funding models.[27]

The Australian Government should consult carefully with people using aged care services and their families, aged care providers, the Royal Australian College of General Practitioners and the Australian College of Rural and Remote Medicine about the new primary health care model.[28] The model needs to take account of the particular needs of people receiving aged care and the interactions with our other recommendations, including a care manager in aged care and the multidisciplinary local hospital network outreach services.

In the new primary health care capitation model that Commissioner Briggs recommends and that Commissioner Pagone proposes be trialled, the Australian Government should determine the amount of the annual capitation payments required to provide adequate incentives to accredited aged care general practices, and the general practitioners and nurse practitioners employed or engaged by them, to meet the care needs of people receiving residential care or personal care at home.

A tiered system for the payments should be established, with differing amounts depending on the level of care needs of the enrolled patients. The tiers would range from lower annual amounts for enrolled patients receiving lower levels of personal care at home up to the highest annual amount for enrolled patients receiving residential care. The amounts would be calculated by reference to the amount of primary health care services typically required by people receiving those respective levels of aged care. They would include a supplement to cover associated services, such as following up on referrals and diagnostic testing, liaison with other health professionals and aged care staff, and communication with family members. They would also include a supplement to compensate accredited general practices for other costs associated with adoption of the model, such as the costs of compliance with accreditation, reporting and other requirements.

If this new model is to succeed, there must be adequate funding for accredited general practices. While not wishing to pre-empt the consultations about the design of the model, Commissioner Briggs envisages that a payment of several thousand dollars might be involved for people with high needs living in residential aged care. Capitation funding carries a financial risk for general practices in respect of more complex patients whose care might cost more than the capitated amount. Patients with more complex needs are to be balanced against patients with less complex needs whose care might cost less than the capitated amount. To be effective, this amount will need to compensate general practitioners, and other staff, for the loss in earnings of leaving their practices to provide outreach services.

This feature of capitation funding presents risks that general practices will seek to underservice patients or to select healthier patients only.[29] In the model, those risks need to be managed. The tiered funding levels should be designed properly to compensate general practices by providing greater funding for patients with more complex care needs. For patients with very complex needs, the multidisciplinary outreach services that we recommend below may, in some cases, be available to complement the care delivered by the general practice.

Accreditation and accountability measures would also maintain standards of care and, in doing so, mitigate against the risks of underservicing and patient selectivity. Such accountability measures should be developed in consultation with the Australian Department of Health and professional bodies. They could include relevant measures from the Practice Incentives Program Quality Improvement Incentive guidelines, including:

- 'proportion of patients with diabetes with a current HbA1c result'
- 'proportion of patients with a weight classification'
- 'proportion of patients aged 65 and over who were immunised against influenza'
- 'proportion of patients with diabetes with a blood pressure result'.[30]

The specific provision in the model for after-hours cooperative arrangements reflects the need of people receiving aged care for after-hours care, and the reality that it is not feasible for a single general practice to be available to enrolled patients 24 hours a day, seven days a week. Therefore, to provide for 24/7 coverage, accredited general practices would need to participate in cooperative arrangements with other general practices that provide after-hours care to enrolled patients. Where people receiving aged care access general practitioner services outside the accredited aged care general practice or the cooperative arrangement, the capitation funding for the accredited general practice would be reduced by an amount equal to the item billed under the Medicare Benefits Schedule. This approach would help drive continuity of care through a single general practice and protect the Australian Government from paying for services twice: through both capitation and fee-for-service.

It must be emphasised that participation in the new model, by general practices and patients alike, would be voluntary. It would be a matter for a general practice if it wished to provide services to patients receiving aged care by the new model or by the existing fee-for-service model. A general practice's patients would not be obliged to enrol, either. An accredited general practice could have two groups of patients receiving aged care, those funded under the new model and those funded under the traditional fee-for-service model. The adoption by a general practice of this model for provision of services to people receiving aged care would not affect the general practice's ability to provide services, through the Medicare Benefits Schedule fee-for-service model, to the rest of the population who are not receiving aged care.

Such a reform would represent a significant change to the way in which primary health care would be provided to people receiving aged care. Not all witnesses who gave evidence before us about improving access to primary care supported a departure from the existing fee-for-service model.[31] Some responses to Counsel Assisting's final submissions argued against the adoption of a capitation model and Commissioner Pagone accepts that they have considerable force and that careful testing and evaluation is needed. The Australian Government said that it does not support reforms specifically for delivery of primary care solely to people receiving aged care and refers to its broader 'Primary Care Reform agenda'. The Royal Australian College of General Practitioners was concerned that it should be consulted about the details of any possible capitation model. The Australian Medical Association was concerned that obligations would be imposed to accept patients for enrolment and that capitation might promote underservicing.[32] That is why the capitation model that Commissioner Briggs proposes and that Commissioner Pagone considers appropriate to be trialled must be voluntary for both general practices and patients and is subject to accountability measures. It is also why Commissioner Pagone considers that the model should first be trialled and for six to ten years. Any trial should be broad-based and should ensure that the existence of incentives to take up other funding models does not distort evaluation of the outcome of the trial.

Commissioner Briggs notes that many other submissions responding to Counsel Assisting's final submissions supported the adoption of a capitation model.[33] The National PHN Cooperative, representing all 31 Primary Health Networks, said that:

> The PHN Cooperative supports the recommendation to implement a new voluntary primary care model for people receiving aged care. We would argue that the new model should incorporate proactive monitoring approaches for healthy ageing, interfacing with aged care services as older people's needs change, to enable ongoing management of older people's long-term conditions and to support their transition into aged care services.[34]

Commissioner Briggs considers that significant reforms to primary care arrangements are urgently needed to ensure that older people get the medical services they need as and when they need them.

9.3 Accreditation of general practices providing primary care to people receiving aged care

Innovative general practice business models geared towards providing general practice services to people receiving aged care in their own homes or in residential aged care facilities should be encouraged. At the Canberra Hearing, we heard evidence about some of these models and the outreach services they provide.[35] The accreditation standards of the Royal Australian College of General Practitioners, the *Standards for general practices* (5th edition), can act as a barrier to these models and should be amended.[36]

Recommendation 57: Royal Australian College of General Practitioners accreditation requirements

By 31 December 2021, the Royal Australian College of General Practitioners should amend its *Standards for general practices* to allow for accreditation of general practices which practise exclusively in providing primary health care to people receiving aged care in residential aged care facilities and in their own homes.

Accreditation of general practices by the Royal Australian College of General Practitioners is important to ensure that general practices provide safe primary care to their patients. This accreditation is also a prerequisite for eligibility for additional remuneration for work in aged care. General practices need to be accredited against the *Standards for general practices* to be eligible for the additional funding available through the Australian Government's Practice Incentives Program.[37]

In the *Standards for general practices*, GP Standard 2 states that the 'scope of general practice is not limited by age, gender, body system, disease process, or service site'.[38] GP Standard 5 sets out the physical standards that the clinic for a general practice must meet and assumes the existence of a physical facility with equipment on site.[39] These requirements may have the practical effect of preventing innovative mobile general practices specialising in aged care from attaining accreditation.

Dr Paresh Dawda, a general practitioner and Principal and Director of Prestantia Health, and Dr Wallett experienced difficulty obtaining accreditation in establishing their mobile businesses.[40] Dr Dawda said that 'it seems to me a little bit of a paradox when our whole service is designed to cater for people who can't get into [the] practice, that we can't be accredited just because we haven't got a height-adjustable bed, for example'.[41] Those kinds of practices should not have to comply with these requirements in order to attain accreditation against the Royal Australian College of General Practitioners Standards.

The Royal Australian College of General Practitioners stated in December 2019 that it intended to start work in 2020 on identifying the requirements that mobile-type general practitioner services would need to meet for accreditation purposes.[42] That work should involve amendment of the *Standards for general practices* to ensure that innovative mobile practices specialising in aged care can attain accreditation despite only providing services to people receiving aged care at their places of residence in residential aged care facilities or in their homes. That work should be completed by 31 December 2021.

9.4 Multidisciplinary outreach services for access to specialists and other health practitioners

People receiving aged care need improved access to multidisciplinary specialist care.

People receiving residential aged care and personal care at home are increasingly frail and have high rates of comorbidities.[43] Older people living in residential aged care have less access to health care provided by specialists than their peers in the community. We heard evidence that some specialists do not visit residential aged care facilities and that sometimes people receiving aged care are denied access to the State or Territory public health services they need, such as palliative care and subacute rehabilitation.[44]

In 2016–17, only 32% of older people living in residential aged care facilities received a medical specialist consultation, funded under the Medicare Benefits Schedule, at least once. During the same period, 73% of older people receiving home support and 65% of older people receiving aged care at home had at least one medical specialist consultation funded under the Medicare Benefits Schedule.[45]

At the Canberra Hearing, Ms Glenys Beauchamp PSM, the then Secretary of the Australian Department of Health, acknowledged that Australian Institute of Health and Welfare data 'would tend to suggest there may be an issue with access' to specialist services for people living in residential aged care.[46] She noted that poor access could be due to difficulties for older people with travelling to services and specialists not visiting them, as well as problems that the general population experiences in accessing specialists, including lack of availability and cost.[47]

Recommendation 58: Access to specialists and other health practitioners through Multidisciplinary Outreach Services

1. By 1 January 2022, the Australian and State and Territory Governments should introduce Local Hospital Network-led multidisciplinary outreach services.
2. These services should be funded through amendment of the National Health Reform Agreement, and all people receiving residential care or personal care at home should have access based on clinical need.
3. The amended National Health Reform Agreement should include a recurrent and sustainable funding mechanism to stimulate outreach services. The level of funding should be based on underlying costs as determined by the Independent Hospital Pricing Authority.
4. The key features of the model should include:
    a. provision of services in a person's place of residence wherever possible
    b. multidisciplinary teams, including nurse practitioners, allied health practitioners and pharmacists
    c. access to a core group of relevant specialists, including geriatricians, psychogeriatricians and palliative care specialists
    d. embedded escalation to other specialists (including endocrinologists, cardiologists, infectious disease specialists and wound specialists), who are already salaried within the hospital and assigned to the model for part of their work
    e. 24 hour a day on-call services available to:
        i. people receiving residential care or personal care at home
        ii. the families of those people receiving aged care, and
        iii. staff of aged care services
    f. proactive care and rehabilitation
    g. a focus, where feasible, on skills transfer to staff working in aged care
    h. a specific focus on palliative care outreach services
    i. clinical governance arrangements involving Local Hospital Networks and relevant aged care and primary care providers.

Greater access to multidisciplinary health care professional teams is needed to support and empower older people with complex health and care needs. Throughout our inquiry, we heard that multidisciplinary care teams are fundamental in the care of people with chronic complex health conditions so that the person receives a comprehensive envelope of care and can have the best quality of life possible.[48] We were told that having access to allied health staff is critical to a geriatrician's practice.[49] Also critical is access to a physiotherapist and occupational therapist to maintain an older person's independence and reduce the incidence of joint replacements.[50]

Nowhere is the need for multidisciplinary services more apparent than at the interface between the hospital system and the aged care system, where we are convinced that the Australian and State and Territory Governments should introduce Local Hospital Network-led multidisciplinary outreach services. These services typically work out of a hospital to deliver specialist health care in the community. They should be accessible to all people receiving residential care or personal care at home, based on clinical need.

Local Hospital Networks manage the delivery of public hospital services as well as associated health services. They are geographically-based and managed by State and Territory Governments. They are variously called Local Health Districts, Local Health Networks, Hospital and Health Services, or Health Services. Except when referring to a particular jurisdiction, we refer to these organisations generically as Local Hospital Networks.

To be effective, the multidisciplinary outreach services should, wherever possible, provide services in an older person's place of residence, building on Hospital in the Home as well as telehealth and other technology-based initiatives. Those services should be delivered by multidisciplinary teams, including specialists, nurse practitioners, pharmacists, and allied health practitioners, including, for example, speech pathologists, occupational therapists and physiotherapists. Witnesses have explained how multidisciplinary teams are especially effective in caring for older people with complex needs, and this can be useful for addressing either episodes of acute ill health or chronic illnesses.[51]

The multidisciplinary outreach services should provide older people with access to a core group of relevant specialists, including geriatricians, psychogeriatricians, and palliative care specialists, with embedded escalation to other specialists—such as endocrinologists, cardiologists, respiratory physicians, infectious disease specialists, wound specialists, neurologists and urologists—who are already salaried within the hospital and assigned to the model for part of their work. Outreach services should also provide specialist palliative care services for people with highly complex end-of-life care needs.[52] These services will complement but not replace the palliative care that should be part of the core business of aged care providers.

Twenty-four-hour on-call services should be available every day. Performance measures and benchmarks should apply. There should be clinical governance arrangements involving Local Hospital Networks and relevant aged care and primary care providers to ensure proper understanding and performance of their respective roles and responsibilities.[53]

The Australian and State and Territory Governments should agree on joint funding for the multidisciplinary outreach services and set out that agreement in the National Health Reform Agreement. There should be sufficient flexibility in funding to implement these services according to different models of care designed to meet the needs of the local population, variations in State and Territory health systems, and other service infrastructure.[54] The National Health Reform Agreement should include a recurrent and sustainable funding mechanism to stimulate outreach services. The level of funding should be based on underlying costs as determined by the Independent Hospital Pricing Authority.

Currently, most, if not all, States and Territories have some form of hospital-based outreach service into aged care facilities and older people's homes in some of their Local Hospital Networks.[55] However, these services are not universally available, and many older people in need miss out. Outreach programs are not currently available to all people receiving aged care. The coverage is patchy, haphazard, and subject to local funding restrictions and availability of local hospitals.[56]

The existing outreach programs are intended to improve older people's access to health care where they live, and to avoid unnecessary hospitalisations. For example:

- Clare Holland House's Palliative Aged Care Specialist team provides nurse practitioner-led care rounds in aged care facilities. These rounds include the provision of specialist palliative care and case conferencing with the resident and relatives, facility staff members, the treating general practitioner, and relevant health care providers. The team also works with the aged care facility staff members to identify people who might benefit from palliative care planning.[57]
- Queensland Health's Comprehensive Aged Residents Emergency and Partners in Assessment Care and Treatment (CARE-PACT) provides care for people in residential aged care who would otherwise be sent to a hospital emergency department.[58]

Outreach services of this kind are multidisciplinary and cover a range of important services, including: aged care rounds; telephone triage; acute care in the residential aged care facility environment as an alternative to emergency department transfer; nursing assessments for people presenting to hospital; discharge planning, coordination and transitional communication; follow-up services within seven days of discharge; and specialist telehealth consultative services.

People receiving aged care derive significant benefits from access to these outreach programs.[59] Many of the health professionals and State and Territory and Australian Government representatives who gave evidence at the Canberra Hearing supported, in principle, greater national consistency of access to multidisciplinary outreach services.[60] The role and responsibilities of outreach services should be carefully defined to ensure that approved providers do not call upon them to act as a substitute provider of primary health

care services. There will need to be coordination and cooperation between the outreach services and approved providers and general practices, including on clinical governance. Professor Leon Flicker, Professor of Geriatric Medicine at the University of Western Australia, when asked whether multidisciplinary outreach services would be unnecessary if there were better access to comprehensive and effective primary health care, said:

> I totally disagree…and the reason being is that within residential care and high level community care services we have the sickest, frailest, most disabled and the most complicated Australians. And those Australians normally would get specialist care from all sorts of different specialists. And for saying that because they are now in a facility they don't require specialist care is totally foreign to me.[61]

These programs can also achieve economic benefits, including savings to State and Territory Governments occasioned by reduced hospital admissions.[62] However, the benefits of the proposed model of outreach services extend beyond mere hospital avoidance. The outreach services should help to improve quality of health care for people receiving aged care more generally, including by increasing the capacity and knowledge of staff members working at residential aged care facilities. We heard, for example, that the Clare Holland House service offered an educational component for residential aged care staff, which improved their knowledge of palliative care.[63] The establishment of relationships between aged care providers and a multidisciplinary outreach team led by a Local Hospital Network would provide access to specialists and associated allied health practitioners and staff members to address people's complex health issues outside the scope of primary care. In this way, the multidisciplinary outreach services would complement, but not conflict with, the new primary health care model we have described above.

9.5 Improved access to Older Persons Mental Health Services

All State and Territory Governments, except the Northern Territory Government, provide a mental health service specifically for older people with severe and complex mental health conditions. In the main, these mental health services are multidisciplinary, and include specialist, medical, nursing and allied health practitioners. They typically provide services to older people in hospitals and community settings and are delivered by Local Hospital Networks.

Older people receiving residential aged care or personal care at home should have the same access to these mental health services as their peers in the community. They experience severe and complex mental health conditions just as others do in the community. Some innovative models provide outreach services to people in residential aged care, including to people with dementia.[64]

Recommendation 59: Increased access to Older Persons Mental Health Services

By 1 January 2022, the Australian and State and Territory Governments should:

a. **fund separately, under the National Health Reform Agreement, outreach services delivered by State and Territory Government Older Persons Mental Health Services to people receiving residential aged care or personal care at home**

b. **introduce performance measures and benchmarks for these outreach services**

c. **promulgate standardised service eligibility criteria for hospital, community-based, and aged care Older Persons Mental Health Services that do not exclude people living with dementia from eligibility for such services.**

However, the adequacy of delivery of Older Persons Mental Health Services to people living in residential aged care varies.[65] Differences in the ways Local Hospital Networks deliver Older Persons Mental Health Services include:

- different eligibility requirements and/or referral processes for access to the service
- whether or not they provide services to people living in residential aged care
- whether or not they provide services to people with severe behavioural or psychological symptoms associated with dementia
- whether or not services have partnerships with residential aged care facilities.[66]

Some of these differences in service provision are also a result of constrained resources.[67] Under-resourcing of Older Persons Mental Health Services is a major problem, forcing some services to prioritise clients.[68] Funding for these services should be increased. Associate Professor Stephen Macfarlane, a geriatric psychiatrist, said that 'funding is constrained to the extent that resources have to be rationed' and 'if more funding was available, the availability of services would flow on to patients who would otherwise have been prioritised lower down the tree of need'.[69]

The Australian and State and Territory Governments jointly fund Older Persons Mental Health Services through the National Health Reform Agreement. While Older Persons Mental Health Services should work closely with the proposed Local Hospital Network-led multidisciplinary outreach services described above, there should be a specific stream of funding for Older Persons Mental Health Services to ensure transparency about the use of resources and delivery of services specifically for mental health. We have heard evidence that State and Territory Governments have not previously had to account for how they have allocated mental health funding and have sometimes repurposed mental health funding into other health care services.[70]

Commissioner Briggs observes that mental health services are shifting to activity based funding under the National Health Reform Agreement and Independent Hospital Pricing Authority Pricing Framework for Australian Public Hospital Services.[71] She considers that the activity based funding system for mental health should include appropriate cost weights for the provision of services by Older Persons Mental Health Services to aged care residents. While this will ensure that funding at a service level increases with activity, we also consider that governments should commit to an expansion of services by agreeing on performance benchmarks and targets.

The policy documents governing Older Persons Mental Health Services in most States and Territories suggest that they provide services to people with severe behavioural or psychological symptoms associated with dementia. However, this does not always occur in practice.[72] Mr Mark Silver, a social worker and Coordinator of the Wellbeing Clinic for Older Adults at Swinburne University of Technology, said that 'it is extremely unjust to exclude' people living with dementia and their families from mental health services, particularly given the majority of people receiving residential aged care have dementia.[73] Dr Alison Argo, a clinical geropsychologist, said that services should assess cognition alongside mental health, and those that do not are 'delivering, in my opinion, half a service'.[74] Commissioner Briggs notes that it is particularly challenging to access services in regional, rural and remote areas, with variability of access for people with dementia particularly concerning.[75] While Older Persons Mental Health Services are run by State and Territory Governments, the Australian Government funds a number of dementia-specific programs for people receiving aged care. These dementia-specific programs include the Dementia Behavioural Management Advisory Service and the Severe Behavioural Response Teams.[76] The Australian Government is also establishing a Specialist Dementia Care Program which will provide specialist psychogeriatric clinical in-reach services to the specialist dementia care units that sit within larger residential aged care facilities, and will aim to meet the needs of people living with very severe behavioural and psychological symptoms of dementia.[77]

Fragmentation between services can mean that people with dementia and psychiatric comorbidities, for whom there might be some debate about whether any given behaviour reflects either dementia or a comorbidity, 'may often fall between the gaps' or be 'referred to multiple different services' until mental health care is provided.[78] Standardised eligibility criteria should promote a consistent approach and ensure that older people with mental health care needs are not prevented from accessing services from Older Persons Mental Health Services because they are living with dementia.[79]

9.6 A Senior Dental Benefits Scheme

Older people are far more likely to have poor oral health.[80] Poor oral health has obvious adverse consequences, including social isolation, functional impairment, pain and discomfort, ill health and even death.[81] It can affect a person's ability to speak, eat and socialise. It can contribute to serious health conditions, including tooth decay, aspiration pneumonia and mouth cancer. It is also linked with other chronic conditions, such as diabetes, respiratory diseases and cerebrovascular diseases.[82] As people get older and increasingly frail, the ability to adhere to good oral health practices can decline rapidly.[83]

To address the risks posed by poor oral health, older people at home, people moving into residential aged care and people receiving residential aged care need improved access to the full range of oral and dental services, including those provided by oral health practitioners, general and specialist dentists, and dental prosthetists.

Older people with a low socioeconomic status and people receiving residential aged care are at particularly high risk of experiencing oral health problems.[84] This can be a result of access barriers such as public dental service wait lists and private dental costs.[85] It can also be because of a person's reduced capacity to undertake their own personal oral hygiene.[86] People often arrive in residential care with oral health problems.[87]

To remedy these problems, we recommend that the Australian Government establish a Senior Dental Benefits Scheme. The Senior Dental Benefits Scheme would fund dental services to people who live in residential aged care and people who live in the community and receive the age pension or qualify for the Commonwealth Seniors Health Card. The risks of excessive costs under the Senior Dental Benefits Scheme should be managed by limiting eligibility for the scheme to these cohorts, and by limiting the scope of services provided under the scheme to those services necessary to maintain a functional dentition, that is, 20 or more teeth. This limitation on the scope of services means that, for instance, benefits for prosthodontics—such as implants or bridges to replace missing teeth—would only be paid if the treatment was necessary to maintain 20 teeth.

Recommendation 60: Establish a Senior Dental Benefits Scheme

The Australian Government should establish a new Senior Dental Benefits Scheme, commencing no later than 1 January 2023, which will:

a. **fund dental services to people who:**
    i. **live in residential aged care, or**
    ii. **live in the community and receive the age pension or qualify for the Commonwealth Seniors Health Card**
b. **include benefits set at a level that minimises gap payments, and includes additional subsidies for outreach services provided to people who are unable to travel, with weightings for travel in remote areas**
c. **provide benefits for services limited to treatment required to maintain a functional dentition (as defined by the World Health Organization) with a minimum of 20 teeth, and to maintain and replace dentures.**

Oral health practitioners should form part of the allied health teams available for people receiving residential care or personal care at home. Those practitioners should engage in a range of preventative treatments, such as scaling, cleaning and fillings, as well as undertaking routine oral health assessments and care planning. They should also, through education and training of aged care staff and people receiving aged care, improve daily oral health management such as tooth brushing and denture cleaning. Nevertheless, even with the best preventative treatments, people receiving aged care will still need, from time to time, access to dental services from dentists and dental surgeons.

The introduction of a Senior Dental Benefits Scheme is intended to ensure that oral health practitioners who conduct routine assessments in aged care will have a more readily available avenue for referral to other types of dental services when necessary.[88] Long wait lists and the lack of outreach dental services make referrals ineffective.

To overcome the reduced mobility of many people receiving aged care, dental services should, when needed, be provided to older people at their place of residence. Many dental health services can be delivered in residential aged care facilities or within the community. At a minimum, outreach dental services require a clean and well-lit area that has access to running water and capacity for portable equipment.[89]

There are already some dental outreach services being delivered in aged care settings across Australia.[90] As with other outreach programs, these dental outreach services are not consistently provided. They should be. Outreach dental services should be publicly funded under the proposed Senior Dental Benefits Scheme for people living in residential aged care. A large proportion of those people are likely to be eligible for public dental services.[91] However, public dental services are already at capacity, with long wait lists. Private dental services need a financial incentive to offset the lost costs of leaving their practices to conduct an outreach service. We consider that a targeted dental scheme is the most appropriate way to fund these outreach services.

The proposed scheme would also provide comprehensive dental health care to older people who cannot afford to fund it themselves, before they have any need to access residential aged care services. The consequences of poor oral health can worsen people's overall health and functioning to the point that they need residential aged care earlier than they might otherwise.[92] Again, many of these people would already be eligible for adult public dental services but cannot access them due to excessive wait lists. Older people often enter residential aged care with poor oral health. Because of this, Ms Nicole Stormon, an oral health therapist and Vice President of the Australian Dental and Oral Health Therapists' Association, said the 'opportunity to prevent oral diseases is largely missed'.[93]

The Senior Dental Benefits Scheme should be funded by the Australian Government.[94] Improved oral health for older people will have a beneficial effect on the overall health and wellbeing of people who are, or may in future be, accessing aged care. The Australian Government already funds other targeted public dental schemes, such as the Child Dental Benefits Schedule, the Cleft Lip and Palate Scheme and the Department of Veterans' Affairs Scheme.

The Senior Dental Benefits Scheme should apply to all dental practitioners. Under the Child Dental Benefits Schedule, dental hygienists, dental therapists, oral health therapists and dental prosthetists can provide services, within their scope of practice, 'on behalf of' a dentist.[95] We heard that most dental practitioners work in teams, develop strong relationships with each other, and cannot undertake all aspects of dental and oral health care.[96] The funding of the Senior Dental Benefits Scheme should support this multidisciplinary approach.

The proposed Senior Dental Benefits Scheme would provide national consistency, avoid wait lists and provide ongoing systemic funding for dental services. Such a scheme would be a modified version of what the Australian Dental Association proposed in its 2019 Dental Health Plan.[97]

The Senior Dental Benefits Scheme should not be paid for by a reduction in funding for already overstretched public dental services. Ensuring funding is in addition to the already existing public dental services will redirect some demand for those services and may reduce the wait time for people aged under 65 years who need those public dental services.

9.7 Medicare Benefits Schedule changes

The proposed improvements to access to primary health care, specialists and mental and dental health care will take time to develop and implement. So, too, will our recommendations in Chapter 4: Program Design for allied health services in aged care (see recommendations 36 and 38). These services will not come into effect immediately. In the short term, other measures should be put in place as a matter of priority to improve poor access to health care services by people receiving aged care. Some of those short-term measures will not be required once longer-term improvements commence.

Recommendation 61: Short-term changes to the Medicare Benefits Schedule to improve access to medical and allied health services

The Australian Government should:

a. **create specific Medicare Benefits Schedule items by 1 November 2021 to allow for a benefit to be paid for a comprehensive health assessment, whether conducted by a general practitioner or a nurse practitioner, when a person receiving aged care begins to receive residential aged care or personal care at home and at six month intervals thereafter, or more frequently if there is a material change in a person's circumstances or health**

b. **immediately amend the Medicare Benefits Schedule to allow benefits to be paid under the GP Mental Health Treatment items 2700 to 2717 to patients receiving these services at a residential aged care facility**

c. create specific Medicare Benefits Schedule items by 1 November 2021 for:

   i. a mental health assessment, and subsequent development of a treatment plan, by a general practitioner or psychiatrist, within two months of a person's entry into residential aged care

   ii. three-monthly reassessments or reviews of a mental health assessment by a general practitioner, psychiatrist, or psychologist

d. create new Medicare Benefits Schedule items by 1 November 2021, with the value of the benefit aligned with recommended professional fees, for allied mental health practitioners (including psychologists, occupational therapists and social workers) providing services to people in residential aged care and:

   i. the number of services for which a benefit is payable should be based on clinical advice

   ii. these benefits should cease on 30 June 2024, when the aged care allied health funding arrangement is established

e. amend the General Practitioner Aged Care Access Incentive payment to:

   i. increase the minimum annual number of services required by general practitioners to qualify for the payment and the amount of the corresponding payment

   ii. introduce incremental increases to the amount of the payment for general practitioners who deliver more than the minimum annual number of services

   and index these amounts on the same basis as Medicare Benefits Schedule general practitioner attendance items.

9.7.1 Comprehensive health assessments

General practitioners and other medical practitioners can currently access Medicare benefits for comprehensive health assessments for a range of groups, including people living in residential care and people aged 75 years and over.[98] This restricts older people who receive aged care in the community and are aged between 65 and 74 years from accessing subsidised comprehensive health assessments. In 2018, the Medicare Benefits Schedule Primary Care Clinical Committee reviewed the Medicare Benefit Schedule health assessment items for the Medicare Benefits Schedule Review Taskforce.[99] While the review identified that there was limited evidence of the benefits of comprehensive health assessments overall, some populations appeared to receive a benefit. This included older people, over the ages of 65 and 75 years, who reported improvements in health associated with health assessments.[100]

For those items relating to people living in aged care facilities, the Medicare Benefits Schedule recommends that new residents should receive the health assessment as soon as possible after admission, preferably within six weeks following admission into a residential aged care facility.[101] However, claims against these item numbers are capped at once every 12 months and do not include exceptions for changing health circumstances. This means that when an aged care resident experiences a significant change in health, even one requiring hospitalisation, the person is not eligible for a Medicare-subsidised comprehensive health assessment if they have received such an assessment in the previous 12 months. This should be redressed.

Medicare-subsidised comprehensive health assessments should be available when an older person first begins to receive residential aged care or personal care at home and then at six-month intervals or more frequently if there is a material change in a person's circumstances or health. Medicare should fund the aged care comprehensive health assessments whenever they are clinically required.

The relevant items in the Medicare Benefits Schedule should also be made available to nurse practitioners. They are currently not eligible to receive Medicare funding for conducting comprehensive health assessments, but are able to provide these services in the State and Territory public hospital system.[102]

Specific new Medicare Benefits Schedule items should be introduced for aged care comprehensive health assessments, rather than amending existing Medicare Benefits Schedule item numbers. The creation of new items specific to people receiving aged care will facilitate monitoring of the adoption and impact of the items.

9.7.2 Better access to Medicare-subsidised mental health services

People living in residential aged care should have access to mental health services to meet their needs. At a minimum, they should have access to the same mental health services as people in the community. This is not currently the case.

Poor mental health is a serious problem in aged care. Just under half of permanent aged care residents have a diagnosis of depression.[103] That compares with the general rates of depression for people aged 75 years and over, which were 7% for males and 12% for females.[104] Depression in older people is associated with a decline in overall wellbeing, daily functioning, independence and autonomy, as well as disability, suicidal ideation, and mortality.[105] Access to allied mental health practitioners, such as psychologists, social workers and occupational therapists, will assist in maintaining the mental health of older people.

Immediate access for aged care residents to Medicare benefits under the Better Access Initiative

Under the Better Access Initiative, Medicare benefits are payable for general practitioners and psychiatrists to assess and diagnose someone with a mental illness and establish a mental health treatment plan. When a mental health treatment plan is in place, it allows referrals for:

- 10 Medicare-subsidised 'psychological services' per year, which include a broad range of allied mental health services provided by clinical psychologists, registered psychologists, social workers, occupational therapists, or general practitioners who have completed accredited mental health training
- 10 Medicare-subsidised separate services for the provision of group therapy, either as part of psychological therapy or focused psychological strategies.

However, aged care residents are not eligible for general practitioner mental health treatment plans under the Better Access Initiative. As a result, people receiving residential aged care cannot access the psychological services and group therapy services referred by general practitioners under the Better Access Initiative. There is no clear policy rationale for this position. Ms Penny Shakespeare, Deputy Secretary of the Australian Department of Health, said that:

> We're not exactly sure why that decision was made but that—that has been continued through.[106]

Professor Sunil Bhar, Professor of Psychology at Swinburne University of Technology, said:

> The inequity and division between community-dwelling older adults and residential aged care residents in accessing Medicare benefits for psychological treatment must cease. The division has created confusion in the sector, and an unintended perception that aged care residents' needs for such treatment are less important compared to the needs of their community dwelling counterparts.[107]

The consequences of lack of access to services under the Better Access Initiative were apparent during the COVID-19 pandemic in 2020, when the Australian Government made a number of incremental expansions to the program.[108] To benefit from these expansions, people needed to be eligible for the Better Access Initiative. Aged care residents did not initially get that benefit. They should have.

In 2018, the Australian Government attempted to bridge the gap in access to mental health services between the community and residential aged care by allocating $82.5 million over four years to Primary Health Networks to commission psychological services for people living in residential aged care.[109] So far, this program has produced very limited increases in access to mental health services—it is not clear that this situation will change.[110] As at 30 June 2020, a maximum of only around 3600 people had accessed any mental health services under this initiative over an 18-month period.[111] Within this total, there were large variations between Primary Health Networks.[112] Commissioner Briggs finds these numbers concerning given that about one in two people in residential aged care experience depression.

In response to our special report *Aged care and COVID-19*, the Australian Government announced, on 30 November 2020, that eligibility requirements for the Better Access Initiative would be temporarily expanded to 30 June 2022 to permit older people in residential aged care to receive up to 20 individual psychological therapy sessions where a general practitioner or psychiatrist determines they would clinically benefit from additional mental health support.[113]

This temporary Better Access Initiative access arrangement falls short of the access that other members of the community receive. Any remaining barriers to aged care residents using Medicare-subsidised services under the Better Access Initiative should be removed immediately.

Medicare benefits for aged care residents' mental health assessments and plans

Entry into residential care and the institutionalised environment will itself often contribute to mental health problems.[114] Not only is entering residential care a major life event, it is often associated with the death of a spouse or other carer, or a major debilitating injury or illness.

People entering or living in residential aged care are not systematically assessed for mental health conditions.[115] The assessment for depression that is undertaken under the Aged Care Funding Instrument is insufficient—it does not adequately cater for the broad spectrum of mental health illnesses and often does not inform delivery of care.[116] The care that people receive is primarily determined by the aged care provider and the care plan that staff members develop with the resident. It is dependent on residential aged care staff identifying when people have mental health needs and seeking an assessment. Aged care staff members are not well equipped to undertake that task.[117]

The mental health assessment and treatment process in aged care requires significant improvements. Given the high rates of mental illness in residential aged care, new specific Medicare Benefits Schedule items should be introduced to:

- support mental health assessments—and development of a mental health treatment plan, when required—for all older people within two months of entry to residential aged care, or at any subsequent time if a resident or the resident's care provider seeks an assessment,[118] and
- support regular three-monthly reviews of treatment plans.

These assessment and planning processes should be carried out by a psychiatrist or a general practitioner who has undertaken mental health skills training as defined under the Medicare Benefits Schedule. Reviews should be undertaken by a psychiatrist, a general practitioner, or a psychologist.[119] The treatment plans should include referrals for treatment provided by appropriate allied mental health practitioners and reimbursed through the Medicare Benefits Schedule.

These measures will restore equity in access to mental health services for people living in residential aged care.

Expanded access to Medicare-subsidised allied mental health services

We have received evidence about the extensive use of psychotropic medication in residential aged care facilities to manage people's behaviours and address mental health conditions such as depression and anxiety.[120] We have also received evidence that there is a lack of access to psychosocial supports and psychological services.[121] We have heard that simple reminiscence, life review, life review therapy, cognitive behaviour treatment and behavioural activation can be effective in treating some mental health conditions.[122] Commissioner Briggs notes that it is well established that psychotherapy can be as effective as pharmacotherapy in the treatment of depression, and that combined psychotherapy and pharmacological therapy may generate better results.[123]

Our recommendations for the expansion of the eligibility requirements of some of the existing items in the Better Access Initiative and new specific items for assessments and treatment plans should be accompanied by specific Medicare subsidies for the allied mental health services that are referred under the treatment plans. The Better Access Initiative provides for subsidised access to 10 individual and 10 group mental health services provided by a range of mental health providers.[124] As noted above, as part of the Australian Government's response to COVID-19, eligibility requirements for the Better Access Initiative are being temporarily expanded to 30 June 2022 to permit older people in residential aged care to receive up to 20 individual psychological therapy sessions.

In 2019, the Australian Government created a package of new Medicare Benefits Schedule items for treating eating disorders. Under these arrangements, patients with anorexia nervosa and other eating disorders can receive up to 40 Medicare-subsidised psychological treatment services in a 12-month period.[125] Evidence before us supports making a similar number of subsidised services available to people receiving residential aged care because of their increased frailty, comorbidities and reduced mobility.[126] The precise number of services for aged care residents for which a benefit is payable should be based on clinical advice.

Commissioner Briggs notes evidence from Professor Bhar that, in his experience of providing mental health services to aged care residents, the need for services can take an extended period of time due to the following factors:

> (a) the problems are rarely self-identified by the residents
>
> (b) the problems are chronic and complex due to multiple comorbidity and
>
> (c) the treatment needs to involve others such as family, friends and staff.
>
> All together, we have found that treatment is best conceptualised as a 9 month program, where sessions are held weekly[127]

The Medicare Benefits Schedule rebates for mental health services are significantly lower than the fees recommended by professional bodies.[128] As a result, allied mental health practitioners will often charge an out-of-pocket fee to patients. This is likely to create a barrier to access for the many people living in residential aged care who are full or part pensioners. The Medicare benefits for these services should be set at a level to minimise out-of-pocket charges, recognising the range of fees commonly charged by the relevant professional groups. The value of the new Medicare Benefits Schedule items for allied mental health practitioners providing services to people in residential aged care should more closely align with recommended professional fees.

The Australian Government has expressed concern about any reforms to Medicare that create inequity.[129] Commissioner Briggs considers that providing increased access to services to a small group of aged care residents with high mental health needs is warranted and justifiable on the basis that they need the care and have not received it when rationed services are allocated.

These benefits should cease once the aged care allied health funding arrangements detailed in Chapter 4: Program Design are established.

9.7.3 Changes to the General Practitioner Aged Care Access Incentive Payment

The General Practitioner Aged Care Access Incentive payment seeks to encourage general practitioners to deliver more services to people living in residential aged care and to support continuity of care through funding general practitioners to continue seeing patients living in residential aged care.[130]

The current General Practitioner Aged Care Access Incentive is a tiered payment system. The Tier 1 threshold pays $1500 to general practitioners who provide at least 60 services annually—little more than one service per week—in residential aged care. Under the Tier 2 threshold, a further $3500 is available to general practitioners who provide 140 services annually.[131] This still only amounts to fewer than three services per week.

This incentive payment needs to reflect better the additional burden on a general practitioner's time when attending a patient in a residential aged care facility. That burden exists by reason of, for example: travel to and from, and orientation at, the facility; discussions with staff and family; attendances on higher acuity patients; greater medication management; and keeping and reviewing records at the facility.[132] Similarly, a greater burden is placed on a general practitioner's time when attending high acuity patients in their homes.

Changes to the General Practitioner Aged Care Access Incentive payment should address this issue, in part, until any introduction or trial of the new primary care capitation-based funding model described above. Table 1 shows one possible form of change.

Table 1: Primary care capitation-based funding model: an example[133]

Example of Proposed Changes to Primary Care Capitation-Based Funding				
Tier	**Current qualifying service level**	**Current service incentive Payment**	**New qualifying service level**	**New service incentive payment**
Tier 1	60 services in a financial year (1.1 service per week)	$1500	120 services in a financial year (2.3 services per week)	$3000
Incremental increase	No incremental increase	Not applicable	160 services in a financial year (3 services per week)	$4000
			200 services in a financial year (3.8 services per week)	$5000
			240 services in a financial year (4.6 services per week)	$6000
Tier 2	140 services in a financial year (2.7 services per week)	$3500	280 services in a financial year (5.4 services per week)	$7000

The exact nature of the increase in qualifying services and corresponding payments should be ascertained by the Australian Government. There should be incremental steps for additional services so that a practitioner who provides, say, 279 services does not receive the same incentive as a person who provides 120 services.

These payments should be indexed on the same basis as Medicare Benefits Schedule general practitioner attendance items. This measure should only be a temporary one until any new primary care funding model of the kind described above is implemented. Once that has occurred, this measure could be phased out. During this interim period, the payment should be extended to services provided in a person's home for people who are currently on Level 3 or 4 Home Care Packages.

9.8 Enhanced access to specialists

9.8.1 Access in regional, rural and remote areas

Recommendation 62: Enhance the Rural Health Outreach Fund to improve access to medical specialists for people receiving aged care

The Australian Government should:

a. amend the priorities of the Rural Health Outreach Fund by 1 July 2021 to include delivery of:

   i. geriatrician services in regional, rural and remote Australia, and

   ii. medical specialist services to people receiving aged care in regional, rural and remote Australia

b. increase, for these additional priorities, the annual funds available by $9.6 million, starting in the 2021–22 financial year, and

c. ensure that these additional priorities of the Fund are maintained on an ongoing basis.

The Rural Health Outreach Fund was established by the Australian Government to 'improve health outcomes for people living in regional, rural and remote locations by supporting the delivery of outreach health activities'.[134] The fund is intended to improve access to services provided by medical specialists, general practitioners, nurses, allied health professionals and multidisciplinary teams in regional, rural and remote areas of Australia. [135] The funding provided through the Rural Health Outreach Fund is intended to address financial disincentives associated with health professionals providing outreach services in regional, rural and remote locations, including travel, accommodation, and equipment and room hire.[136] At present, the four priorities of the Rural Health Outreach Fund are chronic disease management, eye health, maternity and paediatric health, and mental health.[137]

People receiving aged care in regional, rural and remote locations have poor access to health care.[138] This is particularly so in relation to access to specialists.[139]

The Australian Government accepts that an additional priority of the Rural Health Outreach Fund should be geriatrician outreach services.[140] We agree with prioritising funding for geriatricians under the Fund.

This will not, of itself, address the problems that people receiving aged care face in accessing specialist services. Even though chronic disease management and mental health are current priorities for the Rural Health Outreach Fund, and many aged care residents suffer from chronic disease and mental illness, there is no evidence that these needs are being addressed adequately through the Fund.[141]

Aged care should itself be added as a further priority area of the Rural Health Outreach Fund so that the full suite of specialist services are available for older people who live in aged care facilities in regional, rural and remote areas.

The Australian Government currently spends a little over $27 million annually on four priority areas through the Rural Health Outreach Fund.[142] Based on the number of older people in regional, rural and remote locations and the current per capita spend of the program, estimated additional funding of around $9.6 million annually (indexed) is required to address aged care and geriatricians as priority areas.

9.8.2 Access to specialist telehealth services

Recommendation 63: Access to specialist telehealth services

By 1 November 2021, the Australian Government should:

a. **expand access to Medicare Benefits Schedule-funded specialist telehealth services to older people receiving personal care at home**

b. **require aged care providers delivering residential care or personal care at home to have the necessary equipment and clinically and culturally capable staff to support telehealth services.**

The World Health Organization defines telehealth as 'the use of telecommunications and virtual technology to deliver health care outside of traditional health-care facilities'.[143] The use of telehealth has become widespread as a result of the COVID-19 pandemic in 2020 and the Australian Government's expansion of telehealth to reduce community transmission of the virus.[144] On 27 November 2020, the Australian Minister for Health announced that 'telehealth will become a permanent part of the Medicare system'.[145]

Telehealth will continue to provide benefits in aged care beyond the COVID-19 pandemic. In short, it is a means of avoiding the potential harm and distress caused by travel for frail older people. Before the pandemic, specialists and aged care providers underused telehealth services.

There should be increased use of telehealth for medical specialist consultations with people receiving residential care or personal care at home. That is not to say that telehealth should replace all face-to-face consultations. A physical examination may be necessary and physical contact may itself have therapeutic and human benefits. We acknowledge that in some cases, telehealth will not be appropriate to deliver health care to people receiving aged care. For example, telehealth may not allow for proper treatment of some people living with dementia.

The Australian Government introduced telehealth Medicare Benefits Schedule items in 2011 to address barriers patients faced to accessing specialist services.[146] These items allow consultant physicians, psychiatrists or specialists to claim rebates for video consultations provided to patients in specified locations. These subsidised specialist telehealth services are available to people living in residential aged care. They are not available to older people who access aged care from their homes unless they live in remote Australia or access an Aboriginal Medical Service.[147] However, increasing numbers of older people are accessing aged care services from their homes.[148] As this occurs, a greater number of older people with high levels of frailty need to receive proper health care in their homes. There should be greater availability of specialist services for these people as well. Telehealth can help to achieve this.

Aged care providers need to support the provision of telehealth by ensuring that the right equipment and staff members are available to people receiving aged care, whether they are receiving residential care or personal care at home, to access telehealth services. In particular, aged care providers should ensure that there is a qualified and trusted health professional present with the older person during the telehealth consultation to record the outcomes of the consultation and take action to initiate any recommended changes to medication, diet or other regimes. They should also ensure that interpreter services are available when required.

The Australian Medical Association and medical colleges should also encourage their members to increase the use of telehealth services. These bodies should report annually to the Australian Government on their members' use of telehealth services.

9.9 Better medication management

9.9.1 Access to medication management reviews

Recommendation 64: Increased access to medication management reviews

The Australian Government should immediately improve access to quality medication management reviews for people receiving aged care by:

a. **allowing and funding pharmacists from 1 January 2022 to conduct reviews on entry to residential care and annually thereafter, or more often if there has been a significant change to the person receiving care's condition or medication regimen**

b. **amending the criteria for eligibility for residential medication management reviews to include people in residential respite care and transition care**

c. **monitoring quality and consistency of medication management reviews.**

In aged care, medication management reviews are critical to reduce chemical restraint and other inappropriate use of medications.[149] Medication management reviews allow for assessment of all of the medicines that a person is taking and not just medicines used for chemical restraint. Accredited pharmacists performing medication management reviews can look at whether the long-term medicines a person is taking are still necessary or appropriate based on changes to the person's health condition. They can also look at whether medicines are interacting with other medicines or causing potentially harmful side effects. People receiving aged care need improved and more frequent medication management reviews.[150]

Commissioner Briggs understands that people in residential aged care take about a median of 11 medicines at the same time.[151] Problems with medication use and management are common in residential aged care.[152] However, only one-third of people living in residential aged care receive a medication management review annually. The Australian Medical Association, it its submission, said:

> The AMA [Australian Medical Association] believes that medication reviews [Residential Medication Management Reviews and Home Medicines Reviews] should occur annually, and then on an as-needed basis to ensure medications are appropriate for older people. Pharmacists who work with doctors have an important role in: assisting with medication adherence; improving medication management; and providing education about medication safety.[153]

In Chapter 4: Program design, we make recommendations and observations about the provision of allied health services in aged care, including the involvement of pharmacists.[154] Pharmacists engaged by, or who have arrangements with, approved providers as part of their allied health services should, among other things, undertake a review of a person's medications whenever appropriate, including when there has been a significant change to the older person's condition or medication regimen. Implementation of that recommendation will take time. Other measures can be put in place in the interim.

Australian Government-subsidised reviews of medication regimes, known as Medication Management Reviews, are currently governed by the Community Pharmacy Agreement. Under the Community Pharmacy Agreement, people living in residential aged care can have a Residential Medication Management Review performed by an accredited pharmacist when referred by their general practitioner.[155] These reviews are not available for people receiving respite or transition care.[156] The accredited pharmacist generates a report at the end of each review, which the general practitioner can use to develop or revise the resident's medication management plan. A Home Medicine Review service is available for those who live in the community.[157] Pharmacists are paid a fee for each review that they perform.[158]

At present, people living in residential aged care are entitled to only one Residential Medication Management Review every 24 months unless there are significant changes to the person's medical condition or medication regimen.[159] They are also entitled to two follow-up interviews by an accredited pharmacist no earlier than one month and

no later than nine months after the initial medication review. In its response to Counsel Assisting's final submissions, the Australian Government submitted that:

> these follow up services provide an appropriate opportunity for the identification of care recipients who are experiencing ongoing issues with their medication management and, where necessary, for a new referral for a further full medication management review, to be arranged, maintaining the General Practitioner as central to the patient's care.[160]

However, these follow-up interviews are not comprehensive reviews.[161] By way of contrast, general practitioners can access Medicare funding for engaging in medicine review services once in a 12-month period or when there is a significant change to the resident's condition or medication regimen.[162] The different funding criteria make little sense, and cause practical difficulties for older people when trying to access medication reviews.

The Australian Government should enable more frequent reviews by pharmacists. Those reviews should occur at least annually and more regularly if there has been a significant change to the resident's condition or medication regimen. Pharmacists should communicate effectively and promptly with others responsible for the delivery of care to residents, including general practitioners and the clinical staff in residential aged care services, about the outcomes of medication reviews.

We acknowledge the Australian Government's stated preference for 'a model based on clinical need, rather than time intervals which may not be aligned with a patient's health needs'.[163] However, the evidence before us of medication mismanagement in aged care suggests that a new approach is warranted in which, at a minimum, each aged care resident has access to one funded medication review each year.

Residential Medication Management Reviews should also be available to people who receive respite care or transition care in a residential aged care facility. Not all people who receive short-term care will need to have a Residential Medication Management Review. This does not mean that all people receiving short-term care should be excluded from getting such a review.[164]

On 1 February 2020, the Pharmacy Programs Administrator commenced active monitoring and compliance activities for services delivered through the Community Pharmacy Agreement.[165] This work should extend to medication management reviews in aged care. It is not yet clear what effect these compliance activities will have on the provision of medication management reviews. Guidance documents released by the Pharmacy Programs Administrator appear to focus on administrative and eligibility requirements rather than outcomes.[166] There is limited information available on how services will be assessed for quality. The Australian Government should ensure that compliance activities for Medication Management Reviews focus on the quality of the services being provided as well as the accuracy of claims for payment. Pharmacists not providing a quality service should be suspended from providing services while they undertake further training. Commissioner Briggs considers that there should also be monitoring of how general practitioners respond to medication management reviews to ensure ongoing better practice prescribing.

9.9.2 Greater safeguards against inappropriate prescription of antipsychotics

Recommendation 65: Restricted prescription of antipsychotics in residential aged care

By 1 November 2021, the Australian Government should amend the Pharmaceutical Benefits Scheme Schedule so that:

a. **only a psychiatrist or a geriatrician can initially prescribe antipsychotics as a pharmaceutical benefit for people receiving residential aged care, and**

b. **for those people who have received such an initial prescription from a psychiatrist or a geriatrician, general practitioners can issue repeat prescriptions of antipsychotics as a pharmaceutical benefit for up to a year after the date of the initial prescription.**

In the Interim Report, Commissioners Tracey and Briggs identified widespread use of chemical restraints in the purported 'care' of many older people in residential aged care.[167] Such widespread use of chemical restraints is plainly unacceptable.

In response to the Interim Report, the Australian Government announced changes intended to address problems with medication management.[168] They included changes to prescribing criteria for the antipsychotic risperidone under the Pharmaceutical Benefits Scheme Schedule, education resources to support the appropriate use of antipsychotics and benzodiazepines in residential aged care, funding for medication management programs, and increased dementia training and support for aged care workers and health sector staff.

These measures are commendable, but they do not go far enough to address properly what is a problem that has persisted for decades.[169] Education and training programs will need to be implemented nationally and consistently. Numbers of care staff employed in residential aged care will have to be increased to ensure more time for better management of behavioural and psychological symptoms of dementia.

There should also be stricter requirements for prescribing antipsychotic medicines for people receiving residential aged care. Under the Pharmaceutical Benefits Scheme Schedule, risperidone is only subsidised for the treatment of autism in children if the treatment is 'under the supervision of a paediatrician or psychiatrist'.[170] A similar practice should apply to residential aged care, such that only a psychiatrist or geriatrician should be able to initiate treatment with antipsychotic medicines for people receiving residential aged care. This will ensure that every person in residential aged care is reviewed by a specialist before antipsychotic medicines are started.

Such a requirement will relieve the pressure on general practitioners and care staff at residential aged care facilities by increasing the availability of specialised psychiatric and geriatric knowledge and care. It is not intended to prevent general practitioners from writing repeat prescriptions for antipsychotics or from exercising their clinical judgement and knowledge to ensure that people experience continuity of care. However, general practitioners should only be able to write those repeat prescriptions for a period of 12 months from the initial prescription by a psychiatrist or geriatrician.

If, at that 12-month mark, there is a perceived need for ongoing use of antipsychotics, a further prescription should be obtained from a psychiatrist or a geriatrician. Any person who needs to use antipsychotics for a period of more than 12 months is more likely to be, and indeed should probably be, under the care of a psychiatrist or a geriatrician or both. In any event, the involvement of a psychiatrist or a geriatrician once per year does not impose an undue burden on specialists or prevent appropriate prescription of antipsychotics for people receiving residential aged care. Our recommendations for Local Hospital Network-led outreach services and expanded older persons mental health services should also improve access to geriatricians and psychiatrists to review people receiving residential aged care and initiate treatment for them if required.

We note the concerns expressed by the Royal Australian College of General Practitioners and others.[171] In spite of those concerns, we consider that our recommendation on prescription of antipsychotics strikes the right balance for involvement of general practitioners on the one hand and specialists on the other, and does not detract from the vital role played by general practitioners in the provision of health care to people receiving residential aged care.

9.10 Improving transition between hospital and residential aged care

There is a need for improved communication and collaboration between people working in the aged care system and people working in the health care system. The health care needs of older people cannot be safely and comprehensively met when there is poor communication and collaboration between these systems.[172] We have heard evidence about inadequate sharing of health information about older people as they move between the health and aged care systems.[173]

With respect to information about older people being transferred from hospital to residential aged care, Ms Tess Oxley, an experienced New South Wales paramedic, said that in New South Wales, the quality of the information provided in discharge summaries can be variable.[174] Mr Thomas Woodage, Facility Manager at a Baptistcare facility, told us that staff members at his facility have had ‘enormous difficulty’ in obtaining discharge summaries at all.[175]

The information provided to hospitals by residential aged care providers can also be variable.[176] Representatives from State Government health departments, hospital emergency clinicians and ambulance workers told us that often hospitals did not receive useful information about aged care residents when residents presented at hospital or when an ambulance was called to a residential aged care facility.[177] Dr Clare Skinner, emergency physician and Director of Emergency Medicine at Hornsby Ku-ring-gai Hospital, said that she would often only receive five or six lines about a resident's presenting problem and past medical history, in 'broad-brushstrokes terms' and with little detail about the origins of the condition or past treatment.[178] Ms Jo-Anne Lovegrove said that a hospital transfer form referred to her father's diagnosis of Alzheimer's without reference to his behavioural risks.[179]

Recommendation 66: Improving the transition between residential aged care and hospital care

The Australian and State and Territory Governments should:

a. **by 1 July 2022, implement, and commence publicly reporting on compliance with, hospital discharge protocols that ensure that discharge to residential aged care from hospital should only occur once appropriate clinical handover and discharge summary (including medications list) has been provided to and acknowledged by the residential care service, and provided to the person being discharged**

b. **by 1 December 2021, require staff of aged care services, when calling an ambulance for a resident, to provide the paramedics on arrival with an up-to-date summary of the resident's health status, including medications and advance care directives.**

9.10.1 Transfer from hospital to residential aged care

The requirements for transfer and clinical handover processes from hospital to residential aged care are unclear. The National Safety and Quality Health Service Standards comprehensively set out the requirements for clinical handover between health facilities, but they do not provide any indication of what is specifically required for clinical handover from hospital to residential aged care.

Nationally consistent hospital discharge protocols should be developed and implemented to ensure that discharges to residential aged care only occur once appropriate clinical handover and discharge summaries have been provided to and acknowledged by the residential care service. Those materials should also be provided to the person being discharged.

The Australian Government and most State and Territory Governments support the introduction of hospital discharge protocols to ensure that discharge summaries are consistently and promptly provided by hospitals to staff members in residential aged care facilities.[180] To improve the quality of discharges to residential aged care, the health care

and aged care systems should have the same standards for transitions of care, and clinical communication should be the same.[181] Future health funding agreements between the Australian Government and State and Territory Governments should include a requirement for strengthened hospital discharge protocols, including clinical handover.

9.10.2 Transfer from residential aged care to hospital

There is significant variation in the information staff at residential aged care facilities provide to paramedics or hospitals when residents are transferred to hospital. The hospital should receive enough information to support safe and effective continuity of care. At a minimum, the hospital should be provided with an up-to-date summary of the resident's health status, including medications and advance care directives.

The current Aged Care Quality Standards are vague about the information-sharing responsibilities of approved providers. They require an approved provider to ensure that 'information about the consumer's condition, needs and preferences is documented and communicated within the organisation, and with others where responsibility for care is shared'.[182] Guidance material for the Quality Standards refers in broad terms to sharing information with other health care providers, such as when an older person is being transferred to hospital.[183]

This lack of specificity about what, and how, information should be shared permits variability in the transfer practices of approved providers, to the detriment of older people's care. There should be greater standardisation of requirements for clinical handover during the transfer from aged care facilities to hospitals. The requirement to provide information to paramedics and hospitals should not dissuade or delay the calling of an ambulance. Approved providers should, as a matter of course, keep up-to-date records for the people to whom they provide residential aged care. A summary of those up-to-date records should be capable of being made readily available at short notice.

Staff members at residential aged care facilities need to ensure that sufficient, appropriate and consistent information is provided to paramedics and hospitals to treat residents upon any transfer to hospital.

9.11 Better collection, sharing and analysis of health data for people receiving aged care

In the course of our inquiry, we have encountered deficiencies in the data about access to health care by people receiving aged care. The health care system generally does not identify when people in aged care receive health care services. Governments and providers of aged care and health care must be able to monitor whether the health care needs of older people receiving aged care are being met on an ongoing basis.

Without improved collection, linkage and use of such data, it will be difficult to assess whether people receiving aged care are accessing the health care that they need, and whether our recommendations in this chapter are working as intended.[184]

The new 2020–25 Addendum to the National Health Reform Agreement commits the Australian and State and Territory Governments to achieving comprehensive health data access, usage and sharing, while maintaining data security and preserving individuals' privacy.[185] It also commits the Governments to develop agreed indicators and measures and associated data collections, and to resolve 'system interface issues' involving the health, aged care and disability services systems.[186] In that context, we make the following recommendations.

Recommendation 67: Improving data on the interaction between the health and aged care systems

The Australian Government and State and Territory Governments should improve the data available to monitor the interaction between the health and aged care systems and improve health and aged care planning and funding decisions. In particular:

a. **the Australian Government should implement an aged care identifier by no later than 1 July 2022 in the Medicare Benefits Schedule and Pharmaceutical Benefits Scheme Schedule datasets to allow regular public reporting on the number and type of medical and pharmaceutical services provided to people receiving aged care**

b. **by no later than 1 July 2023, all health National Minimum Data Sets reported to the Australian Institute of Health and Welfare (other than those relating to maternity, neonatal and paediatric care) should include an item identifying whether a person is receiving aged care services and the type of aged care the person is receiving**

c. **National Minimum Data Sets covering all State and Territory Government-funded health services should be implemented by no later than 1 July 2023**

d. **all governments should implement a legislative framework by no later than 1 July 2023 for health and aged care data to be directly linked, shared and analysed to understand the burden of disease of current and prospective people receiving aged care and their current and future health needs**

e. **the Australian Government should direct the Australian Institute of Health and Welfare to include data tabulated on the basis of aged care recipient status in any relevant health statistical publications, and make the de-identified data publicly available through the Australian Government's data portal data.gov.au.**

9.11.1 Aged care identifier

The Australian Government currently spends around $45 billion every year on benefits for medical services and pharmaceuticals under the Medicare Benefits Schedule and the Pharmaceutical Benefits Scheme Schedule. It also spends around $21 billion on aged care each year. Despite this significant investment in health care and aged care, the Australian Government is unable to determine precisely how much of the spending on health care is used by people receiving aged care.

As a result of this lack of information, the Australian Government has no proper basis for assessing whether or not health programs are meeting the needs of older people receiving aged care. This needs to be rectified.

The Medicare Benefits Schedule data collection contains information on health services that qualify for a benefit under the *Health Insurance Act 1973* (Cth) and for which a claim has been processed. The Medicare Benefits Schedule data includes information on the patient (date of birth, gender, and postcode) and the service (the date it was provided, Medicare Benefits Schedule item number, provider identifier, fee charged and benefit paid).[187] For services that involve consultation by a general practitioner or a specialist, there is no information on the reason for the consultation. Apart from services specifically provided by a general practitioner in a residential aged care facility, the data does not show whether a patient is also receiving aged care.

Similarly, until 2017, the Pharmaceutical Benefits Scheme Schedule data did not record whether a medicine had been dispensed to a person in residential aged care. The Australian Government took steps to address this shortcoming in July 2017, by introducing the residential aged care facility identification number.[188] However, use of this data field is voluntary. As of May 2019, pharmacists were not using the residential aged care facility identification number to an extent that would allow for meaningful evaluation, through the Pharmaceutical Benefits Scheme Schedule data, of aged care residents' medicine use.[189] The identification number also does not extend to identifying people receiving aged care in the community.

Services Australia administers Australian Government payments for the Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, and aged care. It should be empowered to apply a common personal identifier across all three systems to allow the Australian Government to record the number and type of medical services and medicines used by people receiving aged care. The data should be provided to the Australian Institute of Health and Welfare and made publicly available for use by, among others, researchers and people who are planning service provision.

9.11.2 Minimum health dataset

Data on the use of State and Territory Government-funded health services by older people living in residential aged care is not consistently or comprehensively captured. There is no accurate record of the number of people living in residential aged care facilities who have used those health services. Among other things, there is no accurate and comprehensive dataset relating to their presentations to emergency departments or their hospital admissions, nor is useful information available on the health conditions that occasioned those attendances. This absence of data capture contributes to a lack of integrated planning for the aged care and health care systems because it inhibits analysis and understanding of the interaction between these systems.

State and Territory Governments collect data on public hospital activity in three datasets: the Admitted patient care dataset covering acute admitted patient care and subacute admitted patient care, including rehabilitation, palliative care, geriatric evaluation and management, and psychogeriatric care; the Non-admitted patient emergency department care dataset; and the Non-admitted care dataset, covering outpatient clinics.[190]

The Admitted patient care dataset and Non-admitted patient emergency department care dataset are health sector National Minimum Data Sets. The Australian Institute of Health and Welfare defines a National Minimum Data Set as 'a set of data elements agreed for mandatory collection and reporting at a national level'.[191] These National Minimum Data Sets contain standardised health data and are used to 'help health care organisations to identify where safety and quality problems exist, to identify trends, and to develop practical approaches to addressing these problems'.[192] Of all the States and Territories, only Victoria and the Northern Territory have an aged care indicator in the hospital datasets.

From 2020–21, it is intended that the admitted patient care National Minimum Data Set will capture all movements between hospitals and residential aged care.[193] This work is progressing in the Health Aged Care Interface Data Project under the auspices of the Australian Health Ministers Advisory Council.[194] This project is designing and working towards the implementation of an aged care identifier in the hospital National Minimum Data Set.[195] Any minimum dataset including aged care data should have items identifying whether a person is receiving aged care services and, if so, the type of aged care they are receiving.

This work is encouraging but long overdue. It should be completed quickly. It should extend to all State and Territory Government-funded health services, including those the subject of our recommendations in this chapter. The resulting data and reports should be held by the Australian Institute of Health and Welfare and, in a de-identified form, made publicly available. Access to this data is integral to inform policy design, service delivery planning, monitoring, research, and evaluation.[196] It is particularly important that de-identified data is made available to researchers outside government without them being required to seek further consent from data custodians.

Once people receiving aged care can be better identified in the Medicare Benefit Schedule data and Pharmaceutical Benefits Scheme Schedule data and in State and Territory health services data, the next step should be to link the data with aged care data to allow comprehensive analyses of older people's access to health services and their health care needs.[197]

9.11.3 Approved providers' adoption of digital technology interoperable with My Health Record

Recommendation 68: Universal adoption by the aged care sector of digital technology and My Health Record

The Australian Government should require that, by 1 July 2022:

a. every approved provider of aged care delivering personal care or clinical care:

i. uses a digital care management system (including an electronic medication management system) meeting a standard set by the Australian Digital Health Agency and interoperable with My Health Record

ii. invites each person receiving aged care from the provider to consent to their care records being made accessible on My Health Record

iii. if the person consents, places that person's care records (including, at a minimum, the categories of information required to be communicated upon a clinical handover) on My Health Record and keeps them up to date

b. the Australian Digital Health Agency immediately prioritises support for aged care providers to adopt My Health Record.

Aged care providers should be using digital care management systems. Professor Johanna Westbrook, Director of the Centre for Health Systems and Safety Research, Australian Institute of Health Innovation, Macquarie University, gave evidence that the aged care sector currently relies heavily on faxing, scanning, emailing and, in some instances, mailing information between external care providers and service providers. She said that this 'increases the risk of error' and 'is resource intensive and inefficient'.[198]

Electronic medication management systems are particularly important in aged care given the high use of medicines by people receiving aged care. We are encouraged that the Australian Government is trialling an Electronic National Residential Medication Chart in a number of residential aged care facilities.[199]

My Health Record is an Australian Government online summary of a person's key health information. It is progressively being adopted across the health care system. The Australian Digital Health Agency has stated, however, that 'while a number of aged care clinical information systems are conformant and can connect to My Health Record, it is not extensively used across the aged care sector'.[200] In October 2019, only 247 out of a possible 1800 aged care residential and home care providers (14%) were registered for My Health Record.[201] The Australian Digital Health Agency stated that aged care is 'a key priority area for future focus'.[202]

Universal adoption by approved providers of My Health Record should be an immediate focus. Given the high frailty and acuity of older people receiving aged care and their increased need for health care, it is appropriate to expect that all approved providers should be using My Health Record by no later than 1 July 2022. This will ensure that multiple health care and aged care providers can access one central source of health information about people receiving aged care. Any improved information sharing will depend on the person receiving aged care having a My Health Record and giving prior consent to their health records being accessed, used and shared in this way.

System interoperability will support communication and information sharing between the aged care sector and the health care sector.[203] For instance, system interoperability between the clinical systems of general practice and approved providers would 'improve communication and minimise any errors in treatment, particularly when a GP [general practitioner] is required to respond to a clinical situation'.[204]

Interoperability should be pursued in the short term through My Health Record. The adoption of My Health Record, and systems interoperable with it, will assist with information sharing between care providers and others and hence assist with improved and safe care. Data interoperability, whereby data is captured according to a common set of definitions, is also worthwhile pursuing.

The Australian Government has agreed that all residential aged care services should move to digital electronic care records.[205] The Government has further supported the use of electronic discharge summaries through My Health Record.[206] The Government also supports changes to encourage the use of My Health Record by aged care providers.[207] The Government has, however, submitted that 'My Health Record has been designed as a fundamentally voluntary system' and that 'the My Health Record system is voluntary for providers as well as health care recipients'.[208] We accept that a person receiving health care is entitled not to participate in the My Health Record system, but observe that the Australian Digital Health Agency has said that over 90% of Australians have a record.[209] We also do not consider that the participation of aged care providers should be voluntary.

Paper-based systems are outdated, inefficient, and can lead to errors during the transfer of residents between residential aged care and hospital settings. Transition to a digital care management system interoperable with My Health Record will result in a safer, more efficient and more comprehensive transfer of critical information relating to a person's relevant care and medical history. Such a transition by approved providers should be supported by the Australian Digital Health Agency.

9.12 Understanding who should deliver health care to people receiving aged care

There is a lack of clarity and certainty about the respective roles and responsibilities of aged care and health care providers among staff members at aged care services, people receiving aged care and their families and carers, and health care providers.[210]

Commissioner Briggs has heard evidence that this lack of clarity and certainty can allow both aged care providers and health care providers to avoid responsibility for providing or arranging health care, or to pass on the responsibility for arranging access to health care to people receiving aged care and their families.[211] Providing health care must be the shared responsibility of the aged care and health care providers, and of the Australian Government and the States and Territories. Commissioner Briggs considers that the processes for ensuring this shared responsibility should be specific and entrenched. They should be open to public scrutiny.

9.12.1 Clarification of respective roles and responsibilities

In future, there must be far greater clarity about who is responsible for what health care services for people receiving aged care.

Recommendation 69: Clarification of roles and responsibilities for delivery of health care to people receiving aged care

1. By 31 December 2021, the Australian and State and Territory Governments should amend the National Health Reform Agreement to include an explicit statement of the respective roles and responsibilities of approved aged care providers and State and Territory health care providers to deliver health care to people receiving aged care, similar to the Applied Principles and 'tables of supports' for the National Disability Insurance Scheme, on the basis that, among other things:
    a. allied health care should generally be provided by aged care providers
    b. specialist services, including specialist palliative care and subacute rehabilitation, should be provided by State and Territory health care providers, even if these services involve allied health practitioners
    c. less complex health conditions should be managed by aged care providers' staff, particularly nurses.
2. By 31 December 2021, the Australian Government should amend the *Quality of Care Principles 2014* (Cth) to clarify the role and responsibilities of approved providers to deliver health care to people receiving aged care, including but not limited to their particular role and responsibilities to deliver allied health care, mental health care, and oral and dental health care.

While the *Quality of Care Principles 2014* (Cth) set out in broad terms the care and services that should or may be provided by approved providers, they do not provide sufficient detail or clarity. Perspectives on the existing health care responsibilities of approved providers, and what their responsibilities should be, vary.[212] Where responsibility lies for each aspect of the care provided to older people at any particular time is uncertain.[213] This lack of clarity results in part because responsibility for meeting the health care needs of people receiving aged care is shared between the Australian and State and Territory Governments and between health care providers and aged care providers. Professor Flicker suggested that this split responsibility between Australian and State and Territory Governments had led to governments at each level attempting to minimise their own participation in this area because they are able to regard it as 'somebody else's responsibility'.[214]

This split of responsibilities is reflected in different streams of funding for different aspects of health care and aged care. These different funding streams for particular types of care, such as general practice, aged care, mental health and public hospital care, can lead to care provision becoming fragmented and service providers seeking to pass responsibility for care to other parts of the system.[215] Dr Nigel Lyons, Deputy Secretary, Health System Strategy and Planning, New South Wales Ministry of Health, emphasised the importance of clarifying roles and responsibilities across health care and aged care services:

> the foundational piece is actually defining the respective roles and responsibilities in relation to health care provision, the role of the residential aged care provider, the role of primary care, and the role of the public state health system as well as the role of other private providers and non-Government providers in delivering health care to residents, and I think having clarity around their respective roles and responsibilities is absolutely key, and it's critical then to designing a system that can best support the care needs of the residents.[216]

We agree. The fragmentation and passing of responsibilities between the aged care and health care systems should be dealt with by the Australian and State and Territory Governments.[217] It must be made very clear by all governments, and to all governments and care providers, who exactly within the system is responsible for what and where the funding will come from to achieve the desired result.[218]

The Applied Principles and 'tables of supports' for the National Disability Insurance Scheme are an example of principles agreed by the Australian and State and Territory Governments to define the funding and service responsibilities of multiple systems, including the disability, health, aged care, justice and education systems.[219] A similar exercise should be undertaken, through the National Health Reform Agreement, for provision of health care services to people receiving aged care.

To determine the respective roles and responsibilities of approved aged care providers and State and Territory health care providers, the Australian and State and Territory Governments should take into account a number of recommendations we have made in this chapter and throughout this report. We recommend increased responsibilities for aged care providers, including a larger and more present clinical workforce, coordinating the care of older people, and providing palliative care, dementia care, and allied health care as part of routine practice. We also recommend an improvement in the provision of care by the health sector, including in delivering multidisciplinary outreach services, specialist palliative care, and subacute rehabilitation.

Consistent with these recommendations, the Australian and State and Territory Governments should follow these principles when clarifying respective roles and responsibilities:

- allied health care should generally be provided by aged care providers
- specialist services, including specialist palliative care and subacute rehabilitation, should be provided by State and Territory health care providers, even if these services involve allied health practitioners
- less complex health conditions should be managed by aged care providers' staff, particularly nurses.

The Australian Government should legislatively define the roles and responsibilities of aged care providers. That clarification should include measurable requirements for health care provided by aged care providers, including mental, dental and allied health care. Given the high rates of mental health conditions and poor oral health in aged care, aged care providers' responsibilities for the mental and oral health of residents should be made clear. The measurable requirements should be informed by clinical experts.

9.12.2 Improved access to State and Territory health services by people receiving aged care

Recommendation 70: Improved access to State and Territory health services by people receiving aged care

By 1 July 2022, the Australian and State and Territory Governments should amend the National Health Reform Agreement or any future health funding agreement to include explicit commitments by State and Territory Governments to provide:

a. access by people receiving aged care to State and Territory Government-funded health services, including palliative care services, on the basis of the same eligibility criteria that apply to residents of the relevant State and Territory more generally

b. clinically appropriate subacute rehabilitation for patients who:

i. are receiving residential aged care or personal aged care at home, or

ii. may need such aged care services if they do not receive rehabilitation,

as well as performance targets and reporting requirements on the provision of subacute rehabilitation care to people receiving aged care.

People receiving aged care should have the same access to State and Territory health services, such as hospital services, specialist palliative care services and subacute rehabilitation services, as other people in Australia. We have received evidence that that does not always occur.[220] Ms Nikki Johnston, palliative care nurse practitioner at Clare Holland House, Calvary Public Hospital, told us that:

> Specialist palliative care in Australia is, generally, funded by the States. Commonwealth funds home-care packages and residential aged-care. So at the moment there's many State-run services that won't walk through the front door of a residential-aged-care facility. There's other services that won't as well—community nursing, wound care, lots of other people that just don't—so that reduces access.[221]

We have heard evidence that older people who currently receive aged care services do not receive adequate levels of subacute rehabilitation following a major injury or illness. This is particularly true for those who live in residential aged care.[222] By way of stark example, in 2018, only 18% of people who lived in residential aged care and received acute care for a hip fracture received subacute rehabilitation, compared with 51% of people living in the community.[223]

Commissioner Briggs considers that good access to subacute rehabilitation is particularly important. It is clinically aimed at optimising or restoring a person's functional ability, independence and quality of life following injury or illness.[224] Without it, older people lose their opportunity to regain as much of their former quality of life as possible after serious adverse events. Subacute rehabilitation can be provided either in hospital, in the community, or in residential aged care.

However, witnesses told us of their family members' experiences of missing out on subacute services.[225] Professor Christopher Poulos, a consultant physician in rehabilitation medicine, told us that there are multiple reasons why older people receiving residential aged care are less likely to access, or be given the choice to access, hospital-based rehabilitation. These include:

- health care sector staff members may believe older people receiving aged care are unable to tolerate the intensive rehabilitation delivered in hospitals due to their greater complex functional and medical requirements
- the high prevalence of dementia among the residential aged care cohort and the unfounded belief by hospital staff members that people with dementia are unable to participate in, or benefit from, rehabilitation
- a mistaken belief by hospital staff members that residential aged care services can provide adequate rehabilitation.[226]

Commissioner Briggs considers that another reason for the lack of access to rehabilitation services is compartmentalised funding between the Australian and State and Territory Governments.[227] This can lead to aged care providers and health care providers believing that rehabilitation of a person accessing aged care is the other party's responsibility.

State-based public health services must be available to all people receiving aged care to meet their care needs. Under the National Health Reform Agreement, the State and Territory Governments have committed to providing health and emergency services through the public hospital system, based on what are termed the 'Medicare principles'. These are a set of principles that have been in successive health funding agreements and outline universal access to State and Territory hospital services:

> (a) eligible persons must be given the choice to receive public hospital services free of charge as public patients;
>
> (b) access to public hospital services is to be on the basis of clinical need and within a clinically appropriate period; and
>
> (c) arrangements are to be in place to ensure equitable access to such services for all eligible persons, regardless of their geographic location.[228]

It should be explicit in the National Health Reform Agreement that State and Territory health services, such as hospital services, specialist palliative care services and subacute rehabilitation services, should be available to people receiving aged care as they are to others. The State and Territory Governments should, through monitoring and benchmarking, be held accountable for the delivery of these health services to people receiving aged care. These services should be delivered in an appropriate setting for the patient, whether that is hospital-based or through outreach or hospital in the home, including at a residential aged care facility.

The recommendations made by us above for improved data collection and linkage will facilitate this monitoring and benchmarking. This data should be reported publicly by the Australian Institute of Health and Welfare on a regular basis.

9.12.3 Ongoing intergovernmental consideration of health care for people receiving aged care

Recommendation 71: Ongoing consideration by the Health National Cabinet Reform Committee

The Health National Cabinet Reform Committee should require the Australian Health Ministers' Advisory Council to:

a. consider the full suite of the Royal Commission's recommendations related to the interface of the health care and aged care systems and report to the next meeting of the Committee

b. include a standing item in all future meetings of the Council on the aged care system and its interface with the health care system.

Many of our recommendations directed to improving access to health care for people receiving aged care require considerable cooperation between the Australian and State and Territory Governments.[229]

The Australian Health Ministers' Advisory Council is the advisory body to the Health National Cabinet Reform Committee. It is comprised of a representative from the heads of the respective health departments of the Australian and State and Territory Governments. Among other things, the Australian Health Ministers' Advisory Council is to advise on strategic issues relating to the coordination of health services across Australia.

Under the new 2020–25 Addendum to the National Health Reform Agreement, the Australian Health Ministers' Advisory Council will monitor 'interface issues' that arise between the health system and the aged care system.[230]

As part of this work, the Australian Health Ministers' Advisory Council should consider our recommendations as they relate to the aged care system and its interface with the health care system, and report to the Health National Cabinet Reform Committee with a proposed approach to implementation of those recommendations.

The Australian Health Ministers' Advisory Council should, on an ongoing basis, have regard at its meetings to problems with the interface between the aged care system and the health care system and how those problems are to be resolved. We agree with Professor Flicker, who said that:

> I have no doubt that without coordination of all levels of government that we will continue to see substandard and inappropriate care for the health issues for older people and this will be manifested by completely unacceptable sentinel events.[231]

9.13 Conclusion

In the long term, the recommendations in this chapter and across this report that are directed at addressing the intersection between the aged care and health care systems would, if implemented, create better health care for people accessing aged care. Many more older people would receive health care commensurate with their needs on the same basis as other Australians. The respective roles of the health care system and the aged care system in delivering health care to people receiving aged care would be clearly defined and generally understood.

Aged care providers would look after the functional capacity needs, wellbeing and oral health needs of people accessing their care. They would do this through their aged care allied health teams. People receiving aged care would receive regular oral health, mental health and functional capacity assessments. They would also have regular monitoring of their medication needs and use. Aged care providers would identify health care needs, seek medical assistance when required, and coordinate care between different health care providers.

People living in residential aged care and people with high needs receiving aged care in their homes in the community could be under the care of an accredited aged care general practice if they so choose. Those accredited practices would provide proactive, preventative, and coordinated care. The practice and the aged care provider would use the person's record in My Health Record to maintain an accurate, comprehensive and up-to-date account of their health status and treatment regime.

People receiving aged care would be able to access publicly funded dental care through the Senior Dental Benefits Scheme when they needed to. These services would be provided at their places of residence.

People receiving aged care would be able to access Medicare-subsidised mental health support. People with severe mental health needs, including those with dementia, would also be able to access Older Persons Mental Health Services on an outreach basis. Fewer people receiving aged care would be prescribed antipsychotic drugs, because they would have access to psychosocial support. Antipsychotic drugs would only be able to be prescribed by geriatricians and psychiatrists.

Every residential and high-needs home care provider would have an established relationship with a multidisciplinary outreach team led by a Local Hospital Network. This would provide access to specialists and associated paraprofessionals to address complex health issues beyond the scope of primary care. Specialist palliative care services would also be provided on this basis. As a result, unplanned hospital attendances would be relatively rare. People receiving aged care would also have better access to consultations with private specialists provided through telehealth or through fly-in-fly-out arrangements supported by the Rural Health Outreach Fund.

State and Territory public health services would provide clinically appropriate subacute rehabilitation for older patients in community and residential aged care programs, as well as to other patients at risk of entering aged care without rehabilitation. This care would be delivered in an appropriate setting for the patient, whether in hospital or at the person's place of residence—including a place of residence in residential aged care.

Relevant up-to-date clinical data about a person receiving aged care would be available to all care providers as the person moves from one care setting to another. The Australian Institute of Health and Welfare would curate a dataset including the Medicare, Pharmaceutical Benefits Scheme, and hospital data on all people receiving aged care and make it publicly available for monitoring, planning, and analysis.

The Australian and State and Territory Governments and health practitioners and aged care providers must all work together to meet the health care needs of people receiving aged care. For too long, people receiving aged care have been left to suffer as a result of the fragmentation between the health care and aged care systems.

Endnotes

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10. Aged Care for Older People with Disability

The support available from the National Disability Insurance Scheme should be available to all Australians who need it. However, the scheme does not provide those supports to people who acquire a disability after they turn 65 years of age.[1] Nor does it provide supports to people with disability, whenever acquired, who had already turned 65 years when the National Disability Insurance Scheme came into operation in their local area.[2] That includes people with lifelong disability. In addition, the scheme ceases to provide supports to people with disability who first receive residential or home care services, on a permanent basis, after turning 65 years.[3]

Mrs Elizabeth Karn, a 68-year-old woman with a disability who was ineligible for support under the National Disability Insurance Scheme due to her age, described the effect that differences between the aged care and disability systems had on her:

> As a Deaf Elder, I'm exhausted. I feel broken-hearted. So many of my friends are in the same situation as me. We feel excluded, ignored and isolated. Because of our age and our disability, we are forgotten. Where do we belong? When are we going to be included and accepted as a valued part of the Australian citizen?[4]

We are authorised to inquire into 'how best to deliver aged care services to…people with disabilities residing in aged care facilities' and to have regard to, among other things, 'the interface with other services accessed by people receiving aged care services, including…disability services'.[5] Reasonably relevant to this is how best to deliver aged care services to people with disabilities living in their homes.[6]

The establishment of the National Disability Insurance Scheme transformed the provision of disability services in Australia. The scheme has changed, for the better, the lives of hundreds of thousands of people with disability by providing them with the reasonable and necessary supports that they need to live an ordinary life.

10.1 Equitable access to support

Despite the landmark contribution made by the National Disability Insurance Scheme to the lives of people with disability, many people with disability aged 65 years and over are prevented from accessing it and obtaining the benefits of an individualised plan of supports.[7] Mr Roger Beale AO described his experience of being a person with disability over the age of 65 years when the scheme rolled out in his area:

> This leaves people who were disabled, but over 65, at the time of the introduction of the NDIS [National Disability Insurance Scheme] and people who acquire a disability after the age of 65 without support equivalent to the NDIS. They are simply excluded and must rely on the inferior state and territory schemes for assistive technology that are far less comprehensive, subject to budgetary constraints which result in significant queuing and in some cases...are not available to people who are not pensioners or holders of a pensioner health care card.[8]

Mr Beale has faced financial consequences as a result of not being entitled to access the National Disability Insurance Scheme, including the need to self-fund home modifications and assistive technologies—something that not all older people with disability are able to do. People who are unable to self-fund the supports they need are left to 'accept constraints on their ability to participate fully in Australian life'.[9]

In 2018, there were 1.9 million people with disability in Australia who were aged 65 years and over.[10] However, a 2019 report by the Australian Institute of Health and Welfare estimated that only around 15,000 people aged over 65 years, compared to around 460,000 aged under 65 years, would have access to the National Disability Insurance Scheme and its benefits when the rollout was completed in 2020.[11] According to the National Disability Insurance Scheme's quarterly report dated 30 June 2020, 11,476 people aged over 65 years were active scheme participants.[12] They represented 3% of all active participants.

The Australian aged care system must itself provide comprehensive care including, where required, support for disability. By design, the National Disability Insurance Scheme lawfully discriminates against older people on the basis of their age.[13] In the absence of any relaxation or removal of the age requirements for the National Disability Insurance Scheme, other government programs are required to fill the entitlement gap and provide analogous benefits for those people with disability aged 65 years and over who cannot access the scheme.[14]

Elizabeth Karn

Mrs Elizabeth Karn, a 68-year-old woman who is profoundly deaf, described the gap in services between the National Disability Insurance Scheme and aged care services. This left her feeling 'isolated and left out', and facing a 'barrier' that she and other deaf people aged 65 years and over 'just can't push through'.[15]

Mrs Karn was born with the ability to hear. She became profoundly deaf at the age of four years after contracting meningitis.[16] Auslan, Australian Sign Language, is her language.[17]

Mrs Karn was 'almost 64' when she 'jumped in and applied to the NDIS [National Disability Insurance Scheme]'.[18] She had heard about it through the Deaf Society:

> we were so excited, I caught a train all the way to Sydney to get the information and go to a workshop, filled out some application forms and they said, 'How old are you?' and I said 'I'm not 65 yet.' As soon as they found out where I lived they said, 'Roll out doesn't happen in your area for a couple of years' so I was almost 64 and they told me I was going to miss out.[19]

Because the roll out of the scheme in Mrs Karn's area would not occur before she turned 65 years, she was ineligible. Mrs Karn then made an application through My Aged Care.[20]

Mrs Karn had hoped that she could secure access to Auslan interpreters and to aids—a flashing fire alarm and front doorbell, and access to an iPad to use video replay interpreting—through the National Disability Insurance Scheme.[21] When she applied to My Aged Care, she asked only for access to Auslan interpreters. She was told that My Aged Care provided interpreters for spoken languages but not for Auslan.[22] This left her feeling 'really excluded' and 'like they forgot deaf people'.[23]

Auslan interpreters were available through the National Disability Insurance Scheme. But Mrs Karn could not access them through My Aged Care.[24] She was left to rely on her daughter to assist her as an interpreter.[25] Mrs Karn explained that:

> We just want the right to gain access to services and funding that allows deaf seniors, deaf elders, to have the right to communicate freely in our country. …Auslan Deaf elders wish to access My Aged Care, Auslan-interpreting packages, like our deaf peers who are under 65, who now have the NDIS [National Disability Insurance Scheme]. This would provide us with the access to the wider community without the language and communication barriers that are experienced in our everyday life.[26]

There are existing government programs that provide some disability services to some people with disability aged 65 years and over who cannot access the National Disability Insurance Scheme, including the Commonwealth Continuity of Support Programme.[27] However, eligibility for the Continuity of Support Programme is limited to those people with disability who do not qualify for the National Disability Insurance Scheme and are 'an existing client of state-managed specialist disability services at the time the CoS [Continuity of Support] Programme commences in their region'.[28] In this context, continuity of support means 'supporting clients to achieve similar outcomes to those they were achieving' under specialist disability services programs previously administered by State and Territory Governments. The Continuity of Support Programme commenced on 1 December 2016 'in line with' the National Disability Insurance Scheme and was available in all States and Territories by the end of June 2020.[29] The Continuity of Support Programme provides accommodation support, community support, community access and respite services.[30] Unlike the National Disability Insurance Scheme, the Continuity of Support Programme does not fund specialist disability services aimed at supporting people to gain employment.

Programs of this kind have not consistently and comprehensively given people with disability access to the nature and extent of supports available to others under the National Disability Insurance Scheme.[31]

The Australian Government announced in the 2020–21 Budget that it will provide, from 2020–21 to 2023–24, $125.3 million for a new Disability Support for Older Australians Program to replace the Commonwealth Continuity of Support Programme.[32] The new program will commence on 1 July 2021. According to the Australian Government:

> The Australian Government will continue to support vulnerable older Australians who cannot access the National Disability Insurance Scheme (NDIS).
>
> …
>
> Approximately 3,600 Australians currently use the CoS [Continuity of Support] Programme. It is vital that they receive support that is comparable to people on the NDIS.[33]

It remains to be seen whether the new Disability Support for Older Australians Program will provide 'support that is comparable' to people on the National Disability Insurance Scheme. It is also unknown what will happen after 2024. Such a situation of uncertainty is not acceptable for older people with disability who are reliant on support to live with some quality of life.

The new program will only be available to people who were receiving services under the Continuity of Support Programme.[34] Those people, presently numbering around 3600, are likely to represent only a fraction of the people with disability aged 65 years and over who cannot access the National Disability Insurance Scheme.[35] The Continuity of Support Programme has been closed to new entrants since July 2020.[36] Given that the Continuity of Support Programme is being phased out and available only for a limited group of older people, the number of people receiving services under the new Disability Support for Older Australians Program will only diminish in future as those people die.

As Australia's population ages, it is likely that a larger number of older people with disability will need to access aged care to obtain the supports and services they need.[37] That will particularly be so if they are not National Disability Insurance Scheme participants. But if a participant in the National Disability Insurance Scheme receives aged care services, on a permanent basis, for the first time after turning 65 years, that person loses the ability to participate in the scheme forever.[38]

If older people with disability have to access aged care to obtain the support they need, they should not have to accept something less than that which others in similar circumstances can access under the National Disability Insurance Scheme. Commissioner Briggs points out that this fails the 'horizontal equity' test, where those in similar circumstances should be treated similarly by the Australian Government.

Recommendation 72: Equity for people with disability receiving aged care

By 1 July 2024, every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person under the age of 65 years with the same or substantially similar conditions.

The disability services and aged care systems are different philosophically and operationally.[39] Discrete Australian Government legislation governs each program area separately. Each area has its own responsible Minister. Disability services and aged care are financed differently and each offers a different range of services. The National Disability Insurance Scheme is not means tested, while aged care services involve consumer contributions. Aged care services are rationed in the existing system, while support provided by the National Disability Insurance Scheme is not. There are strict statutory age requirements for the National Disability Insurance Scheme, but not for aged care.

In principle, the objective of providing reasonable and necessary support to a person with a disability should apply equally where disability occurs after turning 65 years or continues after entering the aged care system. There may need to be careful provision of that support to ensure equivalence rather than, for example, double benefit. But what is provided in aged care must be the care that is needed, including the care called for to support a disability.

We have received evidence and information about inconsistencies between the supports and services available under the National Disability Insurance Scheme and those available in the aged care system, including greater access in the National Disability Insurance Scheme to specialised care, aids, equipment and therapy.[40] The schedule of supports available to participants in the National Disability Insurance Scheme is more comprehensive than is presently available in aged care.[41] The average amount of funding available for supports is often greater in the National Disability Insurance Scheme than in the current aged care system. As at October 2020, the highest level of government funding available to an aged care resident was $81,446.10 plus supplements each year (if classified as 'High High High' for the Aged Care Funding Instrument) but, on average, an individual plan for a National Disability Insurance Scheme participant receiving Supported Independent Living care supports was about $325,000 a year without any user contribution.[42] Spinal Cord Injuries Australia, described the difference between these systems as 'stark'. The submission gave this example:

> This is particularly the case for anyone with a significant acquired disability such [as] a traumatic spinal cord injury. The highest level of funded support in the home that is available through My Aged Care is a level 4 Home Care package which is currently priced at $50,000. Unlike tailored supports that are available through the NDIS [National Disability Insurance Scheme], and assessed according to need, My Aged Care services are capped. Unfortunately this has led to a two-tiered system of supports with an arbitrary age factor (65) deciding who gets access to the NDIS or My Aged Care. The current system is not equitable for those people with disability receiving My Aged Care. The most anyone with a disability will get is $50,000 which is woefully inadequate for anyone with a high level spinal cord injury such as quadriplegia. This amount must cover their personal care requirements, domestic assistance, as well as equipment (Assistive Technology) needs which would include wheelchairs (power and manual), commode/shower chair, hoist (floor or ceiling), electric bed and pressure relief (alternating air mattress and pressure cushion for wheelchair use). Given that someone with this level of disability would normally require at least five hours of care per day (approximately costing $75,000), the funding amount available is manifestly inappropriate and not fit for purpose.[43]

Older people with disability should not, as a matter of principle, be disadvantaged because they access support through the aged care system instead of the disability services system. That accords with one object of the new Act we propose for aged care: to provide for 'a system of aged care based on a universal right to high quality, safe and timely support and care to assist older people to live an active, self-determined and meaningful life'.[44] It is also a matter of equity.

The aged care system is not set up or funded to provide disability care, support and rehabilitation.[45] Commissioner Briggs considers that there are reasons for this, especially that the aged care program is necessarily focused on older people and that historically not all people with disability lived to old age due to their life circumstances. However, advances in medical technology and greater opportunities for people with disability mean that many people with disability are living longer. Commissioner Briggs contends that the aged care system should adapt to these changes.

We consider that the aged care program should provide people with disability who are receiving aged care daily living supports and equipment, such as assistive technology, aids and equipment, equal to those available to a person, with similar needs, under the National Disability Insurance Scheme.[46] Giving practical effect to this principle will likely require considerable cooperation between the government entity responsible for management of the aged care system and the National Disability Insurance Agency.[47] The aged care system manager will need to know about and understand daily living supports and outcomes that are available under the National Disability Insurance Scheme and the fair and efficient pricing of those goods and services. The respective regulatory frameworks for disability and aged care service providers might also, where possible, be coordinated or combined to reduce confusion and cost.

We have indicated that the measures necessary for this recommendation should be in place by no later than 1 July 2024 to coincide with the implementation of the new aged care program (see Recommendation 25). Nonetheless, the Australian Government should adopt interim measures, before 1 July 2024, to address inequities in supports for older people with disability who are currently affected.[48]

10.2 Reporting on outcomes

Australia's 10-year National Disability Strategy ended in 2020.[49] The National Disability Strategy set out a cooperative 10-year plan for the Australian and State and Territory Governments to improve life for people with disability, their families and carers. A purpose of the Strategy was to establish a high-level policy framework to give coherence to, and guide government activity across, mainstream and disability-specific areas of public policy. At the time of us writing this report, the Australian Government was developing a new National Disability Strategy.

The current 10-year Strategy emphasises the human rights of people with disability. The Australian Government describes it as the main way 'Australia implements the United Nations Convention on the Rights of Persons with Disabilities'.[50] Under the Strategy, the Australian Human Rights Commission has an important role to ensure that the Strategy upholds the human rights of people with disability.[51]

The Australian Human Rights Commission should continue this role under the new Strategy. To that end, the Disability Discrimination Commissioner and the Age Discrimination Commissioner should be required, as part of the new National Disability Strategy, to report annually to the Australian Parliament on the numbers and circumstances of all people with disability who are aged 65 years or older and receiving aged care. In particular, they should report on the ability of those older people with disability to access, through the aged care program, daily living supports and equipment equivalent to those available under the National Disability Insurance Scheme. Dr Ben Gauntlett, Disability Discrimination Commissioner, put it this way:

> People who are living in aged care with disabilities do not, unfortunately, have a voice. They're often in circumstances where they feel extremely challenged by the life in which they lead, they may be depressed, they may have a cognitive impairment and they may have an intellectual disability. But that lack of a voice does not mean circumstances such as the Royal Commission and the Human Rights Commission for that matter should not shine a light on the issue that exists.[52]

We consider that it is necessary for the Australian Government to be held to account for the results of our proposed changes to aged care services for people with disability, and the best way to do that is to report annually to the Parliament on the outcomes achieved.

The Australian Government supports the intent of the reporting requirement but suggests that the Australian Human Rights Commission, and the Disability and Age Discrimination Commissioners, are not best placed to undertake this reporting given the 'data capabilities' of the Australian Human Rights Commission.[53] However, the scope and nature of the reporting falls within the Australian Human Rights Commission's remit.[54] We are satisfied that the Disability and Age Discrimination Commissioners can and should carry out this reporting function and that, to do so effectively, they should be provided with appropriate resources and the means to access all necessary data and information.

Recommendation 73: Annual reporting to Parliament by the Disability Discrimination Commissioner and the Age Discrimination Commissioner

By 1 July 2024, the Disability Discrimination Commissioner and the Age Discrimination Commissioner should be required, as part of the new National Disability Strategy, to report annually to the Parliament on the number of people receiving aged care with disability who are aged 65 years or older and their ability to access daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those available under the National Disability Insurance Scheme.

Endnotes

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33 Australian Department of Health, *Budget 2020–21 Aged Care – Commonwealth Disability Support for Older Australians*, 2020, https://www.health.gov.au/sites/default/files/documents/2020/10/budget-2020-21-aged-care-commonwealth-disability-support-for-older-australians.pdf, viewed 20 November 2020.
34 The Australian Government has said that the people who will benefit from the new Disability Support for Older Australians Program are 'Close to 3,600 existing CoS [Continuity of Support] clients'. See Australian Department of Health, *Budget 2020–21 Aged Care – Commonwealth Disability Support for Older Australians*, 2020, https://www.health.gov.au/sites/default/files/documents/2020/10/budget-2020-21-aged-care-commonwealth-disability-support-for-older-australians.pdf, viewed 20 November 2020.
35 Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings 2018*, 2019, https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2018, viewed 20 November 2020.
36 Australian Department of Social Services, Disability and Carers, 6 August 2020, https://www.dss.gov.au/disability-and-carers/transitioning-to-the-ndis, viewed 20 November 2020.

37 For example, in 2016–17 the age-specific rate for spinal cord injuries was highest for people aged 75 years and over (13.0 cases per million population). See Australian Institute of Health and Welfare, *Spinal cord injury, Australia, 2016–17*, 2020, p 12, https://www.aihw.gov.au/getmedia/2b78577a-dcfc-41ed-9071-938d87594fe0/aihw-injcat-209.pdf.aspx?inline=true, viewed 20 November 2020.

38 *National Disability Insurance Scheme Act 2013* (Cth), s 29(1)(b).

39 Transcript, Adelaide Hearing 2, Hal Swerissen, 21 March 2019 at T1037.46–1038.6.

40 Transcript, Adelaide Hearing 2, Paul Sadler, 18 March 2019 at T732.9–17; Transcript, Adelaide Hearing 2, Lynda Henderson, 18 March 2019 at T690.10–16; Transcript, Melbourne Hearing 1, Michael Lye, 10 September 2019 at T4975.1–15; Spinal Cord Injuries Australia, Public submission, AWF.500.00190.0001_0004 at 0009.

41 National Disability Insurance Scheme, *Price Guide 2020–21*, 2020.

42 Australian Department of Health, *Aged Care Subsidies and Supplements New Rates of Daily Payments from 20 September 2020*, 2020, https://www.health.gov.au/resources/publications/schedule-of-subsidies-and-supplements-for-aged-care, viewed 20 November 2020; National Disability Insurance Agency, *Annual Report 2019–20*, 2020, p 41.

43 Spinal Cord Injuries Australia, Public submission, AWF.500.00190.0001_0004 at 0009.

44 See Chapter 1 on foundations of the new aged care system.

45 Transcript, Adelaide Hearing 1, Ian Yates, 11 February 2019 at T59.27–29, T59.36–37; Exhibit 9-8, Melbourne Hearing 1, Statement of Neale Radley, WIT.1251.0001.0001 at 0003 [20]; [22]–[24]; Exhibit 9-12, Melbourne Hearing 1, Statement of Carol Littley and Kevin Littley, WIT.1242.0001.0001 at 0007 [57]–[59]; Exhibit 9-9 Melbourne Hearing 1, Statement of Robyn Spicer, WIT.1245.0001.0001 at 0008 [73].

46 See also Recommendation 34 (Assistive technology and home modifications category) in Chapter 4, Volume 3 of this report, on aged care program design.

47 Submission of Roger Beale and Peter Freckleton, Response to Counsel Assisting's final submissions, 2 November 2020, RCD.0013.0001.0005 at 0007–0008.

48 Submission of Senior Rights Service Ltd, Response to Counsel Assisting's final submissions, 12 November 2020, RCD.0013.0010.0073; Submission of Peter Freckleton, Response to Counsel Assisting's final submissions, 12 November 2020, RCD.0013.0012.0042 at 0042; Submission of Uniting Care Australia, Response to Counsel Assisting's final submissions, 12 November 2020, RCD.0013.0012.0058; Submission of COTA Australia, Response to Counsel Assisting's final submissions, 12 November 2020, RCD.0013.0014.0097.

49 Australian Government, *National Disability Strategy 2010–2020*, 2011.

50 Australian Department of Social Services, *National Disability Strategy – Position Paper*, 2020, p 3; Australian Government, *National Disability Strategy 2010–2020*, 2011, pp 3, 9.

51 Australian Government, *National Disability Strategy 2010–2020*, 2011, p 67.

52 Transcript, Melbourne Hearing 1, Ben Gauntlett, 11 September 2019 at T5152.38–44.

53 Submissions of the Commonwealth of Australia, Response to Counsel Assisting's final submissions, 12 November 2020, RCD.0013.0014.0037.

54 *Australian Human Rights Commission Act 1986* (Cth), s 11; *Disability Discrimination Act 1992* (Cth), s 67; *Age Discrimination Act 2004* (Cth), s 53.

11. Younger People in Residential Aged Care

No younger person should have to live in residential aged care. Aged care is not intended for younger people and does not meet their needs.[1] But for too long, too many younger people have fallen into residential aged care because of the absence of suitable alternatives.[2] In the words of Australia's Disability Discrimination Commissioner, Dr Ben Gauntlett:

> younger people in Australia living in old age care institutions, because of their disability or medical condition, is a dark and inappropriate circumstance for this country to have allowed to occur. It is a significant human rights issue that we allow this position to be maintained.[3]

Many younger people living in residential aged care experience isolation, desperation and loneliness. The accounts of Mr James Nutt, Ms Lisa Corcoran and Mr Neale Radley at Melbourne Hearing 1, for example, showed why younger people should not have to live in residential aged care.[4] Mr Radley described his room as a prison cell.[5] He recounted how painful it was to move into residential aged care, where his physical care and social needs differed significantly to those of other residents.

Mr Nutt's evidence of his first night in residential aged care still resonates:

> The first night I was there, I went back into my room after having my tea and I closed my door. I dropped my head into my hands and started crying as I thought to myself, 'I'm only 21 years old. I've got maybe 65 years left in my life, I'll be forced to live here for the rest of my life with no ability of ever getting out.'[6]

The Australian Government has now accepted that no younger person should have to live in residential aged care. In its November 2019 response to the Interim Report, the Government committed itself to ensure that, apart from in exceptional circumstances:

- no person under the age of 65 years enters residential aged care from 2022
- no person under the age of 45 years lives in residential aged care from 2022
- no person under the age of 65 years lives in residential aged care from 2025.[7]

These commitments are commendable. They must be achieved and they must be maintained. Stated intentions must translate to sustainable results. This has not happened in the past.

In fact, for decades, the Australian Government has accepted that younger people should not have to live in residential aged care, but many younger people have continued to find themselves living there. Past initiatives have helped some younger people find alternative accommodation but the benefits have not been sustained. Younger people have continued to enter residential aged care.[8]

We use the term 'younger people' to mean people under the age of 65 years. We acknowledge that some younger people in designated groups, including Aboriginal and Torres Strait Islander people, are otherwise eligible for aged care. We consider their specific needs elsewhere in our report.[9]

At 30 September 2020, there were 4588 younger people living in residential aged care in Australia.[10] Of those 4588 people, 3772 were aged between 55 and 64 years, 697 were aged between 45 and 54 years, 101 were aged between 35 and 44 years, and 18 were under 35 years.[11] Commissioner Briggs heard at Melbourne Hearing 1 that even people aged in their late 50s found aged care isolating and lonely because they shared few common interests and experiences with much older people.

Many younger people move into residential aged care after they are discharged from hospital because there is no alternative accommodation or because the necessary living supports are not available locally or at all. Research from the Office of the Royal Commission shows that when younger people move to residential aged care they tend to move further away from their homes than older people, making it harder to maintain social connection with family and friends and receive informal support from these people.[12]

Too many younger people enter residential aged care because they are not able to access palliative care through their State or Territory Government health system.[13] Information provided by the Australian Department of Health indicates that, during the period from 1 January 2015 to 31 December 2019, 1402 younger people died within six months of admission to residential aged care.[14] From 2017 to 2019, an average of 292 younger people have been admitted annually to residential aged care with 'cancer/tumour' recorded as a health condition.[15]

Under current arrangements, people in these circumstances often fall outside the scope of the National Disability Insurance Scheme, and residential aged care becomes their hospice. A lack of palliative care services and an apparent inability to obtain assistance under the National Disability Insurance Scheme for disabling consequences of cancer and some other terminal conditions leave some younger people with no option but to enter residential aged care. That should not continue. No younger person should be compelled to move into residential aged care because of insufficient palliative care services.[16]

Kirby Littley

Ms Kirby Littley was 33 years old when she gave evidence about her experience of living in Wallace Lodge, a residential aged care facility. She was 28 years old and teaching children with special needs when she was diagnosed with a brain tumour. Following surgery for the tumour, Ms Kirby Littley suffered two strokes. These strokes left her with physical disabilities.[17]

After spending 10 months in three different hospitals, Ms Kirby Littley moved into residential aged care. She explained that she understood that she had to move into residential aged care because that was the only way that she could access

rehabilitation services and receive 24-hour care.[18] Ms Kirby Littley described 'feeling like nobody wanted' her and that was why she 'had to go into aged care'.[19] There were no other options available to her.

Ms Kirby Littley lived at Wallace Lodge for approximately 13 months. During that time she was the youngest person there. As a result of her tracheotomy, Ms Kirby Littley could not speak while she was living in residential aged care. She could, however, understand what people were saying and what was going on around her. She used a communication board to spell out words to communicate with others.[20] Ms Kirby Littley described the experience:

> I was isolated and lonely because I was in a different demographic to most of the residents. I couldn't speak which meant I couldn't socialise with anyone else.
>
> When I first moved to Wallace Lodge, I had visitors but they soon stopped coming to see me. My friends stopped visiting me. I think it was because visiting an aged care facility was quite confronting.[21]

After just over a year at Wallace Lodge, Ms Kirby Littley moved to her parents' home. She described the critical things she needed for this to occur as 'having the right care, the right equipment and home modifications'. She described being 'grateful' that her 'needs were considered', enabling the move.[22]

Ms Kirby Littley became more independent after moving home. Her social life improved and people came to visit again. She also started to relearn how to speak. At home, Ms Kirby Littley 'felt more motivated to regain' her abilities.[23]

Since October 2018, Ms Kirby Littley has lived independently in Specialist Disability Accommodation with 24-hour support. She described her life as 'good now' and said she is 'very happy'. She looks forward to progressing her life further, working towards teaching again and regaining the ability to walk.[24]

The National Disability Insurance Scheme presents a significant opportunity to stop younger people having to live in residential aged care. It is important to recognise, however, that the National Disability Insurance Scheme will not be the solution for everyone.[25] Some of the younger people in residential aged care are not eligible to be National Disability Insurance Scheme participants.[26] For instance, they may not meet the 'disability requirements' in section 24 of the *National Disability Insurance Scheme Act 2013* (Cth). Some of those younger people who are National Disability Insurance Scheme participants are unable to access necessary disability supports, including Specialist Disability Accommodation and Supporting Independent Living supports, through the National Disability Insurance Scheme.[27]

The Australian Government has made some progress toward its commitments to ensure that younger people should not have to live in residential aged care.[28] Between 30 December 2019 and 30 September 2020, the number of younger people in residential aged care fell from 5297 to 4588. But to fulfil its commitments, the Australian Government will need to continue to take dedicated and systematic action to support younger people who wish to move out of residential aged care and to stop new admissions of younger people into residential aged care.[29]

Recommendation 74: No younger people in residential aged care

The Australian Government should immediately put in place the means to achieve, and to monitor and report on progress towards, the commitments announced by the Australian Prime Minister on 25 November 2019 to ensure that:

a. no person under the age of 65 years enters residential aged care from 1 January 2022

b. no person under the age of 45 years lives in residential aged care from 1 January 2022

c. no person under the age of 65 years lives in residential aged care from 1 January 2025

by:

d. referring for assessment by the agency most appropriate for the assessment of the person concerned, such as the National Disability Insurance Agency, and not an Aged Care Assessment Team or Aged Care Assessment Service, any younger person who is at risk of entering residential aged care

e. developing hospital discharge protocols with State and Territory Governments to prevent discharge into residential aged care of any younger person

f. developing, funding and implementing with State and Territory Governments programs for short-term and long-term accommodation and care options for any younger person who is:

    i. living in or at risk of entering residential aged care and

    ii. not eligible to be a participant in the National Disability Insurance Scheme

g. requiring the National Disability Insurance Agency to publish an annual Specialist Disability Accommodation National Plan setting out, among other things, priority locations and proposed responses to thin or underdeveloped markets

h. providing directly for, where appropriate and necessary, accommodation in the Specialist Disability Accommodation market, particularly in thin or underdeveloped markets

i. funding dedicated and individualised advocacy services for younger people who are living in, or at risk of entering, residential aged care

j. collecting data on an ongoing basis, and publishing up-to-date collected data each quarter, on, for each State and Territory, the number of younger people living in residential aged care and, among other things:

   i. their age ranges

   ii. the average length of time in residential aged care

   iii. the numbers of admissions into and discharges from residential aged care, and

   iv. the reasons for younger people exiting from residential aged care, such as death, turning 65 years or moving into the community

k. having the responsible Minister report to the Parliament every six months about progress towards achieving the announced commitments, and

l. ensuring that a younger person will only ever live in residential aged care if it is in the demonstrable best interests of the particular person (and is independently certified to be such by someone with suitable skills, experience, training and knowledge of the person) in limited and exceptional circumstances such as, for instance, where:

   i. the person will turn 65 years within a short period of time, being no more than three months, after entering into residential aged care

   ii. the person's close relatives over 65 years live in a residential aged care facility and the person would suffer serious hardship on being separated from those relatives

   iii. an Aboriginal or Torres Strait Islander person between the age of 50 and 64 years elects to live in residential aged care.

11.1 Information and accountability

If commitments to ensure that younger people are not forced to live in residential aged care are to be achieved and sustained, government, service providers and the community need access to improved information about younger people living in, or at risk of entering, residential aged care and their needs. There has been a longstanding lack of sufficiently detailed and reliable information about younger people in residential aged care.[30] The Australian Government's decision, in November 2019, to commission a survey of younger people in residential aged care was intended as one response to this deficiency. However, the Australian Government has indicated that due to the COVID-19 pandemic that survey did not go ahead in 2020 as planned.[31]

Improved information about younger people in residential aged care is essential to form a proper understanding of the reasons why younger people live in residential aged care, how they can be assisted to leave and the policy changes required to ensure that they are not forced to return to aged care. Without that understanding, it is more difficult to achieve long-lasting solutions.

Dr Bronwyn Morkham, National Director for Young People in Nursing Homes National Alliance, explained:

> The data that is collected is insufficient, it's not giving us the information we need to know. The Australian Institute of Health and Welfare has an aged care data clearing house now which takes information that nursing homes submit quarterly on the number of residents they have and it provides very imperfect information about these younger people. We don't know enough about them. We don't know enough about where they came from to go into nursing homes, we don't know what conditions they present with, acutely. We know something but not enough. We don't know if they would like to leave residential aged care, and if they do, where they would like to go.[32]

A lack of information has inhibited service providers' ability to assess where there is likely to be demand for their services from younger people who are living in, or at risk of entering, residential aged care.[33] A lack of available information of this nature impedes planning for service delivery and commitment to capital investment.[34] Availability of accurate and up-to-date information also enables the matching of prospective tenants with appropriate Specialist Disability Accommodation as it becomes available.

Ongoing collection and quarterly publication of up-to-date information about younger people living in residential aged care will permit scrutiny by interested parties, including advocacy bodies such as Youngcare, Summer Foundation and the Young People in Nursing Homes National Alliance. It will assist investors, developers and service providers in ensuring that there is a suitable supply of facilities and supports where they are needed.

Scrutiny of that information and regular reporting on progress by the Australian Government will promote accountability.[35] Greater transparency will prompt strong and continued action with an emphasis on results. Biannual reporting to the Australian Parliament by the responsible Minister will deliver further enhanced public and political accountability. That reporting should explain the extent of progress towards achieving the Australian Government's commitments.

11.2 Appropriate assessment to prevent entry into residential aged care

The gateway to aged care is the Aged Care Assessment Team. The role and expertise of an Aged Care Assessment Team is to determine a person's eligibility and appropriateness for aged care services, including residential aged care.

If a younger person who is being discharged from hospital is assessed by an Aged Care Assessment Team, it will be more likely that they will enter residential aged care than if the person is assessed for eligibility by, for example, the National Disability Insurance Agency. From 1 January 2019 to 31 December 2019, delegates of the Secretary of the Australian Department of Health rejected only 60 of the 1231 Aged Care Assessment Team assessments recommending a younger person's entry into permanent residential aged care.[36]

Following the Interim Report, the Australian Government introduced the Aged Care Assessment Supplementary Guidelines for Younger People in January 2020.[37] The Supplementary Guidelines state that eligibility for the National Disability Insurance Scheme should be considered before considering access to aged care.[38] They also state that:

> The most appropriate outcome for younger people with a disability is to access age-appropriate accommodation and supports (which will primarily be through the NDIS [National Disability Insurance Scheme]), rather than aged care services.
>
> Aged care should only be used as a last resort for younger people and only where there are no other care facilities or care services more appropriate to meet their need.[39]

This is a step in the right direction. In principle, the Supplementary Guidelines reflect section 6(1)(b) of the *Approval of Care Recipients Principles 2014* (Cth), which provides that a younger person is only eligible to receive residential aged care if 'there are no other care facilities or care services more appropriate to meet the person's needs'.[40]

However, the likely impact of the Supplementary Guidelines is questionable. The Supplementary Guidelines identify urgent circumstances in which a younger person can be assessed by an Aged Care Assessment Team for entry into residential aged care, before National Disability Insurance Scheme or other eligibility is considered. Those urgent circumstances include: upon discharge from hospital, when housing is insecure, when a carer's situation changes significantly, and in other situations of risk.[41]

Inclusion of 'upon discharge from hospital' in those urgent circumstances is significant. As noted above, most younger people entering residential aged care are assessed in hospital or admitted into residential aged care from a hospital inpatient setting.[42] If the assessment is undertaken at discharge, it is more likely that there will be limited alternative options and that the need for accommodation will be considered to be urgent. One Australian Government witness described hospital discharge into residential aged care as a 'worn path'.[43]

To be effective, assessments need to be undertaken much earlier in a younger person's treatment, so that there is time to find suitable accommodation and supports. It must also not be forgotten that eligibility for the National Disability Insurance Scheme does not mean that all of a person's care needs will be the responsibility of, or will be met by, the National Disability Insurance Scheme even with arrangements concerning disability-related health supports. There are many care and health-related needs that are not the responsibility of the National Disability Insurance Scheme but which younger people ought to have met rather than being allowed to 'fall between two stools'.

Despite the introduction of the Supplementary Guidelines, dozens of younger people continue to enter residential aged care every month.[44] As Dr Nicholas Hartland, the then First Assistant Secretary of the In Home Aged Care Division of the Australian Department of Health, acknowledged in his evidence, Aged Care Assessment Team staff are not expected to have a deep understanding of the needs of younger people and appropriate options available to them.[45] If Aged Care Assessment Teams were to continue to assess the needs of younger people, this must be remedied.

Assessments of younger people with significant care needs should be undertaken by assessors with relevant expertise and with knowledge of available service options. The National Disability Insurance Agency will often be best placed to conduct those assessments, irrespective of eligibility for National Disability Insurance Scheme supports and, in particular, Specialist Disability Accommodation. National Disability Insurance Agency assessors are likely to have a greater understanding of age-appropriate alternatives, rather than defaulting to an aged care option. The objective of any assessment, by whichever team undertakes it, is not to see whether the person can be assessed to come within the assessing team's standard offerings but to find what best suits the needs of the person to live a fulfilled and enriched life appropriate to that person's age and individuality. Put simply, the objective is not to make the person fit what is on offer, but to find an offering that fits the person.

11.3 Access to advocacy and improved pathways

Navigation of the interfaces between the health care, aged care and disability services systems is complicated.[46] The complexity is even more pronounced for younger people with a cognitive impairment, without a family advocate or where they are struggling to come to terms with a newly acquired disability or illness. In his 2019 review of the National Disability Insurance Scheme Act, Mr David Tune AO PSM rightly concluded that 'additional support should be provided to assist people with disability to navigate the National Disability Insurance Scheme and its processes'.[47]

Improved advocacy is essential.[48] Such advocacy should focus on knowing available options and alternatives, assisting younger people to make informed decisions, and reviewing regularly the suitability of care and accommodation for younger people living in, or at risk of entering, residential aged care.[49]

The Australian Government announced in its 2020–21 Budget that over three years from 2020–21, it will provide $10.6 million in funding to achieve its commitments, including for a national network of 'up to 40' system coordinators to help younger people find age-appropriate accommodation and supports to allow them to live independently in the community.[50] That is a positive step.

However, this number of system coordinators would appear insufficient, particularly given that they are tasked with helping in excess of 4500 younger people leave residential aged care and reducing the current level of around 1000 younger people each year entering residential aged care.[51] It is also not clear what will happen after 2024. There should be ongoing funding for system coordinators after 2024 to help younger people avoid entering residential aged care in future.

It is not clear what, if any, advocacy role the system coordinators will play for younger people living in residential aged care, including how independent of government they are intended to be. Independent advocacy and supported decision-making are particularly important for younger people with a cognitive disability or early onset dementia. The Australian Government should ensure that resources are made available to support an independent advocacy role for younger people living in, or at risk of entering, residential aged care. Dr Gauntlett explained the importance of this role:

> The best way to ensure that a person is properly represented in those situations is to have some form of independent advocacy for them…That means that there is a clear voice for that individual to enable them to live the life…they choose…there must be a clear mandate for independent advocacy to take place to ensure that a person with a disability knows the rights that they have to seek alternative accommodation options in the community.[52]

Evidence given by compensable scheme representatives from State Governments pointed to the critical role of planners and coordinators in their own schemes.[53] It remains to be seen how the network of system coordinators will work to achieve the Australian Government's commitments. To be effective, coordinators will need to have skills in, and knowledge about, the health system to identify and locate younger people in hospital who are at risk of entering residential aged care and to prevent their discharge into residential aged care.[54] The system coordinators will also need to form local and in-depth relationships with contacts and counterparts in the health system.[55] To reduce the risk of younger people in hospital being discharged into residential aged care, the system coordinators will have to ensure early engagement and planning for future accommodation and care needs.[56] They should have a role in ensuring that younger people are aware of their right to live independently in the community.

The need for system coordinators to closely interact with contacts and counterparts in the health system highlights the need for the Australian Government and State and Territory Governments to work together. Given their responsibility for hospital and subacute health care services, State and Territory Governments play a critical role in reducing the number of younger people in residential aged care.[57] The Australian Government must make sure that it involves State and Territory Governments in the development and implementation of measures to achieve its commitments. This will be critical, for example, in developing hospital discharge protocols to prevent the discharge of younger people into residential aged care. The Australian Government should establish a structured and ongoing mechanism for collaboration with its State and Territory counterparts.

11.4 Limited exceptions

There are likely to be some, albeit very limited, circumstances in which a younger person might enter residential aged care or choose to remain living in residential aged care. Where this is suitable and appropriate, the person must be afforded every opportunity to have access to and choice of the services that they require.

The Australian Government's *Younger People in Residential Aged Care: Strategy 2020–25*, released on 30 September 2020, states that the following principles will guide decisions about the circumstances in which a younger person may enter or remain in residential aged care:

- younger people should be supported to exercise choice and control about where they live;
- strict eligibility conditions will need to be met for a younger person to enter residential aged care;
- each younger person's unique circumstances and goals should always be considered;
- education and support for younger people, and education within health and social supports, is critical to their informed choice;
- a younger person's accommodation and support preferences may change over time; and
- appropriate decision-making mechanisms must be in place to ensure relevant information and advice is considered and there is accountability in decisions.[58]

These principles are generally appropriate. However, they lack detail. For example, without further information about the nature of the 'strict eligibility conditions' governing a younger person's admission to residential aged care, it is not possible to say whether the principles go far enough. It is vital that a younger person has choice, aided by informed and supported decision-making, and coupled with a clear understanding of the options and alternatives available. To enable that choice to be exercised, younger people must have access to the services that are needed, irrespective of the 'system' that provides those services. Regular review, recognising changes in circumstances and service availability, and independent oversight of the process by which these choices are expressed, are also essential.

The Australian Government's *Younger People in Residential Aged Care: Strategy 2020–25* refers to some exceptional circumstances in which a younger person might enter into residential aged care, including that:

(a) the accommodation, for reasons such as remoteness, cultural, community or family considerations, or a specialist support model, is considered to be the most appropriate option for the younger person; or

(b) the younger person is an Aboriginal and/or Torres Strait Islander person who is aged between 50 and 64 years…[59]

We consider that merely living outside of a capital city does not constitute exceptional circumstances justifying the placement of a younger person in residential aged care. That said, it is possible to conceive of specific situations that might warrant consideration of exceptional circumstances provisions. For example, an adult with a disability whose caregiver parent enters residential aged care might wish to join the parent to preserve the family relationship. Similarly, a person with a specific cultural connection to a residential aged care facility might have a strong preference to reside there. An Aboriginal and/or Torres Strait Islander person who is aged between 50 and 64 years and is therefore eligible for aged care services, might elect to live in a residential aged care facility because of its location or connection to community or Country.[60] The point of these examples is to place the individual whose needs are in question at the centre of any inquiry. The inquiry must always focus clearly and openly upon what is best for the person needing care and not upon what care can best be wrangled by an incomplete system.

Jessie Spicer

Ms Robyn Spicer gave evidence about her daughter, Ms Jessie Spicer, who was 37 years old at the time of Melbourne Hearing 1.[61] Ms Jessie Spicer was born with a rare chromosomal anomaly and has physical and intellectual disabilities.[62] Ms Robyn Spicer said that Ms Jessie Spicer is sometimes described as an 'extrovert who can't speak' and 'thrives on communicating with other people in whatever way she can'.[63] This was apparent from Ms Jessie Spicer's evidence at the hearing.

Ms Jessie Spicer moved into a residential aged care facility in Central Victoria when she was in her early thirties. At that age, Ms Jessie Spicer wanted more independence.[64] In determining what would work for Ms Jessie Spicer, Ms Robyn Spicer described feeling 'a bit torn'.[65] But she explained:

> in the end, because nothing else was on offer and I didn't feel that she would be happy in a flat shared with some other disabled person with a carer, I thought this will be worse than being at home for her, we thought it's people that she wants and we could see that her real skill and her whole personality is about people.[66]

Ms Robyn Spicer explained that Ms Jessie Spicer 'needed to be close to us because we felt that it needed to be a shared care arrangement where we could be very much part of her care that she was getting' and that it 'was imperative that she was within five minutes' drive…from us'.[67]

Ms Robyn Spicer explained that, under that shared care arrangement, Ms Jessie Spicer's physical care would be looked after by the residential aged care service and its staff. She said that she and her partner would provide Jessie with emotional support and get her out in the community to keep in touch with family and friends.[68]

Ms Robyn Spicer said that Ms Jessie Spicer leaves the residential aged care facility every weekday to attend a day centre where various activities, including bowling, craft activities and swimming, are organised for Ms Jessie Spicer.[69] National Disability Insurance Scheme funding has provided Ms Jessie Spicer with greater one-on-one services tailored to her individual needs, and Ms Robyn Spicer saves money by performing the coordination role herself.[70]

Ms Robyn Spicer praised the 'dedicated wonderful staff who are doing a fabulous job' in the aged care facility and described her daughter as 'thriving' in that environment.[71] Ms Robyn Spicer observed that 'the residential facility actually takes care of a lot of her social and emotional needs', which she had not anticipated.[72]

Safeguards will, however, be required to ensure that exceptions do not become the rule. Overall, a younger person should only ever live in residential aged care if it is in that person's demonstrable best interests, and that this has been independently certified by someone with suitable skills, experience, training and knowledge of the person.

When exceptional circumstances exist and a younger person enters residential aged care, they should be provided directly with all additional support for which they are eligible. This includes specific health services and other supports from the National Disability Insurance Scheme.[73] From 1 December 2020, residential aged care providers have been obligated to comply with the National Disability Insurance Scheme Act and the *National Disability Insurance Scheme (Provider Registration and Practice Standards) Rules 2018* (Cth) when delivering services to National Disability Insurance Scheme participants in their facilities.[74] These additional services and supports may prove critical for a younger person to maintain independent living skills and social connections, and to enhance the person's opportunities to return to living in the community.

Finally, no younger person living in residential aged care should be forgotten. All younger people in residential aged care should have their circumstances reviewed by system coordinators and independent advocates regularly and at least every six months. They should be able to make informed decisions about their place of residence. They should receive information from those system coordinators and independent advocates about alternative care and accommodation options, without having to hunt for it.[75]

11.5 Transitional accommodation and care

Appropriate accommodation enables people with disability to live as independently as possible. But modifying existing accommodation or building new accommodation can take time.[76] Without appropriate accommodation and the right levels of care in place, the risk of placement in residential aged care is heightened, particularly when someone is being discharged urgently from hospital.[77] This was the experience of Ms Kirby Littley, Mr Neale Radley and Mr Michael Burge.[78] Mr Shane Jamieson from Youngcare warned that without the availability of accommodation and care to support the needs of younger people, aged care becomes a 'go-to option'.[79]

Mr Luke Bo'sher, former Chief Executive Officer of the advocacy group the Summer Foundation, summed up the challenge for people who are ready to leave hospital but do not have suitable accommodation:

> This week we've heard examples of ACAT [Aged Care Assessment Team] assessments being approved in a matter of days, and we've heard what's a very common story about an SDA [Specialist Disability Accommodation] application taking six months to prepare. So we're talking—that's not even the approval process from the NDIA [National Disability Insurance Agency]; that's just the point of submitting a form to apply. And what we've got is a system where inappropriate placements can be funded in two or three days but an appropriate good practice solution will take six months to apply for and then a number of months for the NDIA to make a decision and then a number of more months to transition into that place while it's stood up by a service provider.[80]

The evidence before us has highlighted the need for greater availability of interim or transitional accommodation for people who have completed an acute or subacute phase of care but have no suitable accommodation available to them on discharge from hospital.[81] Interim or transitional accommodation could give a younger person critical time for modifications to be made to their existing home or for approval to be granted to the person for Assistive Technology or for Specialist Disability Accommodation and Supported Independent Living services to become available. Such accommodation could also provide a pathway for younger people out of residential aged care.[82]

Witnesses gave evidence at Melbourne Hearing 1 about how the availability of alternative accommodation to residential aged care would have affected them.[83] They explained how their lives would have been very different if, rather than entering residential aged care, they had been able to access appropriate accommodation at the end of their acute or rehabilitation stay.[84] These younger people should never have had to enter residential aged care in the first place.

The Australian Government's establishment of a Medium Term Accommodation service stream in the National Disability Insurance Scheme will have some positive impact and should be welcomed.[85] However, if it is to prevent younger people entering residential aged care, it must be offered in a timely manner, in the right places and in adequate supply. Like Specialist Disability Accommodation, it must also be offered in conjunction with the appropriate levels of care.

Not every younger person living in, or at risk of entering, residential aged care will be eligible to access accommodation supports under the National Disability Insurance Scheme. The Australian Government should therefore develop, fund and implement, with the cooperation and assistance of State and Territory Governments, accommodation and care options for younger people who are ineligible for National Disability Insurance Scheme supports and who are living in, or at risk of entering, residential aged care.

11.6 Long-term accommodation and care

While the availability of interim or transitional accommodation is an important part of the solution, permanent accommodation options are essential for younger people wanting to establish themselves in the community and have confidence in their future. Specialist Disability Accommodation is a fundamental element of the assistance available to younger people who live in, or are at risk of entering, residential aged care and who are participants in the National Disability Insurance Scheme. Equally important for them are Supported Independent Living care and Assistive Technology, which are also available to National Disability Insurance Scheme participants.

As at 30 September 2020, only 487 of the 3603 younger people living in residential aged care with an approved National Disability Insurance Scheme plan had provision in their plan for Specialist Disability Accommodation (including for some with Supported Independent Living), with another 22 having approval for Supported Independent Living alone.[86] Eligibility for residential aged care is reserved for people who have a condition of frailty or disability requiring continuing personal care and who are unable to live in the community without support.[87] If younger people living in residential aged care are National Disability Insurance Scheme participants and have not yet been assessed for Specialist Disability Accommodation and Supported Independent Living, that must happen as a matter of urgent priority.

Without this support, and something similar for those younger people who are not eligible for assistance under the National Disability Insurance Scheme, the risk of admission to residential aged care increases greatly.

In some rural and remote areas, the supply of Specialist Disability Accommodation and other disability support services is limited and does not meet demand.[88] To address this problem, the Australian Government should develop a Specialist Disability Accommodation National Plan that includes strategies to build a sufficient supply of Specialist Disability Accommodation or viable alternatives in these areas. The plan should set out, among other things, priority locations and proposed responses to the supply of accommodation in areas, such as rural and remote locations, in which the market is not likely to provide a solution within a reasonable timeframe. The plan should be updated annually.

The mere existence of such a plan will not ensure adequate supply of appropriate accommodation and services. At present, the Specialist Disability Accommodation market is not responding quickly or broadly enough. A 2019 report from the Summer Foundation and Social Ventures Australia estimated that the shortfall in Specialist Disability Accommodation, even when taking into account building underway, was around 9000 places.[89] A shortfall of this nature was flagged as early as 2011.[90] Waiting for the market to respond and deliver the requisite accommodation options will not, of itself, ensure that the Australian Government meets its commitments. As Mr Bo'sher observed, the wait for National Disability Insurance Scheme decision-making on Specialist Disability Accommodation supports and for housing approval is compounded by the time required for construction or modification of accommodation.[91]

Such was the case for Mr Radley, who likened his wait for Specialist Disability Accommodation approval to 'climbing a mountain'.[92] When he gave evidence in September 2019, Mr Radley had been in residential aged care for four years and had, following a lengthy application process, received Specialist Disability Accommodation approval under the National Disability Insurance Scheme a few months earlier.[93] A subsequent submission to us from Mr Radley in June 2020 indicated that he was still living in residential aged care and was left 'frustrated and angry because my options are limited…in the nursing home'.[94]

James Nutt

Mr James Nutt was 22 years old when he entered residential aged care, following two years of rehabilitation after a severe brain injury.

Before his injury, Mr Nutt had embarked on a career in the defence industry as an ammunition technician. He had enjoyed a busy social life, and had been close to his family and active at the local football club. All that changed after his injury.

When Mr Nutt was discharged from rehabilitative care, he required a permanent care arrangement. Both of his parents were working full-time and could not meet his care needs without giving up their jobs.[95] Mr Nutt was left with the choice of living in residential aged care or a group home with people who were unable to communicate with him. Faced with this difficult choice, he entered residential aged care, about an hour away from his family and friends.

Mr Nutt said that:

> Living in aged care was so wrong for me. I still had dreams for myself…It was all aborted. I felt like my life was over.[96]

Mr Nutt became so depressed that he contemplated suicide.

Mr Nutt felt isolated. His friends rarely visited and he felt that the staff were not trained or accustomed to caring for a younger person. He was unable to make simple choices such as when to eat, what time to go to bed or who would be caring for him. Any complaints he made seemed 'to fall on deaf ears'.[97]

After Mr Nutt had spent almost five years in residential aged care, a Care Coordinator for younger people in residential aged care became aware of his situation. As a result of this 'happy accident', Mr Nutt's journey out of residential aged care began.[98] It included more than a year in interim accommodation, until he eventually secured his own unit. In all, Mr Nutt spent five years in residential aged care.

Mr Nutt lives in Specialist Disability Accommodation with National Disability Insurance Scheme support and carers he selects himself. He described his new life with three words: choice, control and independence.[99] In residential aged care, he said, 'no one seemed to notice the opportunities that were being taken from me'.[100] He summarised his experience quite simply:

> It should not happen to anyone else.[101]

New approaches to increase the supply of appropriate accommodation are required. The then acting Chief Executive Officer of the National Disability Insurance Agency, Ms Vicki Rundle, gave evidence that the National Disability Insurance Scheme Actuary 'does not have projections of demand and supply' of Specialist Disability Accommodation'.[102] In our view, a lack of available information of this nature impedes the proper planning of services and the commitment to capital investment in additional accommodation. The Australian Government should provide more comprehensive and detailed information on the current supply of and demand for Specialist Disability Accommodation.[103] Improvements to data collection and sharing will assist potential investors and developers by demonstrating the level and location of demand, and the nature of the needs and preferences of the younger people looking for suitable accommodation.

Governments will need to look beyond market-based solutions, however, particularly in the immediate future.[104] Different thinking from all levels of government is needed to increase the supply of suitable accommodation for younger people living in or at risk of entering residential aged care.

The Australian and State and Territory Governments can foster innovation by directly commissioning Specialist Disability Accommodation developments or acting as a service provider in places where the market is unlikely to respond. The Australian and State and Territory Governments might, for example, offer grants to social housing providers to construct suitable accommodation. Local government planning functions could also stimulate the market by, for example, permitting additional units to be built as part of a development if a developer incorporates Specialist Disability Accommodation in the development application.

For younger people living in, or at risk of entering, residential aged care who are not eligible for the National Disability Insurance Scheme, the Australian Government will need to work with State and Territory Governments to find innovative accommodation solutions. Social and community housing has the potential to deliver more accommodation for younger people at risk, particularly for those with psychosocial disabilities, those experiencing homelessness, and other younger people ineligible for the National Disability Insurance Scheme.

Even when suitable accommodation is available, it must be accompanied by the requisite care services and supports. Without those services and supports, a younger person may still be pushed into residential aged care.[105]

In this regard, a June 2019 administrative agreement reached by the Council of Australian Governments Disability Reform Council, which is responsible for overseeing the implementation of the National Disability Insurance Scheme, is to be welcomed. Among other things, the June 2019 agreement provided for access to funding for some disability-related health support services under the National Disability Insurance Scheme.[106] That agreement should be the subject of more formal and enforceable recognition.[107]

The June 2019 agreement did not extend to subacute rehabilitation and palliative care. Continued engagement between the Australian and State and Territory Governments must focus on the provision of adequate levels of care—acute, subacute and maintenance care—to minimise the risk of younger people being admitted to residential aged care unnecessarily.

11.7 Conclusion

The accounts of younger people in residential aged care, such as Mr Nutt, Ms Kirby Littley, Ms Corcoran and Mr Radley, revealed feelings of hopelessness and powerlessness. Ms Kate Roche spoke movingly of her tireless efforts to secure a better life outside of residential aged care for her husband, Mr Michael Burge. All this evidence has demonstrated a stark incompatibility between the social and physical care needs of younger and older people in residential aged care.

The evidence also has shown that once a younger person has entered residential aged care, it is very difficult for them to get out. Ms Kirby Littley entered residential aged care on what was supposed to be a temporary basis, which extended to more than a year.[108] Mr Radley had been in residential aged care for four years at the time of the hearing. Mr Nutt spent more than five years in residential aged care before securing more appropriate care and accommodation.[109] For Mr Nutt, Ms Kirby Littley and Mr Radley, all of whom were under 45 years when they entered residential aged care, their experiences were punctuated by sadness, frustration and social disconnection. They should never have had to enter residential aged care.

Residential aged care is not an appropriate place for younger people to live. Save for very limited exceptions, younger people should not be entering residential aged care by 2022. By 2025, there should be no younger people living in residential aged care.

In the Interim Report, Commissioners Tracey and Briggs stated:

> Action must be swift. It must be thorough. And it must be considered. But most of all, it must be fair and compassionate.[110]

That still holds true. Continually driving improvements in the supports available for younger people in need of care will be essential. Implementation of the recommendation in this chapter will assist younger people to navigate the aged care, disability services and health care systems to achieve the best possible care and accommodation outcomes for their individual needs. But the Australian Government will have to be vigilant to stay the course and to prevent backsliding into an entirely unacceptable state of affairs in which younger people again find themselves forced to live in circumstances totally unsuited to their needs. This has happened before. It must not happen again.

Endnotes

1 See, for example, Exhibit 9-18, Melbourne Hearing 1, Statement of James Nutt, WIT.1237.0001.0001; Transcript, Melbourne Hearing 1, James Nutt, 11 September 2019 at T5153–5174; Exhibit 9-3, Melbourne Hearing 1, Statement of Lisa Corcoran, WIT.1240.0001.0001; Transcript, Melbourne Hearing 1, Lisa Corcoran, 9 September 2019 at T4818–4828; Exhibit 9-8, Melbourne Hearing 1, Statement of Neale Radley, WIT.1251.0001.0001; Transcript, Melbourne Hearing 1, Neale Radley, 10 September 2019 at T4966–4971.

2 As at 30 June 2011, there were 6381 younger people living in residential aged care in Australia. See Australian Institute of Health and Welfare, *Younger people with disability in residential aged care 2010–11*, 2012, p 6. As at 30 September 2020, there were 4588 younger people living in residential aged care in Australia. See Exhibit 23-7, final tender bundle, Australian Department of Health, Response to NTG-0808, CTH.1000.0007.1284 at 1285 [4].

3 Transcript, Melbourne Hearing 1, Ben Gauntlett, 11 September 2019 at T5152.21–25.

4 Exhibit 9-18, Melbourne Hearing 1, Statement of James Nutt, WIT.1237.0001.0001; Transcript, Melbourne Hearing 1, James Nutt, 11 September 2019 at T5153–5174; Exhibit 9-3, Melbourne Hearing 1, Statement of Lisa Corcoran, WIT.1240.0001.0001; Transcript, Melbourne Hearing 1, Lisa Corcoran, 9 September 2019 at T4818–4828; Exhibit 9-8, Melbourne Hearing 1, Statement of Neale Radley, WIT.1251.0001.0001; Transcript, Melbourne Hearing 1, Neale Radley, 10 September 2019 at T4966–4971.

5 Exhibit 9-8, Melbourne 1 Hearing, Statement of Neale Radley, WIT.1251.0001.0001 at 0004 [31]; Transcript, Melbourne 1 Hearing, Neale Radley, 10 September 2019 at T4969.20–23.

6 Exhibit 9-18, Melbourne Hearing 1, Statement of James Nutt, WIT.1237.0001.0001 at 0002 [19]; Transcript, Melbourne Hearing 1, James Nutt, 11 September 2019 at T5161.20–24.

7 Australian Prime Minister, Media Release, *Response to Aged Care Royal Commission Interim Report*, 25 November 2019. See also Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, Vol 1, p 252.

8 See, for example, Australian Institute of Health and Welfare, *National evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot: final report*, 2006, pp 3, 11, 19; Community Affairs Reference Committee, Australian Senate, *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*, 2015, pp 10–11, 79, 127; Exhibit 9-1, Melbourne Hearing 1, general tender bundle, tab 59, RCD.9999.0182.0538 at 0548. See also Australian Government, *Younger People in Residential Aged Care: Strategy 2020–25*, 30 September 2020, pp 6–7.

9 See Chapter 7 on aged care for Aboriginal and Torres Strait Islander people.

10 Exhibit 23-7, final tender bundle, Australian Department of Health, Response to NTG-0808, CTH.1000.0007.1284 at 1285 [4].

11 Exhibit 23-7, final tender bundle, Australian Department of Health, Response to NTG-0808, CTH.1000.0007.1284 at 1285 [5].

12 Office of the Royal Commission, *How far do people move to access aged care?*, Research Paper 16, 2020, p 11.

13 Exhibit 9-1, Melbourne Hearing 1, general tender bundle, tab 28, RCD.9999.0177.0001 at 0023.

14 Exhibit 22-04, Final Hearing, Australian Department of Health Response to Notice to Give Information and Produce Documents NTP-0760 dated 15 July 2020, CTH.1000.0004.9242 at 9251 [33].

15 Exhibit 22-04, Final Hearing, Australian Department of Health Response to Notice to Give Information and Produce Documents NTP-0760 dated 15 July 2020, CTH.1000.0004.9242 at 9251 [31]–[32].

16 Australian Department of Health, *Aged Care Assessment Supplementary Guidelines for Younger People (For purposes of Aged Care Assessment Teams),* January 2020, p 11.

17 Exhibit 9-11, Melbourne Hearing 1, Statement of Kirby Littley, WIT.1241.0001.0001 at 0001 [3]; [5]; [8]–[10].

18 Exhibit 9-11, Melbourne Hearing 1, Statement of Kirby Littley, WIT.1241.0001.0001 at 0002 [11]; [21].

19 Exhibit 9-11, Melbourne Hearing 1, Statement of Kirby Littley, WIT.1241.0001.0001 at 0002 [22].

20 Exhibit 9-11, Melbourne Hearing 1, Statement of Kirby Littley, WIT.1241.0001.0001 at 0003 [27]; [28].

21 Exhibit 9-11, Melbourne Hearing 1, Statement of Kirby Littley, WIT.1241.0001.0001 at 0003 [30]–[31].

22 Exhibit 9-11, Melbourne Hearing 1, Statement of Kirby Littley, WIT.1241.0001.0001 at 0005 [52].

23 Exhibit 9-11, Melbourne Hearing 1, Statement of Kirby Littley, WIT.1241.0001.0001 at 0005 [55]–[56].

24 Exhibit 9-11, Melbourne Hearing 1, Statement of Kirby Littley, WIT.1241.0001.0001 at 0006 [59]–[65].

25 As at 30 September 2020, 3650 younger people living in residential aged care were National Disability Insurance Scheme participants and 3603 of those participants had an approved National Disability Insurance Scheme plan. See Exhibit 23-1, final tender bundle, National Disability Insurance Agency, Response to NTG-0806, CTH.8000.1000.1853 at 1858.

26 *National Disability Insurance Scheme Act 2013* (Cth), ss 21–25.

27 Exhibit 23-1, final tender bundle, National Disability Insurance Agency, Response to NTG-0806, CTH.8000.1000.1853 at 1855 [8]–[9].

28 See, for example, Australian Government, *Younger People in Residential Aged Care: Strategy 2020–25*, 2020. See also Australian Minister for the National Disability Insurance Scheme and Australian Minister for Aged Care and Senior Australians, Media Release, *New funding and support strategy for younger people living in aged care*, 30 September 2020; Australian Minister for the National Disability Insurance Scheme, Media Release, *Delivering the NDIS plan: New medium-term accommodation for NDIS participants*, 2 December 2019; Australian Prime Minister, Media Release, *Response to Aged Care Royal Commission Interim Report*, 25 November 2019.

29 See Exhibit 23-7, final tender bundle, Australian Department of Health, Response to NTG-0808, CTH.1000.0007.1284 at 1285 [4]. See also Australian Government, *Younger People in Residential Aged Care: Strategy 2020–25*, 2020, pp 6–7.

30 See, for example, Transcript, Melbourne Hearing 1, Vicki Rundle, 11 September 2019 at T5076.1–5077.25; Transcript, Melbourne Hearing 1, Peter Broadhead, 10 September 2019 at T5026.45–5027.11. See also Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, Vol 1, p 234.

31 Australian Department of Health, *Analysis of younger people living in residential aged care*, 2020, https://www.health.gov.au/sites/default/files/documents/2020/09/analysis-of-younger-people-living-in-residential-aged-care.pdf, viewed 19 November 2020, p 11.
32 Transcript, Melbourne Hearing 1, Bronwyn Morkham, 13 September 2019 at T5186.38–47.
33 Exhibit 9-6, Melbourne Hearing 1, Statement of Nicholas Hartland, WIT.0374.0001.0001 at 0009 [44]; Exhibit 9-10, Melbourne Hearing 1, Statement of Vicki Rundle, WIT.0436.0001.0001 at 0003 [16].
34 Transcript, Melbourne Hearing 1, Bronwyn Morkham, 13 September 2019 at T5186.38–47; T5201.24–36; Transcript, Melbourne Hearing 1, Luke Bo'sher, 13 September 2019 at T5198.26–36.
35 Transcript, Melbourne Hearing 1, Bronwyn Morkham, 13 September 2019 at T5186.37–46; T5198.1–10.
36 Exhibit 22-04, Final Hearing, Australian Department of Health, Response to Notice to Give Information and Produce Documents NTP-0760 dated 15 July 2020, CTH.1000.0004.9242 at 9250 [28]–[29].
37 Australian Department of Health, *Aged Care Assessment Supplementary Guidelines for Younger People (For purposes of Aged Care Assessment Teams)*, 2020.
38 Australian Department of Health, *Aged Care Assessment Supplementary Guidelines for Younger People (For purposes of Aged Care Assessment Teams)*, 2020, p 4.
39 Australian Department of Health, *Aged Care Assessment Supplementary Guidelines for Younger People (For purposes of Aged Care Assessment Teams)*, 2020, p 6.
40 Transcript, Melbourne Hearing 1, Nicholas Hartland, 10 September 2019 at T4918.4–31.
41 Australian Department of Health, *Aged Care Assessment Supplementary Guidelines for Younger People (For purposes of Aged Care Assessment Teams)*, 2020, pp 12, 15–16.
42 Exhibit 9-1, Melbourne Hearing 1, general tender bundle, tab 28, RCD.9999.0177.0001 at 0011; Transcript, Melbourne Hearing 1, Kym Peake, 13 September 2019 at T5226.17–20. The Australian Department of Health has stated an intention to review the urgent circumstances pathway. The terms and scope of the review are not presently known. Exhibit 23-7, final tender bundle, Australian Department of Health, Response to NTG-0808, CTH.1000.0007.1284 at 1288 [10d].
43 Transcript, Melbourne Hearing 1, Peter Broadhead, 10 September 2019 at T5003.38.
44 Exhibit 23-7, final tender bundle, Australian Department of Health, Response to NTG-0808, CTH.1000.0007.1284 at 1285 [4]; 1286 [6].
45 Transcript, Melbourne Hearing 1, Nicholas Hartland, 9 September 2019 at T4895.27–28. See also Exhibit 9-22, Melbourne Hearing 1, Statement of Kym Peake, WIT.0420.0001.0001 at 0013 [78]–[79].
46 Exhibit 9-12, Melbourne Hearing 1, Statement of Carol and Kevin Littley, WIT.1242.0001.0001 at 0005 [39].
47 David Tune AO PSM, *Review of the National Disability Insurance Scheme Act 2013: Removing Red Tape and Implementing the NDIS Participant Service Guarantee*, 2019, p 39.
48 For evidence about the need for advocacy, see Exhibit 9-12, Melbourne Hearing 1, Statement of Carol Littley and Kevin Littley, WIT.1242.0001.0001 at 11 [99]; Transcript, Melbourne Hearing 1, Luke Bo'sher, 13 September 2019 at T5191.18–26; Transcript, Melbourne Hearing 1, Bronwyn Morkham, 13 September 2019 at T5189.25–42; Transcript, Melbourne Hearing 1, Shane Jamieson, 13 September 2019 at T5188.20–36.
49 Transcript, Melbourne Hearing 1, Ben Gauntlett, 11 September 2019 at T5151.6–36. At the time of writing this report, the National Disability Insurance Agency was developing a dedicated housing support coordinator initiative for younger people in residential aged care who are also National Disability Insurance Scheme participants and who need more specialist support to achieve their housing goals. See Exhibit 23-1, final tender bundle, National Disability Insurance Agency, Response to NTG-0806, CTH.8000.1000.1853 at 1856 [12a].
50 Australian Government, *Budget Measures Budget Paper No 2 2020–21*, 2020, p 91; Australian Government, *Portfolio Budget Statement 2020–21, Budget Related Paper No 1.7, Health Portfolio*, 2020, p 121; Australian Minister for the National Disability Insurance Scheme and Australian Minister for Aged Care and Senior Australians, Media Release, *New funding and support strategy for younger people living in aged care*, 30 September 2020; Australian Minister for Health, *Budget 2020–21: Record health and aged care investment under Australia's COVID-19 pandemic plan*, 2020; Exhibit 23-7, final tender bundle, Australian Department of Health, Response to NTG-0808, CTH.1000.0007.1284 at 1287 [10b].
51 See Exhibit 23-7, final tender bundle, Australian Department of Health, Response to NTG-0808, CTH.1000.0007.1284 at 1285 [4].
52 Transcript, Melbourne Hearing 1, Ben Gauntlett, 11 September 2019 at T5151.22–36.
53 Transcript, Melbourne Hearing 1, Liz Cairns, 11 September 2019 at T5134.36–47; Transcript, Melbourne Hearing 1, Tamara Tomic, 11 September 2019 at T5136.34–39; Transcript, Melbourne Hearing 1, Deborah Hoffman, 11 September 2019 at T5137.3–9.
54 Exhibit 9-19, Melbourne Hearing 1, Statement of Bronwyn Morkham, WIT.0372.0001.0001 at 0013 [48]–[51].
55 Transcript, Melbourne Hearing 1, Tamara Tomic, 11 September 2019 at T5133.17–44; Transcript, Melbourne Hearing 1, Liz Cairns, 11 September 2019 at T5138.45–5139.9; Transcript, Melbourne Hearing 1, Deborah Hoffman, 11 September 2019 at T5137.3–11.
56 Transcript, Melbourne Hearing 1, Liz Cairns, 11 September 2019 at T5131.33–44; Transcript, Melbourne Hearing 1, Tamara Tomic, 11 September 2019 at T5133.5–10.
57 See, for example, Transcript, Melbourne Hearing 1, Michael Lye, 10 September 2019 at T4973.34–40.
58 Australian Government, *Younger People in Residential Aged Care: Strategy 2020–25*, 2020, pp 9–10.
59 Australian Government, *Younger People in Residential Aged Care: Strategy 2020–25*, 2020, p 10.
60 See Chapter 7 on aged care for Aboriginal and Torres Strait Islander people.
61 Transcript, Melbourne Hearing 1, Robyn Spicer, 10 September 2019 at T4983.46.
62 Transcript, Melbourne Hearing 1, Robyn Spicer, 10 September 2019 at T4984.8–9.
63 Transcript, Melbourne Hearing 1, Robyn Spicer, 10 September 2019 at T4984.25–27.

64 Transcript, Melbourne Hearing 1, Robyn Spicer, 10 September 2019 at T4987.5–6; Exhibit 9-9, Melbourne Hearing 1, Statement of Robyn Spicer, WIT.1245.0001.0001 at 0001 [7].
65 Transcript, Melbourne Hearing 1, Robyn Spicer, 10 September 2019 at T4987.27.
66 Transcript, Melbourne Hearing 1, Robyn Spicer, 10 September 2019 at T4987.35–39.
67 Transcript, Melbourne Hearing 1, Robyn Spicer, 10 September 2019 at T4988.16–20.
68 Transcript, Melbourne Hearing 1, Robyn Spicer, 10 September 2019 at T4991.13–16.
69 Transcript, Melbourne Hearing 1, Robyn Spicer, 10 September 2019 at T4989.7–8; T4989.41–4982.1.
70 Transcript, Melbourne Hearing 1, Robyn Spicer, 10 September 2019 at T4992.38–39; T4993.43–44.
71 Transcript, Melbourne Hearing 1, Robyn Spicer, 10 September 2019 at T4994.28; T4984.13–16.
72 Transcript, Melbourne Hearing 1, Robyn Spicer, 10 September 2019 at T4991.18–20.
73 See, for example, Exhibit 9-9, Melbourne Hearing 1, Statement of Robyn Spicer, WIT.1245.0001.0001 at 0007 [67]; Transcript, Melbourne Hearing 1, Robyn Spicer, 10 September 2019 at T4992.29–41.
74 National Disability Insurance Scheme Quality and Safeguards Commission, *NDIS participants in residential aged care,* 2020, https://www.ndiscommission.gov.au/providers/participants-residential-aged-care, viewed 4 December 2020.
75 Transcript, Melbourne Hearing 1, Carol Littley, 11 September 2019 at T5094.28–5095.26.
76 Transcript, Melbourne Hearing 1, Shane Jamieson, 13 September 2019 at T5203.4–26; Transcript, Melbourne Hearing 1, Luke Bo'sher, 13 September 2019 at T5203.36–5204.46.
77 Transcript, Melbourne Hearing 1, Kym Peake, 13 September 2019 at T5230.24–27; Exhibit 9-22, Melbourne Hearing 1, Statement of Kym Peake, WIT.0420.0001.0001 at 0005 [28]; Transcript, Melbourne Hearing 1, Bronwyn Morkham, 13 September 2019 at T5193.38–5194.11.
78 Exhibit 9-8, Melbourne Hearing 1, Statement of Neale Radley, WIT.1251.0001.0001 at 0002 [12]–[14]; Exhibit 9-11, Melbourne Hearing 1, Statement of Kirby Littley, WIT.1241.0001.0001 at 0002 [21]–[23]; Exhibit 9-4, Melbourne Hearing 1, Statement of Catherine Roche, WIT.1238.0001.0001 at 0006 [44].
79 Transcript, Melbourne Hearing 1, Shane Jamieson, 13 September 2019 at T5216.40–45.
80 Transcript, Melbourne Hearing 1, Luke Bo'sher, 13 September 2019 at T5195.23–30.
81 Transcript, Melbourne Hearing 1, Bronwyn Morkham, 13 September 2019 at T5210.39–5211.14; Transcript, Melbourne Hearing 1, Luke Bo'sher, 13 September 2019 at T5211.18–44.
82 Exhibit 9-19, Melbourne Hearing 1, Statement of Bronwyn Morkham, WIT.0372.0001.0001 at 0061 [305]–[308].
83 For a description of the evidence given at Melbourne Hearing 1, see Volume 4 of this report. See also Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, Vol 1, pp 233–252.
84 Exhibit 9-8, Melbourne Hearing 1, Statement of Neale Radley, WIT.1251.0001.0001 at 0003 [25]; Exhibit 9-18, Melbourne Hearing 1, Statement of James Nutt, WIT.1237.0001.0001 at 0003 [21]–0004 [34].
85 Australian Minister for National Disability, Media Release, *Delivering the NDIS plan: new medium-term accommodation for NDIS participants*, 2 December 2019, https://www.ndis.gov.au/news/4069-delivering-ndis-plan-new-medium-term-accommodation-ndis-participants, viewed 20 November 2020.
86 See Exhibit 23-1, final tender bundle, National Disability Insurance Agency, Response to NTG-0806, CTH.8000.1000.1853 at 1859.
87 *Approval of Care Recipients Principles 2014* (Cth), s 6. This includes medical, physical, cognitive, psychological and social factors that result in a loss of function. *National Disability Insurance Scheme Act 2013* (Cth), s 24; *National Disability Insurance Scheme (Specialist Disability Accommodation) Rules 2020* (Cth), pt 2.
88 Transcript, Melbourne Hearing 1, Vicki Rundle, 11 September 2019 at T5073.45–5074.2.
89 Exhibit 9-1, Melbourne Hearing 1, general tender bundle, tab 37, RCD.9999.0178.0029 at 0053.
90 Exhibit 9-1, Melbourne Hearing 1, general tender bundle, tab 146, CTH.0001.8000.0001 at 0009 [17].
91 Transcript, Melbourne Hearing 1, Luke Bo'sher, 13 September 2019 at T5203.36–5204.46.
92 Exhibit 9-8, Melbourne Hearing 1, Statement of Neale Radley, WIT.1251.0001.0001 at 0004 [33].
93 Exhibit 9-8, Melbourne Hearing 1, Statement of Neale Radley, WIT.1251.0001.0001 at 0004 [33].
94 Neale Radley, Public submission, AWF.800.02225.0001 at 0001.
95 Exhibit 9-18, Melbourne Hearing 1, Statement of James Nutt, WIT.1237.0001.0001 at 0002 [10].
96 Exhibit 9-18, Melbourne Hearing 1, Statement of James Nutt, WIT.1237.0001.0001 at 0003 [20].
97 Exhibit 9-18, Melbourne Hearing 1, Statement of James Nutt, WIT.1237.0001.0001 at 0005 [47].
98 Exhibit 9-18, Melbourne Hearing 1, Statement of James Nutt, WIT.1237.0001.0001 at 0005 [48].
99 Exhibit 9-18, Melbourne Hearing 1, Statement of James Nutt, WIT.1237.0001.0001 at 0007 [68].
100 Exhibit 9-18, Melbourne Hearing 1, Statement of James Nutt, WIT.1237.0001.0001 at 0008 [79].
101 Exhibit 9-18, Melbourne Hearing 1, Statement of James Nutt, WIT.1237.0001.0001 at 0009 [80].
102 Exhibit 9-10, Melbourne Hearing 1, Statement of Vicki Rundle, WIT.0436.0001.0001 at 0003 [16].
103 Transcript, Melbourne Hearing 1, Luke Bo'sher, 13 September 2019 at T5209.12–25.
104 Transcript, Melbourne Hearing 1, Vicki Rundle, 11 September 2019 at T5074.46–5075.23; Transcript, Melbourne Hearing 1, Bronwyn Morkham, 13 September 2019 at T5217.40–41.
105 Transcript, Melbourne Hearing 1, Michael Lye, 10 September 2019 at T4956.29–39.
106 Council of Australian Governments Disability Reform Council, *Gold Coast–28 June 2019 Communiqué,* 2019.
107 See, for example, David Tune AO PSM, *Review of the National Disability Insurance Scheme Act 2013: Removing Red Tape and Implementing the NDIS Participant Service Guarantee*, 2019, p 38.
108 Transcript, Melbourne Hearing 1, Kirby Littley, 11 September 2019 at T5088.1–2; Exhibit 9-12, Melbourne Hearing 1, Statement of Kirby Littley, WIT.1241.0001.0001 at 0002 [21]–[22].
109 Exhibit 9-8, Melbourne Hearing 1, Statement of Neale Radley, WIT.1251.0001.0001 at 0001 [3]; Exhibit 9-18, Melbourne Hearing 1, Statement of James Nutt, WIT.1237.0001.0001 at 0002 [17]; 0006 [52].
110 Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, Vol 1, p 252.

12. The Aged Care Workforce

12.1 Introduction

Getting the aged care workforce right is vital to the success of any future aged care system. This is recognised in our Terms of Reference, which require us to inquire into the 'critical' role of the aged care workforce in delivering high quality, safe, person-centred care.[1] There is now a clear and pressing need for a substantial development of the workforce in the aged care sector.

We have heard about the dedication and passion of aged care workers. Ms Sharai Johnson, a Larrakia descendent and aged care coordinator with Larrakia Nation in Darwin, said that the chance to make a positive difference is rewarding both personally and professionally. Referring to her work in aged care, she said, 'It's a wonderful place to be'. Ms Johnson said 'what makes it so rewarding is that you know that you're impacting—you're having a positive impact on each individual's life'.[2] The aged care sector needs to attract and retain more people like Ms Johnson. Our community should recognise and thank them for caring. It is not easy work.

While many excellent people work in aged care, there are systemic workforce problems that must be addressed. Of the public submissions we received, approximately 70% identified staffing as a concern.[3] One of the most common issues raised in complaints about residential aged care made in 2019–20 to the Aged Care Quality and Safety Commission concerned personnel numbers and sufficiency.[4] The majority of the hundreds of witnesses who gave evidence mentioned workforce issues.

Many of the defects that currently exist can, in Commissioner Pagone's view, be traced to funding and the system as designed and operating. Commissioner Briggs makes the following observations.

In a large number of residential aged care facilities there are not enough workers to provide high quality and safe, person-centred care. We have heard this from people receiving aged care, their family members and the staff members and managers of aged care providers. Their views have been supported by those of many independent experts.

In many cases, the mix of staff who provide aged care is not appropriately matched to the care needs of older people. The proportion of professionally qualified staff such as nurses and allied health workers is too low. The proportion of personal care workers is too high. The increasing medical acuity of people receiving aged care is not reflected in the staff mix. In fact, the opposite is the case. The care needs of people receiving aged have been increasing while the proportion of the aged care workforce looking after them who hold professional qualifications has been decreasing.

Workers and their unions have told us that the aged care workforce is underpaid and undervalued. Workers are rushed so much that they cannot always provide the care and

support they consider necessary. The aged care workforce is poorly paid for difficult and important work. There are often not enough staff members to provide the care that is necessary to deliver either safe and high quality care or a good quality of life. There is no time to attend to the little things that make such a difference—to sit and have a chat over a cup of tea or to talk about the things that matter to an older person. Many staff members work in stressful and sometimes unsafe workplaces. Some are untrained, while others have inadequate training—and most need much more training.

Research both here and overseas establishes that the quality of care and the quality of jobs in aged care are inextricably linked. If workers are to provide high quality care, they must themselves be cared for by their employers. As another internationally recognised aged care expert, Dr Lisa Trigg, Assistant Director of Research, Data and Intelligence at Social Care Wales, said:

> To deliver really excellent relationship centred care, care workers have to be more than just respected. They have to be valued and supported.[5]

We both agree that this evidence points to the need for policies and practices to drive a 'virtuous circle', where good working conditions, supportive and visionary management, an empowering work culture, collaborative teams, high quality and relevant education and training, and high job satisfaction among care workers underpin high quality, person-centred care.[6]

Our vision for the aged care workforce has the following key elements:

- strategic leadership and workforce planning
- the right number of staff with the right mix of staff and skills
- a greater proportion of registered nurses, nurse practitioners, and allied health professionals
- better education and training to achieve a more highly professional workforce
- registered personal care workers
- minimum qualifications for personal care workers
- improved pay and conditions
- positive culture and strong leadership.

12.2 Strategic leadership and workforce planning

The number of older people in Australia will grow significantly in the next 30 years, resulting in a substantial increase in the number of people needing different types of aged care. This will have a big impact on the number of people needed to deliver that care and the required size of the aged care workforce. Australia is likely to have an undersupply of aged care workers.

12.2.1 Aged care workforce planning

Recommendation 75: Aged care workforce planning

1. The Australian Government should establish an Aged Care Workforce Planning Division within the Australian Department of Health by 1 January 2022. If an Australian Aged Care Commission is established, the Aged Care Workforce Planning Division should be transferred into that Commission upon its establishment. The Division should be responsible for developing workforce strategies for the aged care sector through:
    a. obtaining up to date data about the aged care workforce with a census that Commissioner Briggs recommends takes place every 2 years
    b. long-term workforce modelling on the supply of and demand for health professionals, including allied health professionals, and care workers
    c. consultation with the providers of education and training for health professionals and personal care workers, in partnership with the State and Territory Governments, universities, registered training organisations, National Boards, professional associations, and colleges
    d. ensuring an appropriate distribution of health professionals and care workers to meet the needs of the aged care sector, particularly in regional, rural and remote Australia
    e. aged care workforce planning, including through modelling, consultation with providers and consideration of immigration.
2. By 1 July 2022, the Aged Care Workforce Planning Division should prepare an interim workforce strategy and planning framework for 2022–25.
3. By 1 July 2025, the Aged Care Workforce Planning Division within the System Governor should prepare a 10-year workforce strategy and planning framework for 2025–35, following the interim 3-year Workforce Strategy.
4. The Aged Care Workforce Planning Division should be supported by an Aged Care Workforce Fund, which Commissioner Briggs recommends should be $100 million per year in line with previous arrangements, that can be used to support training, clinical placements, scholarships and other initiatives to respond in a targeted manner to the workforce challenges that the Division identifies.

Current data about the aged care workforce is limited. The Aged Care Workforce Census and Survey is the most recent and comprehensive data available.[7] In 2016, it reported that there were more than 366,000 pay as you go aged care workers, of whom 235,000 worked in residential facilities and 130,000 worked in home care and home support outlets. The workforce was predominantly female (87%). The median age was 46 years for residential care workers and 52 years for home care workers.[8]

In 2016, 67% of personal care workers in residential care settings held a relevant Certificate III level qualification, while 23% of personal care workers in residential aged care settings had completed a Certificate IV in Aged Care.[9] For personal care workers working in home care, 51% had a Certificate III in Aged Care, and 27% had a Certificate III in Home and Community Care. A total of 15% had a Certificate IV in Aged Care or Service Coordination.[10]

In 2016, almost two-thirds of residential facilities (63%) reported a shortage of workers in at least one direct care occupation. Almost half of home care providers reported skills shortages (49%). Of those, 80% of residential aged care providers and 72% of home care providers reported 'no suitable applicants' as the cause of the shortage. Approved providers responded by having existing staff work longer hours, providing on-the-job training or using agency staff.[11]

We accept the evidence that there is a link between staffing levels and care outcomes. We are very concerned that the current aged care workforce is not large enough to provide high quality aged care services on a consistent basis. Staffing levels within large parts of residential aged care, as a whole, fall well short of good or even acceptable practice standards.

These staff shortages will be further exacerbated by the recommendations we make to increase total staffing levels, provide additional nurses and allied health professionals, change the mix of staffing, and remove the waiting list for home care.

There also needs to be an increase in the use of specialist roles within the aged care workforce. Mr Glenn Rees, Chair of Alzheimer's Disease International, gave evidence about the need for dementia specialists in aged care.[12] Ms Melissa Coad, then Executive Projects Coordinator at union United Voice, explained that formal training in areas such as dementia, palliative care and mental health would open up career pathways for workers to specialise.[13] Dr Drew Dwyer, a consultant nursing gerontologist, said that aged care nursing is a specialisation rather than something that requires only generalist knowledge.[14]

Modelling by Deloitte Access Economics commissioned by us has extrapolated the 2016 National Aged Care Workforce Census and Survey estimates forward, using numbers of people receiving aged care and then projected workforce needs over the long-term based on demographic trends and program use rates. The modelling projects that the number of direct care workers needed to maintain current staffing levels, without implementation of our recommended reforms, would be around 316,500 full-time equivalents by 2050. If there is a 4 star staffing minimum in residential aged care this would increase the number of direct care workers needed to around 363,500 full-time equivalents by 2050. The number of direct care workers currently employed will need to double.

Table 1: Projected number of direct care full-time equivalents in aged care[15]

	2020	2030	2040	2050
Baseline (current policy)[16]	186,100	226,700	269,700	316,500
Minimum 3 star[17]	186,100	238,800	280,000	333,000
Minimum 4 star[18]	186,100	256,800	301,800	363,500
Minimum 5 star[19]	186,100	273,300	322,800	392,700

Source: Commissioned modelling by Deloitte Access Economics.

The composition of the increase between 2020 and 2050 is projected to be:

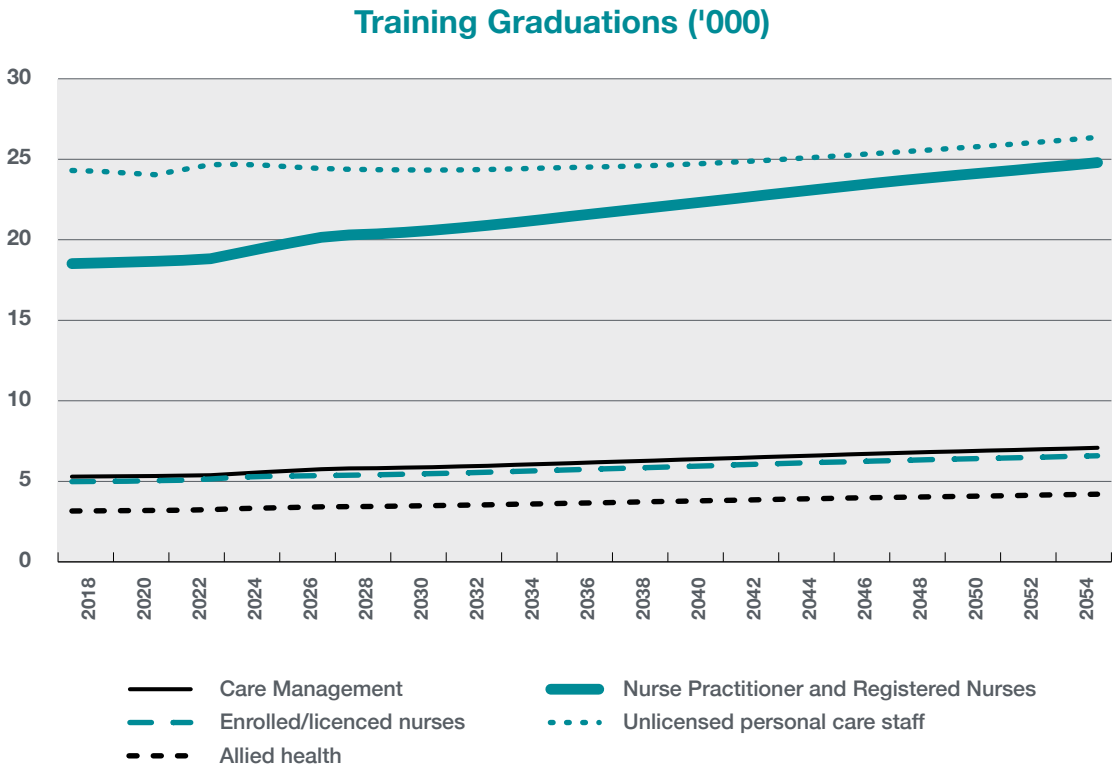
- 15,200 additional care management roles (91% above 2020 levels)
- 35,900 additional nurse practitioner and registered nurse roles by 2050 (a 157% increase)
- 6000 additional enrolled nurses (a 55% increase)
- 113,600 additional personal care workers (a 89% increase).[20]

In addition to direct care workers, more allied health professionals will be needed. The projections suggest the number will need to grow 6600 by 2050 (an increase of 81%).

Almost all of these workers will need to be new workers. They will have to replace the loss of workers each year—about 6000 in 2020 and growing to 12,200 by 2050—as well as fill the growing demand.[21]

This increased demand for new workers will result in a very large increase in demand for higher education and training. Figure 1 projects that graduations of allied health professionals, care managers and enrolled nurses will increase by approximately 1% per annum over the projected horizon. Personal care worker graduations are projected to grow at a slower rate of 0.2% per annum over the same time period. We discuss education and training later in this chapter.

Figure 1: Projected need for higher education and training per year (demand from all sectors)[22]



Source: Commissioned modelling by Deloitte Access Economics.

For some years, there has been a relative decline in the proportion of nurses in the residential aged care workforce and a corresponding increase of personal care workers. In 2003, nurses comprised 35.8% of the workforce. By 2016, this had declined to 24.2%. In the corresponding period, the proportion of personal care workers increased from 56.5% to 71.5%. There has also been a significant decline in allied health professionals as a proportion of the workforce.[23]

These 2016 data are now about five years old and are becoming less useful for many purposes. We recommend far more regular collection of data. Commissioner Briggs recommends that a census should occur every two years, and there should be more reporting about the aged care workforce from approved providers. Commissioner Pagone considers that the Aged Care Workforce Industry Council should consider the form and frequency of future workforce surveys.

Aged care is part of the health care and social assistance sector, which has been the fastest growing industry every year in Australia since 2015. Australian Government research from 2018 projected that there would be 129,100 new jobs for carers or aides in the five years to May 2023.[24] The aged care sector is competing for its workforce with other parts of the health and social assistance sector, especially the disability sector.

Demographic projections by Deloitte Access Economics indicate that there is likely to be a rapid increase in the number of older people in Australia between now and 2050. Deloitte Access Economics reports that the number of people aged 65–69 years will increase by one-third from 2020 to 2050. Over the same period, the number of people aged 85 years and over will more than double.[25]

In turn, the number of people needed to deliver direct care in Australia and the required size of the aged care workforce will also need to increase. The Australian Government recognises there is a need for significant growth of the aged care workforce to meet future demand.[26]

There is a need for strategic workforce planning to meet the medium- and long-term demand for a skilled aged care workforce. For example, we received evidence about the Esperance Aged Care Facility in rural Western Australia. A new residential wing, built in 2019, could not be opened because the approved provider was unable to recruit enough staff.[27]

Ms Glenys Beauchamp PSM, then Secretary of the Australian Department of Health, stated that:

> A key challenge for the future is ensuring the sector can attract and retain a much larger aged care workforce, with the right skills and attributes, required to care for a growing population living longer. In particular, an environment that attracts younger workers and offers a range of career paths with clear career progression is critical as the workforce ages. The disability sector faces the same challenge and we will need to ensure strategies put in place work together to ensure the needs of consumers and workers in both systems are met.[28]

When asked if she had confidence that the workforce planning mechanisms within the Department would ensure that the significant increase in staff numbers to meet demand could be achieved, Ms Beauchamp said:

> I think we need more information in terms of the workforce planning, and I think we need to do, as a Commonwealth, across all of those other Agencies I mentioned earlier, a much better effort around workforce planning.[29]

In recent years, Commissioner Briggs notes, there has been a shift in responsibility for health workforce planning and a splintering of workforce planning functions across a number of Australian Government agencies, leading to both an absence of leadership on workforce planning for aged care and a loss of dedicated funding. There is now no targeted approach to workforce planning for aged care. There is no mechanism in place to identify, fund, implement and evaluate tools to strengthen the aged care workforce.

Commissioner Briggs notes that a Secretaries Social Policy Committee was established in 2019 ostensibly to develop a cross-portfolio approach to aged care workforce planning and strategy, but little has come of it.[30] Changes to the vocational, education and training arrangements have added to the complexity of the system, with a new National Skills Council having broad workforce responsibilities.[31] Commissioner Briggs considers that there is now a lack of clarity about who is ultimately responsible for aged care workforce planning within Government.

We both believe that there should be a clear and strong partnership developed between the System Governor, the aged care sector, and the education and training sector to provide the basis for strategic and effective workforce planning so that the aged care sector has the right people to deliver safe and high quality care as the population ages.

We both consider that strategic workforce planning for aged care will necessarily overlap with workforce planning in the disability sector, and the health sector more broadly. The Australian Health Services Research Institute at the University of Wollongong submitted that 'evidence provided to the Royal Commission showed there are clear synergies between staff working in health, ageing and disability sectors and the opportunities for common processes and standards across all three sectors'. The Institute's view is that 'a standalone workforce strategy for aged care does not make sense financially or practically'.[32] We do not agree that a standalone workforce strategy for aged care does not make sense but we agree that there needs to be coordination with those other sectors.

The Productivity Commission in 2011, Professor John Pollaers, Chair of the Aged Care Workforce Strategy Taskforce, and Professor Kathy Eagar, Director at the Australian Health Services Research Institute, University of Wollongong, each raised concerns about workforce planning in the sector.[33]

The Aged Care Workforce Industry Council does not support the establishment of an Aged Care Workforce Planning Division. It submitted that the Australian Government 'does not have the expertise or understanding of delivery of service and the needs of the workforce to cater for the growing volume, acuity and expectations of the aged care system and therefore the workforce planning response required'. [34] The Council submitted that as an industry body, it was best placed to conduct this work. However, Ms Sandra Hills, Chief Executive Officer of approved provider Benetas, told us that 'stewardship for leading workforce planning in the aged care sector requires more than the collective efforts of approved providers'.[35]

We consider that, as the primary funder of aged care, the Australian Government must be responsible for workforce planning, and be held accountable for the delivery of high quality and safe care. More specifically, the System Governor should assume strategic leadership responsibility for aged care workforce planning.

To do the job effectively, the System Governor will need to gain the expertise and understanding necessary to lead strategic workforce planning. That will require the establishment of an Aged Care Workforce Planning Division within the System Governor.

Our recommendation is that the Australian Government have a dedicated aged care workforce planning capability. We highlight the need for up-to-date data, modelling, consultation, consideration of the needs of regional, rural and remote Australia, and consideration of immigration.

The System Governor will also need access to a dedicated aged care workforce fund. The fund should provide access to education, training and other form of supports—for example, nursing scholarships and financial support for aged care providers to provide training places. It should support targeted training and development for priority groups, including for Aboriginal and Torres Strait Islander people.

We differ in the size of the proposed workforce fund.

Commissioner Briggs considers that a fund with these responsibilities will need to be well-resourced at around $100 million a year for four years to deliver on the urgent workforce mandate. This level of funding is in line with the size of an earlier workforce fund of $302 million established to operate between 2011–12 and 2014–15.[36] That fund was intended to provide training, education and support for the aged care workforce, including via scholarships and training strategies for Aboriginal and Torres Strait Islander people.[37] The fund was depleted by way of various savings measures and abandoned. Commissioner Briggs is concerned that the work to recruit, equip and upskill the workforce to address the significant workforce supply and planning challenges in the years ahead remains to be done. It cannot wait for several years until the Pricing Authority eventually gets to it, as education and training arrangements can take years to put in place and take on students. Action needs to be taken now to address the shortfall in the supply pipeline of workers to deliver the expansion in care in the home and residential care initiatives that we recommend to remove waiting lists and address quality and safety issues. After that, the costs of training and development will be built into the pricing structure of aged care funding arrangements.

Commissioner Pagone considers that in the longer-term, it is aged care employers who have the primary responsibility to train and develop their workforce. Accordingly, the ordinary costs of training and development of the workforce should be reflected in the prices set by the Pricing Authority. Additional support should only be provided by the Australian Government where it is necessary to support priorities outlined in the interim workforce planning framework we recommend be developed by July 2022. In the short-term, we recommend immediate funding for education and training to improve the quality of the current aged care workforce. This is discussed in his chapter on funding the new aged care system.

Accordingly, Commissioner Pagone considers that by July 2022 the Aged Care Workforce Planning Division should recommend to government the amount of funding necessary to support the objectives set out in the interim workforce planning framework. This approach will allow an assessment of the necessary level of investment of taxpayer funds. It will also provide a mechanism to assess how effectively that public investment is directed to achieving the strategic objectives set out in the planning framework and will inform the development of the 10-year workforce strategy and planning framework.

The Australian Government recognised there is a need for significant growth of the aged care workforce to meet future demand.[38] It also agrees that there is a need for strategic workforce planning to meet the medium- and long-term demand for a skilled aged care workforce. [39]

12.2.2 Regional, rural and remote

The challenges involved in attracting and retaining aged care workers are magnified in rural and remote Australia.[40] Tables 2 and 3 provide a comparison of reported skill shortages by location.

Table 2: Proportion of residential facilities reporting skill shortages in 2016 (%) by location and occupation[41]

Whether had skill shortage	Major cities	Inner regional	Outer regional	Remote	Very remote	All facilities
Yes (of all facilities)	46.5	61.9	62.8	59.7	81.1	53.4
Yes (of all facilities with direct care staff)	55.9	72.8	70.8	72.7	87.8	63.2
Skill shortage for occupation:						
Registered nurse	33.9	50.3	51.5	55.2	58.5	41.2
Enrolled nurse	15.8	27.4	31.1	29.9	22.6	21.2
personal care worker	23.6	24.6	30.6	37.3	37.7	25.4
Allied health	6.1	6.3	4.7	11.9	3.8	6.1

Table 3: Proportion of home care and home support outlets reporting skill shortages in 2016 (%) by location and occupation[42]

Whether had skill shortage	Major cities	Inner regional	Outer regional	Remote	Very remote	All facilities
Yes (of all facilities)	40.8	43.4	43.3	43.8	51.4	42.4
Yes (of all facilities with direct care staff)	46.9	49.7	51.1	52.2	60.7	49.2
Skill shortage for occupation:						
Registered nurse	7.3	12.5	12.0	16.5	12.5	10.4
Enrolled nurse	1.7	2.8	3.5	3.4	5.6	2.6
Personal care worker	33.1	33.7	32.3	34.8	43.1	33.3
Allied health	7.1	7.8	6.2	4.1	2.8	6.6

Source: Australian Department of Health, *2016 National Aged Care Workforce Census Survey – The Aged Care Workforce*, 2017.

The Aged Care Workforce Planning Division should plan development strategies to ensure an appropriate distribution of health professionals, including allied health professionals, and personal care workers to deliver high quality and safe care in regional, rural and remote Australia. It should consult with the Remote Aged Care Workforce Accord[43]

12.2.3 Immigration

The modelling by Deloitte Access Economics discussed earlier assumes that about 30% of the number of new aged care workers required each year will come through Australia's skilled migration. Without higher skilled migration, the substantial growth of labour required in aged care may not be achievable. However, higher immigration cannot be the only response given the difficulties in the short-term associated with the COVID-19 pandemic.

Commissioner Briggs considers that the way governments have used immigration to build the aged care workforce has not been particularly targeted or strategic. It appears to her that people migrate to Australia and end up working in aged care, rather than migrating to Australia in order to work in aged care.[44]

The permanent skills migration schemes are used to attract registered nurses but not personal care workers from overseas. Personal care workers are not on the 'skilled occupation lists' that are used to identify skills areas under which prospective immigrants can enter Australia.[45] Temporary immigration is an indirect source of permanent immigrants, with the majority of permanent skilled immigrants having initially entered and worked in Australia as temporary immigrants.[46] Most of the temporary immigrant workforce is not recruited directly from overseas—they come to Australia via other means, such as on working holiday, student visas or with a family member.

Commissioner Briggs considers that despite concerns from a number of professional bodies and unions, immigration is likely to be a small but important part of the Australian Government's toolkit to address the aged care and broader health workforce supply needs of Australia in the coming years, particularly shortages of key health professionals and to address regional, rural and remote requirements, where local workers cannot be engaged in sufficient numbers. Visa arrangements may need to change to address skills shortages.

Commissioner Pagone understands the importance of immigration to the development of the workforce in all sectors of the economy, including aged care. However, he does not believe it should be relied upon as a principal source of a sound, skillful and caring aged care workforce. This is particularly so given the likely impacts of the COVID-19 pandemic on immigration levels.

12.2.4 Aged Care Workforce Industry Council Limited

Recommendation 76: Aged Care Workforce Industry Council Limited

1. By 1 July 2021, the Aged Care Workforce Industry Council Limited should:
   a. invite the Australian Government to become a member
   b. review membership of the Council to ensure it is comprised of individuals, including worker representatives, who represent the breadth and diversity of the aged care workforce with an appropriate mix of skills and experience to lead and drive change across the sector.
2. By 30 June 2022, the Aged Care Workforce Industry Council Limited should:

   Commissioner Briggs

   a. review the qualifications and skills framework to address current and future competency and skill requirements and to create longer-term career paths for aged care workers, in conjunction with the work to be undertaken to seek review of award rates in aged care
   b. review all aged care occupational groups, jobs and job grades to ensure they reflect the skills, capabilities, knowledge and competencies as well as the structure required in the new aged care system
   c. revise the competency and accreditation requirements for all job grades in the aged care sector to ensure education and training builds the required skills and knowledge
   d. standardise job titles, job designs, job grades and job definitions for the aged care sector, and
   e. lead the Australian Government and the aged care sector to a consensus to support applications to the Fair Work Commission to improve wages based on work value and/or equal remuneration, which may include redefining job classifications and job grades in the relevant awards.
3. The Aged Care Workforce Council Limited should work collaboratively with the Aged Care Workforce Planning Division so that its work complements aged care workforce design and planning.

4. **From 1 July 2022, the Aged Care Workforce Industry Council Limited should map career pathways for the aged care sector. These career pathways should:**
    a. **highlight opportunities for nurses to advance in clinical and managerial roles in the aged care sector**
    b. **facilitate personal care workers having opportunities to move laterally across aged care, disability care, community care and primary health care and vertically in aged care by advancing into nursing, specialist care roles and supervisory or managerial roles**
    c. **develop and document career opportunities in the aged care sector for non-direct care workers, including kitchen hands, cooks, cleaners, gardeners, drivers, security and people performing administrative roles.**
5. **By 1 July 2022, the Aged Care Workforce Industry Council Limited should lead a national multimedia campaign aimed at raising awareness of career paths and opportunities in aged care.**
6. **The Australian Government should provide the necessary funding and resources to enable the Aged Care Workforce Industry Council Limited to implement the workforce recommendations of this Royal Commission and to build on its work implementing the Aged Care Workforce Strategy Taskforce's strategic actions.**

The establishment of the Aged Care Workforce Industry Council Limited was one of 14 strategic actions recommended in the Aged Care Workforce Strategy Taskforce's 2018 report, *A Matter of Care – Australia's Aged Care Workforce Strategy*. Strategic Action 14 explained the intent of the Council:

> This is focused on an approach by which industry can lead execution of the strategic actions in a coordinated, sequenced and systematic manner though an Aged Services Industry Council. The council, made up of industry chief executive officers (CEOs), would establish the voluntary code of practice and implement a transformation program based on six cross-industry work streams. Each would be led by a CEO and cover the principal strategic actions with clear accountabilities and timelines for completion.[47]

The object of the Aged Care Workforce Industry Council Limited is to improve the aged care workforce so that:

> 2.1.1 the workforce provides aged care services that can meet the care needs of older Australians now and into the future and
>
> 2.1.2 older Australians have equitable access to aged care and the dignity to age well, irrespective of setting.[48]

We heard from members of the Council during the Melbourne 3 Hearing in October 2019 and attended a meeting of the Council at the invitation of its Chair in November 2020. We have been impressed by the commitment and diligence of the Council's members. However, despite its best efforts and intentions, the existing Council has not been

successful in causing the Aged Care Workforce Strategy Taskforce recommendations to be adopted and implemented within the timeframe proposed in the June 2018 report.[49] In October 2019, Mr Kevin McCoy, then Acting Chair of the Aged Care Workforce Industry Council Ltd, told us that the Council was unlikely to fulfil its role of implementing the strategic actions without strong government support.[50]

Aged care workforce reform is critical and must be implemented as quickly as possible. The Australian Government's approach to its governance, funding and regulatory roles will continue to have an important influence over the sector's 'capacity to compete in the labour market, to create attractive work places, and to foster a positive image of aged care as a career for potential employees'.[51] For this reason, we recommend that the Aged Care Workforce Industry Council Limited invite the Australian Government to become a member of the Council. We also recommend that the Australian Government provide the necessary funding and resources to enable the Council to implement the workforce recommendations of this Royal Commission and to build on its work implementing the Aged Care Workforce Strategy Taskforce's strategic actions.

The Aged Care Workforce Industry Council Limited has 10 members, of whom only one represents a part of the aged care workforce. During our inquiry, we have benefitted from being informed by worker representatives about the day-to-day challenges faced by their members working in aged care. We recommend that the Aged Care Workforce Industry Council Ltd include worker representatives who represent the entire direct care workforce: personal care workers, nurses and allied health workers. The inclusion of Australian Government and increase of worker representation on the Council will, we expect, enable the Council to reflect the breadth of the aged care workforce with an appropriate mix of skills and experience. This will make it better placed to lead and drive change across the sector.

While Commissioner Pagone agrees with the need to review jobs and job grades to ensure that reflect the skills and competencies required in the new aged care system, he considers that work is best done by the Fair Work Commission as part of the review of work value processes recommended later in this chapter.

As outlined in the recommendation, Commissioner Briggs sees the Aged Care Workforce Industry Council Limited playing a leadership role in commissioning and directing this work, including working alongside the relevant bodies and the States and Territories. She notes that responsibility for reviewing qualifications and training packages relevant to aged care lies with the relevant Industry reference committees, skills organisations and skills service organisations. This is consistent with the recommendations of the 2019 Joyce Review of Australia's Vocational Education and Training System.[52]

She points out that a training package is a set of nationally endorsed standards and qualifications for recognising and assessing people's skills in a specific industry, industry sector or enterprise. Training packages are developed by Industry Reference Committees (or Skills Organisations), who work with Skills Service Organisations to ensure that industry skill requirements are met by the national training system. Training packages are ultimately endorsed and approved by the Australian Industry and Skills Committee and the Skills National Cabinet Reform Committee.[53]

12.3 Building an aged care profession

The Australian Council of Professions defines a 'profession' as:

> a disciplined group of individuals who adhere to ethical standards and who hold themselves out as, and are accepted by the public as possessing special knowledge and skills in a widely recognised body of learning derived from research, education and training at a high level, and who are prepared to apply this knowledge and exercise these skills in the interest of others...[54]

The Australian Government, the aged care sector and worker representative bodies must work together to professionalise the personal care workforce. This will require cultural change and improvements to education, training, wages and conditions for personal care workers. As explained by the Health Services Union, 'the direct link between professionalisation measures, increased wages and conditions, and clear career pathways, will make aged care a more attractive career to enter or remain in'.[55]

12.3.1 Designing the future aged care workforce

Ms Coad told us that 'current career paths are non-existent in aged care for most direct care staff'.[56] Ms Carolyn Smith, Aged Care Director, United Workers Union, indicated that 'the structure within aged care for the personal care workforce is very flat with limited career progression opportunities'.[57]

We consider that the occupational and job structure within the aged care workforce must be well designed to respond to the needs of the future aged care system. Now is the right time to review and modernise occupational and job structures to lay the foundation for reforms to pay classifications for people who work in aged care so that the pay classifications reflect their competency and qualifications, and complexity of the work that they do. Occupational and job structures are also important for designing education, training and career frameworks.

We consider that a clear understanding of what a job involves not only informs competency requirements and career paths, it fosters clarity for both workers and people receiving aged care and their families. It also enables the design of effective training and education frameworks. To be sure that education and training frameworks will create a capable workforce that can build a career in aged care, there is a need to understand, standardise and define jobs.

Career paths should be underpinned by planning, training and support. Some providers are already working in this way. For example, Benetas sees the traditional career pathway for its direct care workforce in residential care to be from an entry-level role of personal care worker to enrolled nurse and registered nurse. Personal carer workers at Benetas have progressed to payroll, property, learning and development and quality opportunities.[58] Resthaven offers its staff a series of development programs aimed at advancing their career progression.[59]

In 2018, the Aged Care Workforce Strategy Taskforce recommended that the aged care industry deploy guiding principles and tools to enable a lasting career within a job family or transition between job families. A job family is a cluster of jobs that share a specific set of core characteristics, covering skills, knowledge, behavioural attributes and accountabilities. For example, personal care workers are a job family; nurses delivering clinical care are another job family. The Taskforce saw redefining existing roles and introducing new roles as a way to enable career progression opportunities. It recognised that the combination of roles needed will be influenced by the needs of older people receiving care, the approach of each organisation to workforce planning, and the models of care adopted.[60]

The *Aged Care Award 2010* and the *Social, Community, Home Care and Disability Services Industry Award 2010* set out the grades and levels at which a personal care worker may work and at a general level set out expectations in relation to tasks, supervision and qualifications.[61]

When an enterprise agreement applies to a workplace, the agreement will often do the same. For example, an enterprise agreement template negotiated between Aged & Community Services Australia, the NSW Nursing and Midwifery Association and the Health Services Union established a general employment classification comprising 'care service employees' ranging from entrant level to Care Service Employee Grade 5. At each level, the template agreement describes the level of experience and qualifications expected, the level of supervision and direction required and an indication of the types of duties that might be performed.[62] Each classification level up to and including Grade 4 contains three streams: care stream, support stream and maintenance stream. These streams reflect different roles performed by personal care workers.

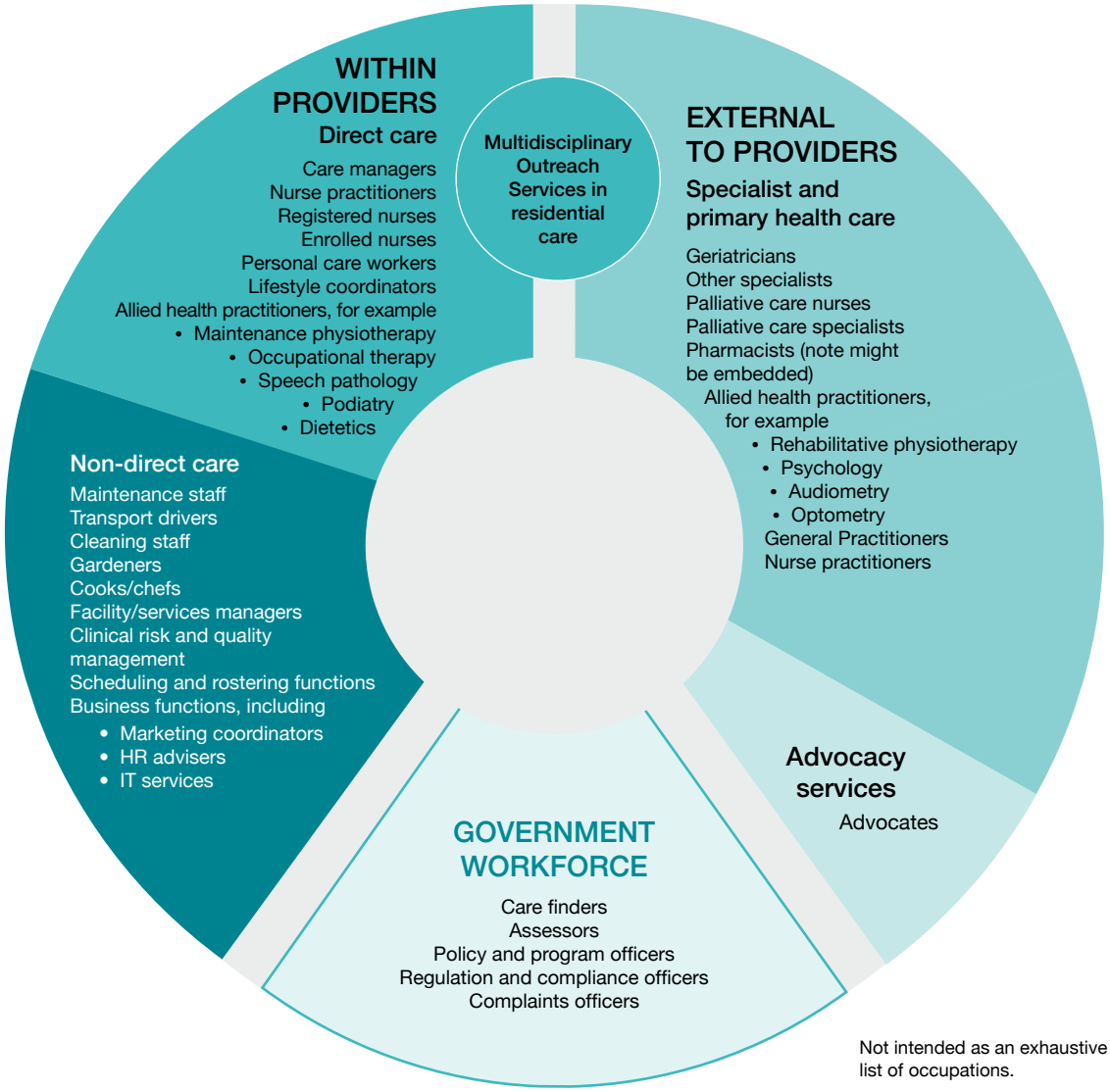
Later in this chapter, we encourage a collaborative approach to address wages for aged care workers. That same collaborative approach presents a practical opportunity to consider how jobs should be valued and designed across the aged care sector and how roles might come together to provide lasting career paths within and between job families. We have no doubt that the creation of long and rewarding career paths will be a key component in improving attraction and retention of aged care workers.[63] Aged care workers should have a clear vision for career progression, and importantly, clarity about what they need to do to achieve progression.

We agree with the Taskforce's observation that many aged care workforce issues are deeply intertwined. Our suggested approach to designing the future workforce must be part of holistic reform. This includes dealing with issues including registration, minimum qualifications, an ongoing commitment to professional development, strong leadership and enhancing a positive culture.

The aged care workforce is often used to refer to the people who provide the direct, day-to-day care and services to older people in their homes, residential facilities or in health care settings. Those who provide direct care, such as nurses and personal care workers, are at the heart of the aged care workforce, but they are a part of a vast network of people shown in Figure 2 who work together to deliver a continuum of care services and related support services to older people. This broader workforce includes doctors, allied health professionals, nurse practitioners and geriatricians.

This network of people should be recognised as being part of an aged care profession, and should be made to feel part of the profession. Prospective aged care workers should feel confident that they can build a career in aged care that will provide opportunities to move across the profession, to work in the public and private sectors, and to work directly with older people as well as in supporting and policy roles, including assessment, care finders and regulatory staff.

Figure 2: The aged care workforce



Not intended as an exhaustive list of occupations.

12.3.2 Turning jobs into careers | Commissioner Briggs

Aged care should be an attractive place to work.

Throughout our inquiry, it has been evident that attraction, recruitment and retention of people into the aged care sector will be enhanced if people can see aged care as a career. People with a real passion and commitment to working in aged care should be given opportunities to work in the sector. They should have options for career development and progression. They should be able to start as, say, a personal care worker and, if so inclined, be able to see a path to becoming an enrolled or registered nurse or a care finder, if this is their preference. Registered nurses with the right skills and aptitude should be able to transition to a nurse practitioner or a clinical manager role.

While there are natural career pathways in nursing, 'current career paths are non-existent in aged care for most direct personal care staff'.[64] This needs to change. Career pathways will be a key component of professionalising the aged care workforce and improving attraction and retention.[65] Career pathways are necessary to make aged care an attractive employment destination.

Successfully embedding clear career pathways across the aged care sector will require defined links to the attainment of relevant skills or qualifications, and associated remuneration levels. Although such pathways exist under the relevant aged care awards, 'pathways are not clearly articulated in a framework with an associated competency framework and development program'.[66]

The Aged Care Workforce Strategy Taskforce identified a need to define and standardise the sector's jobs, including their designs, grades and definitions.[67] It recommended that the Aged Care Workforce Industry Council standardise job classifications, definitions, titles, designs and grades and career pathways across the sector, and extend the levels within the personal care worker occupation so that such workers can be recognised for their experience or skills or additional educational qualifications.[68] It outlined a number of compelling reasons for this:

- there is inconsistency and variable quality in the way jobs are classified and defined[69]
- there is an inconsistent approach to job design, job pathways, career development and succession planning[70]
- the value of the personal care worker role is underestimated[71]
- the education and training skills and qualification framework is not aligned with the nature of the work, 'consumer' relationships and leadership roles now expected[72]
- there are new roles emerging based on new models of care and new career pathways that can be opened up.[73]
- specialisations or higher-skill levels are emerging in dementia care, both for personal care workers and nurses[74]
- progression within the personal care worker job family is limited and based largely on external educational qualifications—Certificate III and IV—rather than on a continuum of behavioural and technical competencies acquired and developed on the job.[75]

I recommend that the revitalised Aged Care Workforce Industry Council should review all aged care occupational groups, jobs and job grades to ensure they reflect the skills capabilities, knowledge and competencies as well as the structure required in the new aged care system. It should also standardise job titles, job designs, job grades and job definitions for the aged care sector.

In doing so, it should consider not just the existing roles, such as personal care workers, nurses and allied health professionals, but also roles that we recommend in this report, such as care managers, care finders and embedded pharmacists. Nurse practitioners should also feature in workforce redesign.

The Aged Care Workforce Industry Council should also look to new and emerging roles. An example is the peer workforce—an emerging mental health workforce.[76] Currently, there is no agreed definition of the mental health peer workforce. It is sometimes referred to as the 'lived experience' workforce.[77] People with lived experience of mental illness as either a person receiving care or carer may gain formal qualifications to become a peer worker by completing a Certificate IV in Mental Health Peer Work.[78]

12.3.3 Attracting people to aged care | Commissioner Briggs

Figure 3 illustrates the interrelated nature of attraction and retention with the other measures that are required to boost the aged care workforce. These include employment conditions, staffing levels, available career pathways, education and training, and good leadership and management.[79] It is vital to address those issues to build the future aged care workforce. The aged care sector needs to step up and take the lead because action on all of them is necessary in order to improve the quality of care.

Figure 3: Workforce attraction and retention measures

It is primarily the responsibility of the aged care sector to attract and recruit the right people to work in aged care and to retain them as employees. Approved providers should take a leading role in progressing these areas. However, there are elements of this work that will require national coordination and support from the Australian Government, and there is a role for the Aged Care Workforce Industry Council to provide best practice guides and to promote careers in aged care.

In the current climate, with the impact of the COVID-19 pandemic on the labour market, it is likely that, more than ever, there are jobseekers on income benefits who have the right attributes to work in aged care, as well as relevant skills from other employment experience.[80] The opportunity exists to support the transition of workers from affected sectors to aged care. The aged care profession attraction plan should consider opportunities to target those industries most affected by COVID-19, such as hospitality, tourism, aviation, the arts and retail.

Because of the projected growth in demand for aged care services, there is an opportunity to promote aged care as a secure and stable career choice. Workforce stability is likely to have increased meaning and value to those entering the workforce at a time when many people have experienced, or are experiencing, the challenge of job insecurity and instability.

There is a need for clear and accurate careers information about working in aged care. There should also be a specific focus on attracting and retaining people in regional, rural and remote locations. The careers information should cover the different roles available in aged care, the nature of the working environment, potential job opportunities and employment conditions, and the associated educational and registration requirements. It should also cover both vocational and higher education pathways into aged care careers. One limitation of some existing careers information services, including the Australian Government's myskills.gov.au website, is that they are limited to a particular educational pathway.

There is a pressing need to raise awareness about the employment and career opportunities in the aged care sector. Aged care is a growing industry section and one that will require thousands of additional personal care workers and health professionals, as well as other support staff. There is a need to promote these opportunities in the community.

As part of this, the Aged Care Workforce Industry Council, working with relevant bodies, such as the Human Services Skills Organisation, should lead a national multimedia campaign aimed at raising awareness of career paths and opportunities in aged care. There is also an important role for the new National Careers Institute, established in response to a recommendation of the Joyce Review, to provide improved careers information about aged care.

12.3.4 Registration for personal care workers

We are in no doubt that a registration scheme is required for personal care workers. The Australian Medical Association submitted that 'personal care attendants spend proportionately more time caring for older people than any other staff type', and that this makes them 'a crucial component to the aged care workforce and a crucial component in influencing safety and quality issues'.[81] The Association proposes that, like health professionals, personal care attendants should be subject to a regulatory scheme which features minimum education and English language proficiency requirements.[82]

Recommendation 77: National registration scheme

1. By 1 July 2022, the Australian Government should establish a national registration scheme for the personal care workforce with the following key features:
   a. a mandatory minimum qualification of a Certificate III
   b. ongoing training requirements
   c. minimum levels of English language proficiency
   d. criminal history screening requirements
   e. a code of conduct and power for a registering body to investigate complaints into breaches of the Code of Conduct and take appropriate disciplinary action.
2. For existing personal care workers who do not meet the minimum qualification requirements, there should be transitional arrangements that allow them to apply for registration based on their experience and prior learning.
3. By 1 July 2021, the Australian Health Practitioner Regulation Agency should start a process to examine the feasibility of a registration scheme under the National Registration and Accreditation Scheme for the occupation of 'personal care worker (health)' or 'assistant in nursing', to inform the National Cabinet Health Council deliberations in Recommendation 77.4. **Commissioner Briggs**
4. By 1 July 2023, the Australian Government should request that the National Cabinet Health Council determine whether to regulate the occupation of 'personal care worker (health)' or 'assistant in nursing' under the National Registration and Accreditation Scheme, established and governed under the Health Practitioner Regulation National Law.

While we differ about the appropriate mechanism, as we explain below, we both consider that regulation of personal care workers by registration, with a mandatory minimum qualification requirement, ongoing training requirements, a code of conduct, and a complaint process, will help to professionalise and improve the quality of the personal care worker workforce. Dr Anna Howe, PhD Consultant Gerontologist, submitted:

> All registered workers should be recognised by the designation Registered Care Assistants or similar in specification of staffing levels. This recognition would enhance the status of these workers and make the field more attractive.[83]

Inappropriate personal care worker practice, compounded by inadequate clinical supervision, can present a serious risk to the health and safety of people receiving aged care. Examples were highlighted in the IRT William Beach Gardens and MiCare Avondrust Lodge cases studies. In the IRT William Beach Gardens Case Study, Commissioners Tracey and Briggs heard that Ms Shirley Fowler suffered repeated pressure injuries. Personal care workers were expected to assess Ms Fowler's care needs and inspect skin

integrity and report to their team leader, who was, in turn, to inform the registered nurse on duty. However, Ms Fowler's developing wounds were not discovered and preventive measures not adopted until after invention by Ms Fowler's daughter.[84] The late Mrs Bertha Aalberts was a resident at MiCare Avondrust Lodge from May 2018. Mrs Aalberts died in August 2018. Her death certificate records that the cause of death included infected ulcers and cellulitis (skin infection).[85] Commissioners Tracey and Briggs found that personal care workers were tasked with daily wound care tasks that should have been performed by a registered nurse.[86]

One of the purposes of any health worker registration scheme would be to receive and investigate complaints about personal care workers potentially leading to restrictions or exclusion from working in the aged care sector. Ms Barbara Spriggs said that she saw signs her late husband, Robert, 'was physically abused and neglected' at Oakden Older Persons Mental Health Services.[87] Ms Spriggs made the following suggestion for reform:

> 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.[88]

Ms Lisa Backhouse, Ms Sarah Holland-Batt and Mrs Noleen Hausler each gave evidence of their loved ones being abused or assaulted by carers in residential aged care facilities.[89] We heard about 'UA', a personal care worker at a residential aged care facility in Melbourne.[90] 'UA' was investigated for allegations of violent and abusive conduct towards several residents. The employer's investigations substantiated the allegations. 'UA' resigned and no charges were laid by the police against 'UA'. He remains free to work in aged care.[91]

In cases such as these where the actions of a personal care worker demonstrate that they are unsuitable to care for older people, appropriate action should be able to be taken to protect the public.

We also heard evidence about the existing National Code of Conduct for Health Care Workers, which is a negative licensing scheme. The States and Territories have taken different approaches to regulation and enforcement of the Code, and the existing system is fragmented.[92] Currently, the Code may apply to aged care workers, but this can depend on the State in which they are employed, their work setting and the type of service they provide.[93] In our view, this Code is not the right tool for the regulation of personal care workers on a nationally consistent basis.

Registration scheme for the personal care workforce

The Australian Government has accepted:

> that there is a need for some form of register of the broad assistant / personal care workforce (across more than aged care) that enables the identification and exclusion of persons of concern, facilitates mandatory police checks, and potentially records qualifications, in line with a minimum qualification requirement for registration.[94]

The Government has told us that 'considerable work has already been done by the Department, with further work underway, in exploring a register which would be proportionate and achievable in a short period of time'.[95]

Mr Martin Fletcher, Chief Executive Officer of the Australian Health Practitioner Regulation Agency, proposed a form of national registration of personal care workers that captures the key elements identified by Counsel Assisting in final submissions, and that builds upon the framework of the National Registration and Accreditation Scheme. Mr Fletcher cautioned that this 'would still require extensive modifications to provide fit for purpose, timely, risk-based regulation which recognises the unique nature of the PCWs [personal care workers] and the distinct features of aged care'.[96]

We recommend that the Australian Government establish a registration scheme for the personal care workforce by 1 July 2022. We encourage the Australian Government to consult with the Australian Health Practitioner Regulation Agency for its 'expertise and understanding of the broader environmental considerations to help inform discussions'.[97] We acknowledge that there may be benefit in such a registration scheme including personal care workers who work in aged, health and disability care.

The National Registration and Accreditation Scheme

Counsel Assisting proposed a regulation scheme for personal care workers administered by the Australian Health Practitioner Regulation Agency under the *Health Practitioner Regulation National Law Act 2009* (Cth).[98]

The Australian Health Practitioner Regulation Agency works with 15 National Boards to help protect the public by regulating Australia's registered health professions, under the National Registration and Accreditation Scheme.[99] The functions include registering practitioners, determining the requirements for practitioners and approving accredited programs of study.[100]

An intergovernmental agreement provides that an unregulated occupation may only be regulated under the National Scheme where:

- the unregulated occupation is assessed against six criteria
- registration is supported by a majority of jurisdictions
- it can be demonstrated that the occupation's practice presents a serious risk to public health and safety which could be minimised by regulation.[101]

The six criteria against which an unregulated occupation is assessed are the following questions:

> It is appropriate for health ministers to exercise responsibility for regulating the occupation in question, or does the occupation more appropriately fall within the domain of another ministry? …
>
> Do the activities of the occupation pose a significant risk of harm to the health and safety of the public?…
>
> Do the existing regulatory or other mechanisms fail to address health and safety issues?…
>
> Is regulation possible to implement for the occupation in question?…
>
> Is regulation practical to implement for the occupation in question?...
>
> Do the benefits to the public of regulation clearly outweigh the potential negative impact of such regulation?[102]

The National Cabinet Health Council consults and assesses submissions addressing the six criteria.[103]

In relation to the second criterion—significant risk of harm to the health and safety of the public—the National Cabinet Health Council refers to 13 risk sub-categories.[104] At face value, it seems to us that at least four of those sub-categories apply to the duties of personal care workers involved in health care: treatment commonly occurs without others present; patients commonly required to disrobe; supplying substances for ingestion; and putting an instrument, hand or finger into a body cavity.

Section 38(1) of the Health Practitioner Regulation National Law requires each National Board to develop registration standards for the profession it regulates. These set out the requirements that must be met to become, and remain, registered.[105] The draft standards must be approved by the National Cabinet Health Council.[106] Registration standards must cover five core matters:

- professional indemnity insurance requirements for practitioners
- criminal history of registration applicants, practitioners, and students, including the matters to be considered in deciding whether an individual's criminal history is relevant to the practice of the relevant profession
- continuing professional development requirements for practitioners
- English-language-skills requirements for registration in the relevant profession, if any
- requirements for registration applicants about the nature, extent, period and recency of any experience practising in the relevant profession.[107]

National Boards use accreditation standards when evaluating programs of study relied upon for registration as a practitioner in the relevant profession. Accreditation standards set out how to assess whether a program of study provides students with the requisite knowledge, skills and professional attributes to practise their chosen profession.

The Australian Health Practitioner Regulation Agency explained the accreditation standards:

> Across the 16 health professions regulated under the National Registration and Accreditation Scheme (the National Scheme), the accreditation standards are generally outcome-focused. The accreditation process emphasis is on expected learning outcomes rather than on detailed curriculum content or prescriptive inputs. Programs of study, including their content, are first prepared and/or reviewed by education providers. They are then assessed by the accreditation authorities against accreditation standards to ensure that a graduate meets the relevant learning outcomes and the minimum competencies / standards for practice for the purpose of registration in the relevant health profession.[108]

Section 43 of the Health Practitioner Regulation National Law requires each National Board to decide whether an accreditation function for the relevant profession is to be exercised by an accreditation committee, which is established by the board, or an external accreditation entity, which is an independent organisation. These are described in the Health Practitioner Regulation National Law as 'accreditation authorities'.[109]

A National Board may also develop codes of conduct and guidelines for professions under section 39 of the Health Practitioner Regulation National Law. Under section 41, an approved registration standard and a code of conduct can be used as evidence of what constitutes appropriate professional conduct or practice for the relevant professions.

We received many submissions in support of the need for a registration system for personal care workers.[110] We also received submissions objecting to the means of registration proposed by Counsel Assisting. Of particular note is the critique from Mr Fletcher, who submitted that the Australian Health Practitioner Regulation Agency expresses 'reservations about whether the National Scheme is the right regulatory framework for the regulation of PCWs [personal care workers]'.[111]

Objections to Counsel Assisting's proposal were broadly on the following grounds:

- There is an absence of an existing definition and professional infrastructure for the personal care workforce, which appears to have no current professional capabilities or identifiable body of professional knowledge.[112]
- Personal care workers usually have vocational education and training qualifications, rather than tertiary qualifications.[113]
- The costs to personal care workers, in registration and insurance fees, would be unfair and deter people from working in aged care, and are unlikely to outweigh any associated benefits for the workers themselves.[114]

Mr Martin Warner, from home care provider Home Instead Senior Care, submitted that regulation by the Australian Health Practitioner Regulation Agency 'may be required for residential care where they separate the skills of workers who provide personal care to the domestic and kitchen staff' but:

> would be a complicated and costly system for home care where a large percentage of services provided include combined domestic services, social support along with personal care. It would be unviable in home care to provide a regulated personal care worker to provide only personal care services and then have to provide an unregulated worker to provide domestic services and social support.[115]

The Australian Government submitted that Counsel Assisting's proposal is 'disproportionate and unlikely to be achievable'.[116] We consider that these objections are well-founded. Commissioner Pagone considers that regulation under the National Scheme for the entire personal care workforce would be disproportionate.

Personal care workers perform a wide range of tasks that comprise social, living, personal and health and clinical care. There is no data on what proportion of personal care workers perform only personal, health and clinical care tasks. Nor do we know what proportion of their time is spent on what tasks. We expect that the number and proportion are both likely to increase in coming years with the predicted increasing longevity of older people, and with older people remaining at home in increasing numbers.

The first recommendation of Emeritus Professor Steven Schwartz AM in his 2019 Independent Review of Nursing Education report, commissioned by the Australian Government, was:

> To protect the public, assistants in nursing (whatever their job title) should have mandated education, English language, and probity requirements, which are accredited, assessed and enforced by a robust quality-assurance regime.[117]

We recommend that a registration scheme for the broader personal care workforce be established by 1 July 2022.

Commissioner Pagone considers that, subject to how that registration scheme is established, it is possible that, to protect the public, personal care workers providing predominantly clinical and health care will require a more 'robust quality-assurance regime' as recommended by Professor Schwartz.

For this reason, following the establishment of the national registration scheme for personal care workers, Commissioner Pagone recommends that the Australian Government request that the National Cabinet Health Council determine whether to regulate the occupation of 'personal care worker (health)' or 'assistant in nursing' under the National Scheme, by 1 July 2023.[118]

Commissioner Briggs is very conscious of the long lead times associated with the formation and implementation of National Boards—in the order of three years in this case, according to the Australian Health Practitioner Regulation Agency.[119] Commissioner Briggs considers that the issue of whether 'personal care workers (health)' or 'assistants in nursing' should be registered through the usual registration system for health workers is so important that it cannot be delayed and should be resolved as soon as possible.

Commissioner Briggs therefore recommends that by 1 July 2021, the Australian Health Practitioner Regulation Agency should begin the process of examining whether personal care workers in aged care providing predominantly clinical and health care meet the requirements for registration via the National Scheme. If the Agency finds that they meet the requirements, then Commissioner Briggs considers that registration under the National Scheme would provide the most appropriate registration regime for these important aged care workers. The National Cabinet Health Council would then be in a good position to determine the matter by 1 July 2023, avoiding any further delay.

12.3.5 Mandatory minimum qualifications for personal care workers

We recommend that a Certificate III be the mandatory minimum qualification required for personal care workers in aged care.

Recommendation 78: Mandatory minimum qualification for personal care workers

1. A Certificate III should be the mandatory minimum qualification required for personal care workers performing paid work in aged care.

2. If a Personal Care Worker National Board is established, it should establish an accreditation authority to: **Commissioner Briggs**
   a. develop and review accreditation standards for the mandatory minimum qualification
   b. assess programs of study and education providers against the standards, and
   c. provide advice to the National Board on accreditation functions.

3. The National Board should approve the accredited program of study, and review the need for personal care workers in home care to have specialised skills or competencies.

There is currently no formal industry standard for an entry-level qualification to work as a personal care worker. The most recent statistics available tell us that in 2016, 67% of personal care workers in residential care settings held a relevant Certificate III level qualification, while 23% of personal care workers in residential aged care settings had completed a Certificate IV in Aged Care.[120]

For personal care workers working in home care, 51% had a Certificate III in Aged Care, and 27% had a Certificate III in Home and Community Care. A total of 15% had a Certificate IV in Aged Care or Service Coordination.[121] The groups may overlap, as workers can hold more than one qualification type, so Certificate IV holders may also have a Certificate III.[122]

The Aged Care Workforce Strategy Taskforce proposed that the Aged Services Industry Reference Committee should identify an industry standard to ensure that all care staff are trained and accredited to work in aged care.[123] We discuss the Aged Services Industry Reference Committee further below.

When speaking about personal care workers, Ms Lisa Backhouse, whose late mother was in a residential aged care facility, said:

> they desperately need more training and better qualifications to meet the increasing demands and the complex needs of residents.[124]

Ms Coad said that there should be a mandated minimum qualification to work in aged care that is transferable and recognised across the sector.[125]

Following a coronial inquest into the death of Mr John Reimers, who died in a residential aged care facility, Coroner Jamieson made various recommendations in the interests of public safety. These included a recommendation that:

> State and Federal Governments create a legislative mandate requiring Personal Care Assistants to hold a Certificate III in Community and Aged Care as a minimum qualification before they can secure employment in the aged care sector.[126]

The purpose of a Certificate III qualification is to qualify individuals who apply a broad range of knowledge and skills in varied contexts to undertake skilled work and to provide a pathway for further learning. Graduates of a Certificate III course are expected to have factual, technical, procedural and theoretical knowledge in an area of work and learning.[127]

The coursework for the Certificate III programs most relevant to personal care workers include individualised support, independence and wellbeing, communication, diverse people, legal and ethical considerations, healthy body systems and safe work practices for direct client care, amongst other modules.[128] Having regard to the nature and content of a Certificate III qualification, we consider it is the appropriate minimum qualification level for aged care work. It will be necessary to ensure that coursework and electives are directed to the competencies required for a personal care worker in aged care and are delivered at a nationally consistent standard. The minimum qualification should be the starting point for career-long learning and professional development. Many submitters have indicated support in principle for this approach.[129]

The Australian Government made early submissions to us that it did not support having a minimum qualification requirement mandatory for personal care workers in residential aged care because it may operate as a 'barrier to entry and retention of staff who have the right attitude and aptitude to provide care'.[130] However, the Australian Government has revised its position in more recent submissions, stating:

> The Commonwealth understands the objectives behind the Recommendation that personal care workers undertaking paid work in aged care should be required to hold a mandatory minimum qualification. The Commonwealth supports that proposal noting that a mandatory minimum qualification should not be a barrier to entry. Transitional arrangements, consideration of thin markets and recognition of prior learning and experience will also be needed.[131]

Mr Jason Burton, Head of Dementia Practice and Innovation at Alzheimer's WA, said that 'despite the complexity of providing high quality person centred care to a vulnerable older person, staff are often lacking in the knowledge and skills that are required to provide care outside of a task focused institutional paradigm'.[132] Mr Burton's evidence raises the question of whether home care workers, who are likely to be required to exercise a greater degree of judgment without direct supervision than personal care workers working in residential care, should be required to have a higher qualification. We address this later in the chapter.

Effective recruitment and retention will balance the need for mandatory minimum qualifications with the importance of engaging and retaining kind and compassionate people to work in aged care. We have heard that 'no amount of training produces kind and compassionate people'.[133] Equally, however, attracting the right people to work in aged care must go hand in hand with appropriate training, so it will be necessary to smooth the transition to the new mandatory minimum requirements.

Mandatory minimum training is an essential part of ensuring the provision of high quality aged care and a necessary part of professionalising the aged care workforce.

As submitted by the Australian Nursing and Midwifery Federation, the introduction of a mandatory minimum qualification must have 'appropriate support and transitional provisions'.[134] The Federation submitted that personal care workers should be provided with support to complete the qualification, including reasonable time to enrol, paid study leave, workplace mentoring support and technological supports to complete coursework.[135] We agree.

Other occupations that have made the transition to a regulated profession have been supported by transitional arrangements to support the workforce to meet mandatory requirements.[136] We encourage consideration of transition supports, including:

- a scheme for recognising people who are working toward the Certificate III to obtain conditional or provisional registration
- scope to enable the Certificate III to be obtained by way of on-the-job training
- options for various paths to obtain the qualification, including through apprenticeships and/or traineeships, short courses and micro-credentialing

- recognition of prior experience and learning
- a bridging or transition time for existing aged care workers, with extended time to accommodate those in rural and remote locations without the training facilities nearby
- financial support, through a subsided Certificate III course.

12.3.6 Proficiency in English

The ability of an older person to develop quality relationships with their carers is central to high quality care. Minimum levels of English language proficiency should therefore be part of the registration standard for personal care workers.

The Australian Department of Health submitted that it 'does not support the introduction of any rigid or set minimum levels of English language proficiency'. It submitted that 'introducing set language levels may impose an unnecessary barrier to entry and may create further workforce supply issues'.[137] The Australian Medical Association submitted:

> Workers from CALD [culturally and linguistically diverse] backgrounds should be supported by employers in aged care to further develop and improve their English language skills… Supporting migrant workers in developing their English language skills can provide multiple benefits to aged care consumers…and CALD aged care workers.[138]

We heard that some older people encounter difficulties when engaging with an aged care worker who is not proficient in English.[139] For example, one witness, DI, described a telephone conversation with a care worker about whether DI's mother should be transferred from residential care to hospital. DI said that the care worker's English 'wasn't great, so it was very difficult to have an informed conversation with her'.[140] It is important that there are no misunderstandings in such circumstances.

We acknowledge the value of bilingual and multilingual speakers in aged care, particularly when the languages in which workers are proficient align with those spoken by older people under their care. Personal care workers are an essential part of multi-disciplinary teams providing high quality and safe care. It is vital to the provision of high quality and safe care that personal care workers can communicate effectively with older people, their families and their colleagues. It is also vital that they understand their obligations and responsibilities and those of their employer. Where required, appropriate supports should be provided to assist existing personal care workers to improve their English language competence.

12.4 Educating and training

12.4.1 Review of certificate-based courses

We both agree that the content of all courses affecting delivery of care should be under constant review. Where we differ is the degree to which we should make recommendations about what should be included in this review. Commissioner Pagone makes no prescription and anticipates a comprehensive review undertaken by those with the necessary skills and experience to do so and the flexibility to respond to emerging circumstances, such as the COVID-19 pandemic. Commissioner Briggs raises a number of specific matters for detailed consideration. These reflect the evidence she and Commissioner Tracey heard from February to August of 2019 about dementia care, person-centred care, respite, cultural safety and many other areas of clinical and personal care, as well as the many stories about serious failings in aged care quality and safety that she heard about in community forums around the country. Commissioner Briggs explains these issues under the section on Review of Course Content below, and recommends that the review should consider in detail the matters set out in her recommendation.

Recommendation 79: Review of certificate-based courses for aged care

1. By January 2022, the Aged Care Services Industry Reference Committee, working with the Australian Government Human Services Skills Organisation as required, should:
   a. review the need for specialist aged care Certificate III and IV courses, and
   b. regularly review the content of the Certificate III and IV courses and consider if any additional units of competency should be included.

Commissioner Briggs

2. As part of any such review, the Aged Services Industry Reference Committee, working with the Australian Government Human Services Skills Organisation as required, should consider if any of the following additional units of competency should be included as core competencies:
   a. personal care modules, including trauma-informed care, cultural safety, mental health, physical health status, wound care, oral health, palliative care, falls prevention, first aid, monitoring medication and dysphagia management
   b. quality of life and wellbeing, including the use of technology, interventions for older people at risk, and recognising and responding to crisis situations.

Although significant numbers of personal care workers and home care workers hold a Certificate III qualification, we have heard about inconsistency in the quality, delivery and duration of the courses leading to that qualification.[141] We have also heard about the impact of inconsistent governance in the registered training organisation sector.[142]

Responsibility for vocational education and training is shared by the Australian Government, the State and Territory Governments, and industry. The States and Territories are largely responsible for the delivery and operation of vocational education and training in their own jurisdictions, including the funding of registered training organisations.[143]

The Australian Skills Quality Authority registers training providers, monitors compliance with national standards, and investigates quality concerns for all States and Territories that have referred their powers. In Victoria and Western Australia, the Australian Skills Quality Authority only regulates providers that enrol international students or are multi-jurisdictional providers. The remaining registered training organisations are registered with either the Victorian Registration and Qualifications Authority or the Training Accreditation Council, Western Australia.[144]

The Australian Industry and Skills Committee comprises government-appointed industry representatives from the Australian Government and each State and Territory. It advises on policy directions and decision-making in the national training system. It is also responsible for coordinating the development of training packages. A training package is a set of nationally endorsed standards and qualifications for recognising and assessing the skills of workers in a specific industry, industry sector or enterprise. Training packages are developed by Industry Reference Committees, working with Skill Service Organisations, to ensure that industry skill requirements are reflected in the national training system.[145]

The most relevant Industry Reference Committees for the aged care sector are the Aged Services Industry Reference Committee and the Enrolled Nursing Industry Reference Committee. They are supported by SkillsIQ Limited, a Skills Service Organisation.[146]

The Aged Services Industry Reference Committee's role was to revisit national competency standards and ensure that the national training system and higher education can address the current and future competencies and skill requirements of both new people entering the sector and existing employees needing to upskill.[147] The Aged Services Industry Reference Committee considered a standalone aged care qualification. However, following feedback from the Disability Support Industry Reference Committee, it accepted that a single qualification with core Units of Competency common to both sectors and specialised elective streams for aged care and disability support respectively was more appropriate.[148]

Pending a full review, the Aged Services Industry Reference Committee made minor changes to the elective requirements for the Certificate III in Individual Support (Ageing), and an amendment to the elective units to include a module on infection prevention and control. The Committee is working with the Disability Support Industry Reference Committee and SkillsIQ to update the existing Certificate III in Individual Support, Certificate IV in Ageing Support and Certificate IV in Disability qualifications and units of competency.[149]

These are positive steps, but progress has been too slow. We consider that this is, at least in part, because of the context in which the Aged Services Industry Reference Committee operates.[150]

In 2019, the Hon Stephen Joyce, in his review, made recommendations for reform to the vocational education and training sector.[151] In July 2020, the Australian Government and the State and Territory Governments signed the Heads of Agreement for Skills Reform, which sets out a commitment to work together on a National Skills Agreement. The Heads of Agreement states that the parties commit to:

> the following immediate reforms that will strengthen the training system:
>
> - Simplifying, rationalising and streamlining national VET qualifications across industry occupations and the Australian Qualifications Framework (AQF), and introducing improved industry engagement arrangements.
> - Strengthening quality standards, building Registered Training Organisations (RTO) capacity and capability for continuous improvements and developing a VET workforce quality strategy.[152]

On 7 August 2020, the National Cabinet established the Skills National Cabinet Reform Committee to 'support the ongoing reforms to vocational education and training outlined in the Heads of Agreement'.[153]

We welcome the proposed reforms, particularly the strengthening of quality standards. These developments should enable the Aged Services Industry Reference Committee, working with the Human Services Skills Organisation as may be required, to progress its work on reviewing the Certificate III and IV to ensure that they equip personal care workers with the skills and knowledge needed for future aged care needs.

Review of Course Content | Commissioner Briggs

Apart from these positive steps, progress has been slow. The Certificate III has not been changed substantively since 2015, despite aged care being a constantly changing care environment. Our recommendations for the future aged care system anticipate smaller accommodation models to deliver subacute care, high-end dementia care and palliative care. The projected growth in home-based care will also require personal care workers to have a broader base of knowledge, skills and competencies. As things currently stand, home care workers often do not have the availability of other resources, peer support or supervision, accessible at all times. Home care workers need to be able to observe the situation and understand when they need to hand it off to somebody else.[154] Home care workers require a level of confidence to deal with new, challenging and unpredictable situations while operating at a distance from supervisors and managers.[155] This may require additional skills, knowledge, and competencies.

The Aged Care Workforce Council, in conjunction with the Australian and State and Territory Governments, should examine the required skills, knowledge and competencies that personal care workers of the future will need. People graduating with Certificate III and IV courses in 2024 should be equipped with a broader base of skills, competencies and knowledge, aligned to specific requirements of residential aged care, home and community-based care or respite, restorative care and palliative care.

There are clear signposts for content development of Certificate III and IV courses.[156] As the Aged Care Workforce Taskforce concluded, there are gaps in knowledge of aged care workers for hydration and nutrition, oral health, diversity, mental health, medication management, dementia, end-of-life care, communication, assisted decision-making, diversional therapy, person-centred care and client relationships.[157]

I recommend that the Aged Care Services Industry Reference Committee should consider whether to make the following units of competency core competencies as part of its first review of the contents of both Certificate III and Certificate IV course for individual support and for home care workers:

- personal care modules, including trauma-informed care, cultural safety, physical health status mental health, wound care, oral health, palliative care, falls prevention, first aid, monitoring medication and dysphagia management
- quality of life and wellbeing, including the use of technology, interventions for older people at risk and recognising and responding to crisis situations.

The Allied Health Professions Association submitted that 'greater consistency in the curriculum of Certificate III courses would reduce uncertainty about the baseline knowledge of personal care workers for employers and the health professionals working with them'.[158] I agree. Accordingly, I recommend that additional core units of competency should be integrated into the existing Certificate III and Certificate IV courses.

These baseline skills will need to be supplemented with on-the-job learning and continuing professional development of registered personal care workers and all other aged care workers.

12.4.2 Dementia and palliative care training for workers

We recognise that dementia is the second leading cause of death in Australia and that it is estimated that it will be the leading cause of death in Australia in 'around five years'.[159]

Recommendation 80: Dementia and palliative care training for workers

By 1 July 2022, the Australian Government should implement as a condition of approval of aged care providers, that all workers engaged by providers who are involved in direct contact with people seeking or receiving services in the aged care system undertake regular training about dementia care and palliative care.

Dementia care

As many as 70% of people in residential aged care could be living with dementia.[160] We have been told that many nurses and general practitioners do not have a full understanding of the symptoms and needs of people living with dementia.[161] This was supported by evidence in the case studies.[162]

The Wicking Dementia Research and Education Centre submitted that all professional health degrees should incorporate core dementia knowledge in their undergraduate studies at an agreed minimum level, higher than is currently provided in many disciplines / programs.[163]

In Chapter 3, which deals with quality and safety of aged care, we explain why high quality dementia care needs to become part of the core business of aged care providers. While this is presently of greater need in the residential aged care sector, over time it will become more important in home care. We consider that the upskilling of the care workforce is an important component of this change.

Palliative care

A number of the case studies raised concerns about the quality of palliative care provided in residential aged care.[164]

While a unit on palliative care is currently part of the Certificate III in Individual Support training package, it is an elective rather than a core unit.[165]

We heard that residential aged care staff members tend to be under-skilled and under-educated in palliative care, and that there is a general lack of suitably qualified staff to manage palliative care adequately.[166] Professor Jennifer Tieman, Director of the Research Centre in Palliative Care, Death and Dying at Flinders University, said that aged care workers should be able to identify the need for palliative care and manage both expected and unexpected issues in the process.[167]

Palliative care, like dementia care, should be part of the core business of approved providers. This will be achieved by ensuring that care workers have the necessary skills and keep up with changes in the provision of palliative care.

12.4.3 Improving the skills of the existing workforce

Aged care workers need to have good quality, and easily accessible, ongoing training and professional development opportunities available to them. Such training and professional development opportunities must reflect the contemporary and future care needs of older people.

Recommendation 81: Ongoing professional development of the aged care workforce

From 1 July 2021, the Australian Government and the States and Territories, through the Skills National Cabinet Reform Committee, should fast-track the development by the Australian Industry and Skills Committee of accredited, nationally recognised short courses, skills sets and micro-credentials for the aged care workforce. The courses should be designed to:

a. improve opportunities for learning and professional development, and

b. upgrade the skills, knowledge and capabilities of the existing workforce.

The Australian Nursing and Midwifery Federation submitted that:

> providers must offer continuing professional development and education opportunities for existing staff. This area requires investment from providers to ensure workforce are continually upgrading and refreshing skills and knowledge.[168]

Although not totally in support of a mandatory minimum qualification, the Australian Government 'strongly encourages aged care providers to invest in the training and qualifications of their staff on an ongoing basis'.[169]

Because the Australian Government contributes 80% of the cost of aged care, with the remaining 20% paid by older people receiving care, we consider that the Australian Government should build into the base aged care subsidies a standard amount per employee to support ongoing training and development for existing and new personal care workers. This is covered in the Funding chapters.

Two of the key features of the recommended registration scheme outlined earlier in this chapter are requirements for a mandatory minimum qualification and for ongoing training and continuing professional development. As such, training will become critical for:

- unqualified existing aged care workers working toward a mandatory minimum qualification requirement during a transition period
- qualified existing aged care workers who may require additional training to address any identified gap in their skills or knowledge
- all personal care workers, and health professionals, to satisfy their continuing professional development obligations.

Approved providers must support the aged care workforce to access ongoing training through financial assistance to cover or part-cover the training, paid leave to attend training, and promotion of an organisational culture that values skills development.

It is not always the case, however, that courses are available locally or that workers are able to attend courses in person due to work and family commitments. It is much easier for them if short courses are available and delivered electronically.

It is very important that all aged care workers are supported as far as is possible to engage in quality training and development, and that these arrangements expand rapidly under the auspices of the Australian Industry and Skills Committee and through accredited courses, skill sets and micro-credentials.

Micro-credentials are an ideal means for aged care workers to undertake ongoing professional development. As an example, the Understanding Dementia course offered by the Wicking Dementia Research and Education Centre provides a baseline understanding of dementia.[170]

The NSW Productivity Green Paper, issued in 2020, explained that micro-credentials are units of competency designed to develop specific skills in an efficient way and can provide skills that cannot be gained through traditional vocational education and training qualification pathways.[171] They are certifications of assessed learning that are additional, alternative and complementary to, or a component part of, a formal qualification. While traditional qualifications usually represent a suite of skills and knowledge, micro-credentials represent specific and usually quite narrow skill sets. They can provide more efficient and targeted delivery of skills, and skills that traditional vocational education and training pathways do not.

Support for the use of micro-credentials as a workforce development tool is strong within businesses, students and governments. According to the Green Paper, micro-credentials will become prominent in training and employment markets as a preferred method of delivering, assessing and certifying the skills and training of workers. It is important that the aged care sector adopts such an approach.[172]

The 2019 Joyce Review of Australia's vocational education and training system and the 2019 Noonan Review of the Australian Qualifications Framework supported a greater use of micro-credentials and skill sets.[173] The Australian Government submitted that important skills 'could be gained through micro-credentials', stating:

> The flexibility of micro-credentials would mitigate against formal qualifications acting as a barrier to entry[174]

High quality and targeted short courses, including micro-credentials, are a suitable way to address skills gaps, satisfy continuing professional development requirements or enable people to gradually work towards a formal qualification in the new aged care system. They can enable new and existing employees to build specific skills of high relevance to aged care work.

In the context of the COVID-19 pandemic, the Australian and State and Territory Governments have fostered the development of short courses to address immediate skills needs and skills upgrades on infection control and other aspects of managing the pandemic.

On 7 August 2020, the National Cabinet established the Skills National Cabinet Reform Committee.[175] Members of the Skills National Cabinet Reform Committee had, in July 2020, signed a heads of agreement on skills reform, which sets out a commitment to work together on a National Skills Agreement. One of the agreed priorities is:

> Developing and funding nationally accredited micro-credentials and individual skill sets, in addition to full qualifications, and supporting lifelong learning through an integrated tertiary education system.[176]

This work should be fast-tracked by the Skills National Cabinet Reform Committee. There should be flexible funding and rapid approval and accreditation processes for short courses and micro-credentials that will support the development of the aged care workforce. In turn, this will provide opportunities for flexible learning and development opportunities for all aged care workers to enable them to upgrade their skills and knowledge.

12.4.4 Review of health professions' undergraduate curricula

We recognise that the changing profile of health and ageing within Australia presents challenges and opportunities for both undergraduate and postgraduate medical, nursing and allied health training. Dr John Maddison, Geriatrician and Clinical Pharmacologist at SA Health and President Elect of the Australian and New Zealand Society for Geriatric Medicine, told us that 'a paradigm shift is required, where curricula are developed to equip the health professionals of the future with the skills and attitudes they need for their core patient groups of tomorrow'.[177]

Recommendation 82: Review of health professions' undergraduate curricula

In conducting their regular scheduled reviews of accreditation standards, the relevant accreditation authorities should consider any changes to the knowledge, skills and professional attributes of health professionals so that the care needs of older people are met.

Dr Maddison reminded us that the vast majority of older people who access geriatric services do so through primary and acute health care services.[178]

Professor James Vickers, Dean of Medicine, University of Tasmania, and Director, Wicking Dementia Research and Education Centre, warned that the current model of teaching medical students to attend to one thing will not be enough 'when it's an older population who has got multiple conditions'.[179] Professor Vickers said that he would 'love to see more on the curricula related to older people, multi-morbidity, frailty, dementia'.[180]

The Australian Nursing and Midwifery Federation submitted that 'it is critical to improve overall knowledge of the conditions of ageing, dementia and care delivery'. It agreed that:

> there is scope to improve the theory and practice on geriatric medicine and gerontology care that could be incorporated into the EN [enrolled nurse] and RN [registered nurse] Accreditation Standards.[181]

At the direction of the Enrolled Nursing Industry Reference Committee, SkillsIQ is undertaking a review of the skills needs of enrolled nurses to inform potential changes to the current Diploma and Advanced Diploma of Nursing.[182] This is in response to skills shortfalls identified by the sector in relation to paediatrics, gerontology, palliative care and the administration of medications.

The Council of Deans of Nursing proposed dedicated or embedded content on gerontology in the undergraduate nursing curriculum.[183]

Mr Fletcher proposed that as part of regular scheduled reviews of accreditation standards, for relevant professions regulated under the National Registration and Accreditation Scheme, accreditation bodies consider whether any changes to the knowledge skills and professional attributes are required to meet the care needs of older people.[184]

We accept that this is an effective way to ensure that future graduates have the education and knowledge to meet the care needs of older people. Accordingly, we recommend that the undergraduate curricula be reviewed by the various accreditation authorities, national boards, professional associations and accreditation bodies for nursing, medicine, audiology, optometry, dietetics, dental practice, psychology, social work, occupational therapy, osteopathy, podiatry, physiotherapy and speech therapy, to ensure that the care needs of older people are met.

12.4.5 Teaching aged care services

Clinical placements are an important part of quality education programs for health care professionals. They enable students to practice their skills and learn through real life experiences, supported by other health professionals. Aged care offers very few such experiences. This limits the number of professionals with the experience and interest to work in aged care because they are not presented with an opportunity to do so during their undergraduate training.

Recommendation 83: Funding for teaching aged care programs

By 1 July 2023, the Australian Government should fund teaching aged care programs for delivery to students in both residential aged care and home care settings. The teaching aged care programs should have designated catchment areas and should:

- **a. collaborate with educational institutions and research entities**
- **b. facilitate clinical placements for university and vocational education and training sector students**
- **c. act as a centre of research and training for aged care in a catchment area**
- **d. act as a hub for approved providers in a particular region and support training of aged care workers from surrounding aged care services.**

Associate Professor Stephen Macfarlane, Head of Clinical Services at the Dementia Centre, HammondCare, described in evidence how he came to be working in aged care. He said that he did not enter medical school with 'a burning ambition to become a geriatric psychiatrist'. He had no idea what the speciality involved and no interest in it until he did a rotation in aged psychiatry during his training. At that point, he said, he 'fell in love with it'. In Associate Professor Macfarlane's view, if there are more opportunities for exposure to aged care for trainee nurses, this will have flow-on effects for recruiting passionate, qualified nurses into the sector.[185] This evidence illustrates how important quality placements are to encourage passion and interest for careers in aged care.

Professor Vickers highlighted the danger of negative attitudes resulting from poorly managed clinical placement programs which can mean that graduates would 'run a mile' from the aged care sector.[186] Adjunct Professor Kylie Ward, Chief Executive Officer of the Australian College of Nursing, told us that 'education providers and students report that the quality of supervision of students by an RN [registered nurse] at an aged care facility is sometimes problematic particularly when there is no RN on duty or one RN running the whole facility'.[187] She explained that 'Clinical supervision, support and role modelling by experienced RNs [registered nurses] is critical for a successful and valued clinical placement'.[188] This underscores the importance of our recommendation later in this chapter for a continuous nurse presence in aged care.

Dr Kate Barnett OAM, Managing Director of Stand Out Report, emphasised the importance of students engaging in a structured program of clinical education, rather than merely shadowing a staff member otherwise going about their normal duties.[189] A study of paramedic clinical placements in residential aged care facilities found that barriers to learning include a 'lack of clarity of placement structure, inadequate clinical liaison support, and limited contact with residents and staff'.[190]

Dr Barnett pointed to the need for a dedicated person within a service to design a program of education and work with educational institutions:

> if you haven't got resources dedicated to someone designing a program of education, working with VET [vocational, education and training sector] providers and higher education providers to tailor that to their course learning goals, having added to that a commitment to people being trained in supervision and having some backfill, so that they've got time to support students, it's most unlikely it will happen.
>
> …
>
> And if you have got to choose between a provision of care and designing a course for students, it's pretty easy to work out what your priorities will have to be…[191]

The Teaching and Research Aged Care Services program ran in Australia from 2012 to 2015. The program was based on the 'teaching nursing home' model operating in Scandinavian countries, the United States and Canada.[192] It also drew on the well-established teaching hospitals program in the Australian health sector. The teaching nursing home model involves strategic partnerships between aged care providers, educators and researchers, providing an 'opportunity for the aged care workforce to be trained in a setting designed to meet the needs of older people'.[193]

The program had the overarching goals of:

> (i) Increased involvement for education and training providers in ageing and aged care research that is based on clinical experience.
>
> (ii) Increased involvement for aged care providers in research and clinical practices that enhance quality of care.
>
> (iii) Enhanced learning opportunities for students based on clinical experience with a TRACS [Teaching Research and Aged Care Services] affiliation.
>
> (iv) Improved quality of care for aged care consumers and their families.[194]

Dr Barnett, who played a significant role in both the design and evaluation of the program, told us that students who participated in it experienced a change in attitude towards working in the aged care sector on 'statistically significant levels'.[195] The involvement of residents in teaching aged care programs can also have significant benefits for resident wellbeing, providing purpose and increasing social interactions for residents.[196]

When appropriately funded and resourced, teaching aged care services can improve standards within the workforce and make it easier to recruit and retain workers.[197] The environment enables interdisciplinary teaching experiences, improves student knowledge and attitudes towards aged care, and allows for professional development of staff members by providing roles as student mentors.[198]

We contemplate that participation by providers in teaching aged care programs will be voluntary. In that context, we note that the obligations of a provider when providing teaching programs will be different to the obligations the provider has in its provision of aged care services. Professor Vickers explained that one of the reasons why teaching hospitals are 'really great places' is because:

> they do have medical students, and medical students have this way of keeping the health professionals and the other doctors on their toes, because they don't necessarily want to be caught out on a particular clinical scenario by the medical student.[199]

We see this same approach applying in the future aged care system. It will be good for both students and workers.

Professor Andrew Robinson, Professor Emeritus at the Wicking Dementia Research and Education Centre, stated that a successful teaching nursing home program requires a 'massive change' for universities as well as approved providers, along with a 'massive reallocation of resources and…interest'.[200]

The Australian Government should commit recurring and sufficient funding for a teaching aged care program. It will be a worthwhile investment. The evidence shows its potential for positive impact on the aged care workforce.[201] The teaching aged care program should operate in both home and residential care settings.

The teaching aged care program should be based on partnerships between aged care providers and one or more education providers, whether universities or registered training organisations. This will make the program well placed not only to build the aged care workforce, by way of placements and education, but also to support research, research translation and innovation. There is an opportunity for providers that participate to become better in practice and to be innovative centres of teaching and research excellence.

The teaching aged care program should operate across Australia. This model will allow for information to be shared by approved providers operating as a 'hub', teaching aged care services and developing workforce learning programs which can then be initiated with other services. This will provide particular benefit to approved providers in rural and remote areas.[202]

Commissioner Briggs considers that there should be at least 31 teaching aged care services across Australia—one for every primary health network. Each centre would be different. The vision is for a network of collaborations between aged care and education / research providers, with the flexibility to include a range of projects that reflect the strengths of the collaborating partners. Each centre would have the flexibility to focus on local issues and to adopt a tailored approach to suit the local environment. Each centre would create relationships with primary health networks, local health networks, other health services and other aged care provides within the primary health network to share research, communicate insights and experiences, learnings and ideas, and to create local networks. Commissioner Pagone does not necessarily dissent, but is unable to form a view on the material available to him as to whether 31 teaching and care services across Australia should be established.

We also suggest that the Australian Government examine the Norwegian experience of teaching nursing homes program that focus on aged care for the Indigenous Sami people to see what lessons can be drawn for improving the quality of aged care for Aboriginal and Torres Strait Islander people.[203]

12.5 Improving pay for the aged care workforce

A wages gap exists between aged care workers and workers performing equivalent functions in the acute health sector.[204] Successive governments have made several failed attempts to address that gap by providing additional funds to providers in the hope that these funds would be passed on to aged care workers as increased wages.[205] For this reason, while our recommendations in our chapts about the funding of aged care will, if implemented, see substantial increases in the subsidies received by providers, we consider that merely increasing subsidies without more is unlikely to translate into higher wages.

In 2018, the Aged Care Workforce Strategy Taskforce recommended that the 'industry develop a strategy to support the transition of personal care workers and nurses to pay rates that better reflect their value and contribution to delivering care outcomes'.[206] The Taskforce considered that this, and its other 'strategic actions,' could be 'executed in one to three years'.[207]

Wage increases have flowed as a result of the annual award reviews by the Fair Work Commission, and there have been some minor improvements to penalty rates as a result of the four yearly review of the *Aged Care Award 2010* by the Fair Work Commission in 2019.[208] But, otherwise, there has been no discernible increase in aged care wage rates in the more than two and a half years since the Taskforce report was published. The Taskforce's proposal of a sector-led process leading to substantial increases in aged care wages rates seems to have limited prospects of success.

In our view, providers, unions and the Australian Government must work together to improve pay for aged care workers. There are two parts to our proposed recommendations on this topic. The first is a work value case and equal remuneration application to the Fair Work Commission that would ask the Commission to examine the terms and conditions in the relevant awards. If successful, this will increase the wages of personal care workers and nurses in both residential and home care. The second is to make wage increases an explicit policy objective of the aged care funding system.

12.5.1 Applications to the Fair Work Commission

Recommendation 84: Increases in award wages

Employee organisations entitled to represent the industrial interests of aged care employees covered by the *Aged Care Award 2010*, the *Social, Community, Home Care and Disability Services Industry Award 2010* and the *Nurses Award 2010* should collaborate with the Australian Government and employers and apply to vary wage rates in those awards to:

a. reflect the work value of aged care employees in accordance with section 158 of the *Fair Work Act 2009* (Cth), and/or

b. seek to ensure equal remuneration for men and women workers for work of equal or comparable value in accordance with section 302 of the *Fair Work Act 2009* (Cth).

In 2011, the Productivity Commission considered that the applicable awards may be an 'important mechanism by which fair and competitive wages are determined'.[209] Although much has changed since 2011, this remains the case.

The Fair Work Commission is empowered to make a determination varying modern award minimum wages if it is satisfied that the variation is 'justified by work value reasons' and such a determination outside of the system of annual wage reviews is necessary to 'achieve the modern awards objective'.[210]

Section 157(2A) of the *Fair Work Act 2009* (Cth) states:

> work value reasons are reasons justifying the amount that employees should be paid for doing a particular kind or work, being reasons related to any of the following:
>
> (a) the nature of the work;
>
> (b) the level of skill or responsibility involved in doing the work;
>
> (c) the conditions under which work is done.

The 'modern awards objective' requires the Fair Work Commission to ensure that modern awards 'provide a fair and relevant minimum safety net of terms and conditions' that takes into account a number of factors, including 'the principle of equal remuneration for work of equal or comparable value'.[211]

In its 2015 *Equal Remuneration Decision*, the Fair Work Commission indicated that any claim to increase modern award minimum wages based on the proposition that the existing wage rates are the product of a gendered undervaluation of the relevant work can be the subject of an application under sections 156(3) or 157(2) of the Fair Work Act.[212] It may even be possible to pursue parallel claims for an equal remuneration order and work value adjustments in the same proceeding.[213]

More recently, in its four-yearly review of the *Aged Care Award 2010*, the Fair Work Commission stated that if United Voice, which represents many aged care personal care workers, was contending that 'the minimum wages rates in this award undervalue the work to which they apply for gender-related reasons then it should make such an application'.[214] There is an urgent need for such a review. We return to this issue shortly.

Professor Andrew Stewart, John Bray Professor of Law, Adelaide Law School, University of Adelaide, stated that, historically, claims for a work value adjustment required the tribunal to be satisfied that there has been a change in the nature of the work, the skill and responsibility required or the conditions of the work.[215] However, given that there is no such requirement in the current legislation, establishing undervaluation of itself may suffice.[216]

Variations to awards for work value reasons may be made on the Fair Work Commission's own initiative or on the application of an employee or an employer covered by the relevant award or a relevant trade union or employer association.[217] The Fair Work Commission must be convinced, on the evidence before it, that such a variation is *necessary* and not merely *desirable* 'to achieve the modern awards objective'.[218]

While the Fair Work Commission would exercise its independent discretion if any such application was made, on the extensive evidence before this inquiry about the work performed by personal care workers and nurses in both home care and residential care, we consider that all three of the section 157(2A) reasons may well justify an across-the-board increase in the minimum pay rates under the applicable awards. There is also a strong argument for parity between residential care workers working under the *Aged Care Award 2010* and social and community services workers who were awarded a significant pay increase as a result of the Equal Remuneration Order made by Fair Work Australia in 2012.[219]

Success is not assured. Ms Smith, from United Voice, explained that:

> In our experience it is extremely difficult to make substantial changes to an Award. Awards operate as a safety net and are a low base. The Fair Work Commission in our view is reluctant to make radical changes which are what would be required for substantial movement to these Awards.[220]

The case will need to be well argued and based on cogent evidence.

The Equal Remuneration Case for social and community services workers suggests that the chances of success in such a case are significantly increased if the Fair Work Commission is presented with an agreed position involving unions, employers and the principal funder, the Australian Government.[221] As Professor Stewart stated:

> If the Commonwealth were willing to fund any increases in labour costs, that would not just improve the chances of turning a contested application into one by consent. It would remove an obvious reason for the FWC [Fair Work Commission] to be concerned about agreeing to an improvement in pay or other entitlements.[222]

The reconstituted Aged Care Workforce Council will be well placed to encourage this cooperative approach.[223] We see this as an important aspect of its future remit and it is why we recommend an increase in the number of its members who represent the workforce.

Any such application should not be confined to the *Aged Care Award 2010* because that award only applies to the residential aged care sector. Home care workers also need improved pay. Employed aged care workers are entitled to the minimum wages prescribed by the *Social, Community, Home Care and Disability Services Industry Award 2010*. The classifications set out in Schedule E of that Award should also be the subject of the proposed work value and or equal remuneration application.

Nurses working in aged care should also not be excluded from this process. We accept the impact of a successful case may be less for nurses, because there are fewer award-reliant nurses compared to personal care workers. However, section 206(2) of the Fair Work Act has the effect of incorporating into an agreement a relevant award rate that exceeds the agreement rate.[224] Section 306 of the Fair Work Act has a similar effect where there is a conflict between an equal remuneration order and an Award term.

Action by the Health Services Union

In November 2020, the Health Services Union and four workers applied to vary the *Aged Care Award 2010*.[225] The applicants sought a 25% pay increase for all classification levels covered by the Award, and a variation to the classification structure in Schedule B of the Award to provide for an additional pay level for personal care workers who have undertaken specialised training in a specific area of care and use those skills.

The applicants sought a variation to the Award on the basis that the current rates 'do not reflect any recent (or possibly any) assessment' of wages by reference to the three factors listed in section 157(2A) of the Fair Work Act and 'significantly undervalue' the work performed by aged care workers.[226] The applicants submitted that a variation of the Award is necessary to achieve the modern award and minimum wages objectives.[227] Common factors listed to support the claim include: the increasing requirement for formal qualifications and additional formal specialised training of classes of workers covered by the Award; the increased prevalence of higher acuity residents; substantial changes to the model and philosophy of care, including the shift to the provision of resident choice-centred care; and increased use and implementation of technology in aged care facilities. At the date of writing, the application had not been determined by the Fair Work Commission.

12.5.2 Improved remuneration a policy goal for price setter

Recommendation 85: Improved remuneration for aged care workers

In setting prices for aged care, the Pricing Authority should take into account the need to deliver high quality and safe care, and the need to attract sufficient staff with the appropriate skills to the sector, noting that relative remuneration levels are an important driver of employment choice.

In 2011, the Productivity Commission proposed a process by which aged care prices should be assessed. It recommended prices be set independently and take account of 'the need to pay fair and competitive wages to nursing and other care staff delivering aged care services'.[228]

Mr James Downie, Chief Executive Officer, Independent Hospital Pricing Authority, told us that 'if there was a clear policy initiative to increase aged care wages by a defined quantum, then a casemix funding model could be adjusted prospectively to ensure that wage increases are accounted for in the price' paid by the Australian Government for aged care services.[229] Professor Eagar said that 'whatever recommendations are adopted in relation to staffing need to feed into the costing process. The costing process then determines the price in the following year'.[230]

In Chapter 2, we recommend that the Pricing Authority should set prices for high quality and safe aged care. We consider that an important part of that work will be to price aged care at a level that enables workers to be remunerated at a level that reflects what similar workers are paid in comparable sectors, such as health and disability.

12.6 Getting staffing right—residential care

There are many ingredients that enable the provision of high quality and safe aged care, but it cannot be achieved without the sector having enough staff with the skills and time to care. Adequate staffing numbers with the right skills are a necessary but not sufficient piece of that puzzle. According to a research study we commissioned, 57.6% of Australian living in residential aged care receive care 'in aged care homes that have unacceptable levels of staffing'.[231] This is entirely unacceptable and partly explains the extent of substandard care that we describe in Volume 2.

Recommendation 86: Minimum staff time standard for residential care

1. The Australian Government should require approved providers of residential aged care facilities to meet a minimum staff time quality and safety standard. This requirement should take the form of a quality and safety standard for residential aged care. The minimum staff time standard should allow approved providers to select the appropriate skills mix for delivering high quality care in accordance with their model of care.
2. From 1 July 2022, the minimum staff time standard should require approved providers to engage registered nurses, enrolled nurses, and personal care workers for at least 200 minutes per resident per day for the average resident, with at least 40 minutes of that staff time provided by a registered nurse.
3. In addition, from 1 July 2022, the minimum staff time standard should require at least one registered nurse on site per residential aged care facility for the morning and afternoon shifts (16 hours per day).
4. From 1 July 2024, the minimum staff time standard should increase to require approved providers to engage registered nurses, enrolled nurses, and personal care workers for the average resident for at least 215 minutes per resident per day for the average resident, with at least 44 minutes of that staff time provided by a registered nurse.
5. In addition, from 1 July 2024, the minimum staff time standard should require at least one registered nurse on site per residential aged care facility at all times.
6. The minimum staff time standard should be linked to the casemix-adjusted activity based funding model for residential aged care facilities. This means that approved providers with a higher than average proportion of high needs residents would be required to engage additional staff, and vice versa.
7. Approved providers should be able to apply to the System Governor for an exemption from the quality and safety standard relating to staff skills mix, but not the standard relating to numbers of staff. Any exemption should be granted for a limited time, and details of the exemption should be published on My Aged Care. The grounds for granting an exemption should include:
    a. specific purpose residential aged care facilities, such as specialist homeless facilities, where the profile of the residents is such that it may be appropriate to substitute a registered nurse with another qualified health professional
    b. residential aged care facilities that are co-located with a health service, such as Multi-Purpose Services, where registered and enrolled nurses are present at the co-located health service
    c. regional, rural and remote residential aged care facilities, where the approved provider can demonstrate it has been unable to recruit sufficient numbers of staff with the requisite skills, and

d. **residential aged care facilities where an alternative skills mix is being trialled and it would be appropriate to substitute a registered nurse with another qualified health professional. There should be a requirement for any such trial to be comprehensively evaluated and publicly reported.**

8. **The Australian Commission on Safety and Quality in Health and Aged Care should review and update this standard as appropriate. At a minimum, this should occur in line with significant revisions of the casemix classification for residential aged care facilities, or at least every five years.**

12.6.1 Why staffing levels matter

Professor Charlene Harrington, Professor Emeritus of Sociology and Nursing at the University of California, San Francisco, and an elected fellow in the American Academy of Nursing and the National Academies of Medicine, told us that research shows overall staffing levels in aged care are linked to quality of care, and that registered nurse numbers are particularly important.[232] This accords with a great deal of other evidence.[233]

Professor Harrington stated that 'the most important policy measure for ensuring appropriate staffing levels is to adopt a regulatory requirement that establishes a minimum staffing level'.[234]

An analysis of nursing homes in the United States found that higher 'nurse' staffing levels were associated with lower rates of COVID-19 cases in residential aged care facilities. The study found that while 'nurse' staffing levels influenced the rate of COVID-19 cases, performance on health inspections and care quality measures did not.[235] We note that the term 'nursing staff' when used in American studies refers to all aged care workers, including registered nurses as well as personal care workers.[236]

In her exploration of the relationship between job quality and quality of care in aged care settings in Australia and other countries, Professor Sara Charlesworth, Professor of Gender, Work & Regulation in the School of Management, RMIT University, found that in the aged care sector:

> Having the 'time to care' emerged as a crucial job quality issue for workers, who clearly want to respond to the individual needs of clients and residents.[237]

Professor Harrington emphasised that inadequate staffing levels and inadequate time to provide care create a vicious cycle of poor outcomes for staff and residents. She explained that missed care can lead to staff 'burnout', low job satisfaction and a high turnover of staff. Quality of care, in turn, continues to suffer.[238]

The Australian Government cautioned that a minimum staffing requirement in residential care 'could stifle innovation and create rigidity in individual provider approaches to workforce staffing which would not necessarily lead to more positive outcomes for care recipients'.[239] However, more recently, the Australian Government accepted that there is 'universal agreement that adequate staffing is a prerequisite for high quality aged care'.[240] Many people who made submissions, including aged care providers, health professional peak bodies and trade unions, expressed strong support for a minimum staffing level.[241]

The status quo is unacceptable. The current requirements under the *Aged Care Act 1997* (Cth), where providers can judge for themselves what staffing numbers are 'adequate' and what skill levels are 'appropriate', have not prevented inadequate staffing nor substandard care and may have in fact have encouraged those outcomes.[242]

Not only will more staff improve the quality and safety of care, more staff will create a safer work environment and, in turn, improve the attraction and retention of workers.

12.6.2 Skills mix

Reforms to the aged care sector in 1997 effectively 'enabled cost savings through replacement of nursing staff with care workers', resulting in compromised care for residents.[243] In 2011, the Productivity Commission identified that the largely unregulated aged care sector provided an incentive to aged care providers to replace higher paid and skilled nurses with lower paid and semi-skilled personal care workers.[244] This trend has continued since 2011, as reported by the 2016 National Aged Care Workforce Census and Survey.[245]

This trend is the opposite of what should have occurred. While there has been an erosion in the capacity and capability of the residential aged care workforce, the needs of people in their care have increased. Reflecting on these trends, Professor Eagar said that:

> when people describe residential aged care as a person's home, it is somehow implying that it's a lifestyle choice rather than people are going into residential aged care now because they are so frail or have other significant care needs that they can no longer be at home. The population currently in care needs more clinical skills, not less.[246]

12.6.3 The value of a continuous nurse presence

We recommend that a residential aged care staffing standard include a requirement for a registered nurse to be on site 24 hours a day, seven days a week at every residential aged care facility to provide, or direct the provision of, clinical care.

The Australian Government submitted that it 'supports the general principle that an aged care provider should have at least one registered nurse on-site at all times to provide clinical care', with 'limited exceptions'. In those exceptions, it submitted that 'it would be appropriate to require the service to have reliable arrangements in place to access expert clinical advice in a timely manner'.[247]

Research in the United States demonstrates the value a continuous nursing presence. The *Nursing Home Reform Act 1987* (US) sought to improve nursing home quality through reductions in the use of medication, restraints, medication errors, pressure ulcers and incontinence. It also established a requirement for a licenced practical nurse, equivalent to an enrolled nurse in Australia, to be on duty at all times and for a registered nurse to be present at least eight hours a day, seven days a week.[248] A 2016 review of 150 studies found a strong relationship between registered nurse staffing and quality.[249] It found that staffing levels and other factors associated with high quality care, such as low turnover rates, consistency of staffing and low use of agency staff, are interrelated.[250]

Several organisations supported the proposal for a registered nurse to be available on every shift in residential aged care.[251] Dr Anthony Bartone, President, Australian Medical Association, advocated for nurses to be on-site 24 hours a day.[252]

To enable the sector to adjust to this requirement, we recommend that it be phased in. From 1 July 2022, the minimum staff time standard should require at least one registered nurse on site per residential aged care facility for the morning and afternoon shifts (16 hours per day). This will increase to a 24-hour presence on 1 July 2024. As with all of the new standards that we recommend, the operation of this staffing standard should be monitored by the Australian Commission on Safety and Quality in Health and Aged Care and adjusted as necessary in future.

12.6.4 International and national benchmarks

Our recommendation for a minimum staff time standard for residential care draws heavily on the work of the University of Wollongong's Centre for Health Service Development, headed by Professor Eagar. The Centre reported in September 2019 on a research study commissioned by us, entitled *How Australian residential aged care staffing levels compare with international and national benchmarks*.[253]

This report concluded that 'on average, each Australian resident receives 180 minutes of care per day, of which 36 minutes are provided by RNs [registered nurses]'.[254] It concluded that staffing levels within large parts of Australian residential aged care, as a whole, fall well short of good or even acceptable practice standards. We heard about one such example in the MiCare Case Study. Older people with high care needs in a residential aged care facility on the Mornington Peninsula in Victoria were receiving an average of only seven minutes of care from registered nurses per day.[255]

The University of Wollongong report found the staffing thresholds or levels used as part of the United States Centers for Medicare and Medicaid Nursing Home Compare rating system are a valid, evidence-based system against which to compare the Australian position.[256] Those staffing levels take into account overall direct care hours and the direct care hours delivered by registered nurses. A greater weight is assigned to registered nursing hours, because, as Professor Eagar explained, '30 minutes of registered nursing time is not equal to 30 minutes of a personal care worker'.[257]

In applying the standard at a particular residential aged care facility, the actual level of staffing required needs to be adjusted to reflect the mix of residents (referred to in the report as 'cases') in that facility. This process is known as 'casemix adjusted funding'. This means that a residential aged care facility with an above average proportion of high needs residents would be required to have additional registered nurses, enrolled nurses and personal care workers, and vice versa. The report concluded that a funding model like the proposed Australian National Aged Care Classification, which we describe in Chapter 17 and 21, could be used to 'casemix adjust' the staffing standard based on each particular facility's resident cohort.[258]

The University of Wollongong report concluded that the minimum amount of staff time per resident per day for 'acceptable care' is 30 minutes of registered nurse time and 215 minutes of total care time of registered nurses and other care workers. The authors explained that these minimums apply across the sector as a whole and 'require casemix adjustment to make them suitable at the facility level'.[259]

The intent of our recommendation is to bring the entire sector up to a minimum level of staffing that exceeds three star staffing under the Centers for Medicare and Medicaid Services Nursing Home Compare system by 1 July 2022. The principal beneficiaries of this will be the residents and staff in the 57.6% of facilities that have staffing levels the University of Wollongong report characterised as 'unacceptable' because they are the equivalent of one or two star staffing under the Nursing Home Compare system. People in these facilities will experience an increase in staffing hours of 37.3%.[260]

The second phase of our recommendation, to be implemented by 1 July 2024, is intended to bring the entire sector up to a minimum level of staffing that equates to four star staffing under the Centers for Medicare and Medicaid Services Nursing Home Compare system. Only 15.5% of residential aged care facilities are currently staffed to this level, with the remaining 84.5% at three stars or lower. The University of Wollongong report estimates that 'the average additional staffing time required for all facilities with 3 stars or lower to achieve 4 stars is 78 minutes (47.0%) in total including 14 minutes (43.8%) of Registered Nurse time'.[261] This translates to an across-the-board increase in staffing of 37.2% in total care staffing compared to current staffing levels.[262] The percentage increase in minutes of care provided by registered nurses from the current average to what will be required in 2024 will be 22%. We consider that this increase in residential aged care staffing by over one-third by 2024 will be challenging but achievable.

The phased approach to reform over three years is intended to give the sector the time that it needs to prepare for these increases.

There also needs to be transparency about staffing levels. This will encourage providers to do more than just meet minimum staffing levels and will mitigate the risk that a mandatory minimum staffing standard will result in a 'race to the lowest common denominator'.[263] We recommend transparency around reporting of staffing levels at Recommendation 122.

12.6.5 Exemptions

To meet the legitimate concerns about the inability of some providers to meet the new standard and the need not to stifle innovation by being overly prescriptive, an exemption mechanism should apply in limited circumstances. Any exemption must be time-limited. Where a provider has a persistent difficulty meeting the standard in a given area, the System Governor should address any underlying structural impediments through appropriate workforce planning and adjustment.

The four categories for exemption we recommend are as follows.

- Specialised services that are designed for people with unique care needs associated with early-onset dementia, addiction and mental health conditions or homelessness. These include services that are designed to meet residents' needs for culturally appropriate care, such as from Aboriginal and Torres Strait Islander health workers, or where people need access to non-English speaking care staff.
- Facilities that are co-located with a hospital, subject to the hospital having sufficient resources.
- Services in remote locations with a demonstrated inability to recruit and retain registered nurses or other care workers.
- Residential aged care facilities trialling an alternative skills mix. These may include settings designed for people living with dementia in which personal care workers are trained and supported to assume a formal care leadership role in close consultation with nurses and other health professionals. Any such trial should be comprehensively evaluated and publicly reported.

12.7 Getting staffing right—home and community care

If older people are to live well in their own homes for longer, personal care workers and health professionals need adequate time to attend to their health, social, emotional and domestic needs. Ms Heather Jackson, an experienced personal care worker, said there were instances where she is allocated 15 minutes to see a client. She said that she 'is on the time clock and it can be quite distressing for myself trying to get the job done if the person is not quite right that day'.[264] This time pressure impacts on the quality of care.[265] Ms Sally Warren, also a home care worker, said that the shortest period of time that she would spend with someone is 15 minutes.[266] She said:

> Now, that could be a welfare check which we just basically have to go in to make sure the person is okay, make them a cup of tea, just keep an eye on them or it could be a 15 minute meal prep, or medication. We might have to administer oral, liquid or topical medication. So, yes, that would be the smallest window that we have.[267]

Ms Warren said that 15 minutes can be sufficient, but that sometimes 'you might be thrown a curly like you can't find a key to a lock box, or the client might have put the paperwork away, and in dementia they might have forgotten to—where they put it'.[268] Ms Warren said that, in her experience, an extra allocation of time for each person makes a difference in such circumstances and that even when she has an extra 10 or 15 minutes, her client is happier.[269]

A 2019 survey conducted by a research team from the University of New South Wales, Macquarie University and the Royal Melbourne Institute of Technology, and commissioned by United Voice, found that 74% of people who were working in home care reported that they had insufficient time 'to listen and connect with older people'.[270]

The impact of time pressure on the capacity of personal care workers to provide high quality care may be compounded by challenges associated with unpaid travel time between visits, safety hazards in people's homes, working in isolation and finding the time to undertake training and administrative tasks. We have heard that many home care workers are not adequately compensated for their travel time.[271]

Ms Coad said that there should be some 'regulation around minimum visit times' in the home care sector.[272] Commissioner Briggs agrees that this is necessary to enable those who provide home care with the time to perform their role effectively to support people to live well and safely in their own homes.

The role of the personal care worker entails physical care, emotional care, housekeeping and daily living assistance, and documenting and reporting. Their work includes assisting people with personal hygiene, eating, position change and movement, exercise, leisure activities, shopping, cleaning and home maintenance. More experienced personal care workers tend to assist people with more complex health and social care needs.

The number and complexity of tasks that a personal care worker will have to perform on each visit varies according to the needs and preferences of the person receiving care. However, even for those people with limited and uncomplicated needs, Commissioner Briggs considers that it is difficult to see how high quality, consumer-directed and person-centred care can be guaranteed in allocated periods of less than one hour.

However, a number of witnesses highlighted that identifying an appropriate minimum period of time would be very difficult, given the large variation in people's needs and preferences. We heard that a minimum care contact time requirement may erode people's choices over their care arrangements.[273] Associate Professor Lee-Fay Low, Associate Professor in Ageing and Health at the University of Sydney, said that a minimum care contact time was too inflexible and would not ensure stability and continuity of care. She said:

> If someone wants someone to drop in on them, like, three times a day for five minutes to give them their tablets and say 'hello', that's what they want.[274]

Nevertheless, if older people are to live well in their own homes for longer, personal care workers need adequate time to attend to their health, social, emotional and domestic needs. This is particularly important when we consider the likely changes in future of the needs of people who access home aged care services.

It will be necessary to ensure that older people who receive care at home receive the standard of care they are entitled to receive and for which they have been assessed. We acknowledge that care time will vary significantly based on the circumstances and needs of the older person, and that this care may well range across clinical and non-clinical streams.

Commissioner Briggs considers that there should be processes developed for checking that care provided is consistent with the assessed need and care plan. If an older person is assessed as needing eight hours of care per week, and is funded to receive eight hours care per week, the older person should receive eight hours of care per week. Where this does not occur, there should be a trigger for review or reassessment by the care finder and assessment service.

12.7.1 Supervision and support for home care workers

Good quality supervision and support can improve working conditions and the performance and wellbeing of home care workers.[275] Research conducted in 2019 found that there is robust evidence that good training and support, including weekly, collaborative supervision, is highly effective in achieving person-centred care.[276] As observed by Dr Fiona Macdonald, a senior research fellow at the School of Management, RMIT University, good supervision and support serve a broader purpose:

> Oversight, supervision, and support to and protection of the health and safety of all workers providing home care services should include time and opportunity at work for observation and feedback on practice, for peer support and for participation in a community of practice.[277]

All personal care workers providing care in the home should be supervised by a registered nurse or allied health professional. This does not mean that a registered nurse will accompany them as they work. It means that there is a health professional that they can go to for advice and support and who can provide appropriate supervision and training. As well as helping care workers provide better quality care to people in their homes, supervision protects older people from the risk that they will receive substandard care or, worse, be the subject of abuse or neglect in their home.

We have considered this issue in the context of the tragic death in 2019 of a participant in the National Disability Insurance Scheme, Ms Ann-Marie Smith. A Safeguarding Taskforce set up by the South Australian Government following Ms Smith's death found that one safeguarding gap in the National Disability Insurance Scheme is that its regulator:

> does not explicitly require of all providers of personal support that there be at least two support workers for that individual (not necessarily at the same time) and that workers in participants' homes have regular supervision.[278]

In Chapter 3, on quality and safety, we recommend that there be an independent review and setting of Aged Care Quality Standards. This review should consider how the Aged Care Quality Standards in relation to human resources can be strengthened to ensure that aged care providers actively supervise and support their employees and, in particular, home care workers, for performance and health and safety outcomes. The Standards should provide specific guidance on how these practices should be demonstrated by providers of home care services.

Although we do not make specific recommendations directed to home care workers, we consider that implementation of the recommendations in this chapter as a whole will improve the working conditions for home care workers and, in turn, the quality of care for older people receiving care in their homes.

12.7.2 Modes of engagement

The 2016 Aged Care Workforce Survey revealed that, in relation to pay as you go workers:

- an estimated 130,263 workers made up the home care and home support workforce[279]
- an estimated 86,463 home care and home support workers worked in direct care roles[280]
- the proportion of home and community care workers employed under permanent part-time arrangements increased from 62% in 2012 to 75% in 2016[281]
- between 2012 and 2016, there was a 19% reduction in the full-time equivalent home care workforce[282]
- between 2012 and 2016, home care and home support workers on casual and contract arrangements decreased from 27% to 14%.[283]

In addition to the pay as you go workforce, 27% of home and community support outlets used at least one non-pay as you go worker during the period surveyed. A total of 21% of non-pay as you go workers were community care workers.[284]

The 2016 Survey concluded that:

> the sector is undergoing considerable structural change and this is reflected in the way labour is used both in numbers but also in the differential use of direct and non-direct care employees. [285]

It stated that there has been ‘an increase in the proportion of workers employed for fewer hours’.[286]

A significant trend in recent years has been the use of 'independent contractors' in aged care. The Report of the Inquiry into the Victorian On-Demand Workforce analysed Australian Bureau of Statistics data for the whole of Australia and reveals that between 2014 and 2018, the number of 'independent contractors' in health care and social assistance increased by 29%, from 70,700 in 2014 to 91,700 in 2018, compared with a 19% increase in the overall health care and social assistance workforce during the corresponding period.[287]

12.7.3 Implications for quality of care

During Sydney Hearing 4, witnesses were asked whether the mode of engagement of home care workers is relevant to the quality of care they provide.

Ms Jessica Timmins, Head of Service of Hireup Pty Ltd, a registered National Disability Insurance Scheme provider, explained that Hireup is also 'an online platform that connects people with disability with support workers'.[288] Hireup provides in-home services, but does not provide aged care services.[289] It employs its support workers as casual employees.[290] Ms Timmins explained that the decision to adopt this structure was a significant one for the business because the 'duty of care that's created when you are an employment model can lead to higher quality support outcomes for people with disability'. She added that Hireup 'wanted support workers to feel part of our team and committed to those same quality outcomes'.[291]

This evidence was supported by that of Ms Jaclyn Attridge, Head of Operations, Home and Community Care, Uniting NSW.ACT, and by Mr Ahilan St George, Director and Co-Founder of Vitality Club. UnitingCare Australia and Vitality Club each provide home care services through both the Commonwealth Home Support Programme and the Home Care Packages Program.[292] Ms Attridge explained that, from UnitingCare Australia's perspective, 'in terms of monitoring and checking the quality of care, that is far simpler when you're employing the staff directly'. She said this is because employees 'are aware of your policies and your training programs'.[293] Mr St George said that 'direct employment is significantly easier to control' because it is 'easier to train and ensure quality and in terms of incident reporting, complaints management'.[294] In contrast, he added, it is very difficult to get subcontractors to 'deliver a model of care as opposed to just a service'.[295]

Mr Peter Scutt, Founder and Chief Executive Officer of Mable Technologies Pty Ltd, agreed that Mable is 'a platform that facilitates engagement between care workers who have put a profile on Mable and third parties who want to engage those workers'.[296] Historically, the third parties have been individual people receiving care but more recently they have included approved providers.[297] Mr Scutt explained that Mable is not the employer of the care workers on its platform. He described the care workers as 'customers of the platform'.[298] He said that where there is an approved provider involved, the provider is responsible for complying with the Aged Care Quality Standards.[299]

Dr Jim Stanford, Director, Centre for Future Work at the Australia Institute, told us that 'the idea that merely facilitating communication between a client and a contracted service provider…will, somehow, ensure the quality of the service delivered, I would say that idea is naive and, in fact, dangerous'.[300]

In responding to Counsel Assisting's final submissions about the link between employment arrangements and quality of care, Mable submitted that 'the evidence presented is weak as to the link between provider employment and quality care'. Mable submitted that 'What is most important to quality outcomes is not whether the worker is employed by a provider, but the worker's values, motivations, training and their understanding of person-centred care'.[301]

Professor Paula McDonald, Professor of Work and Organisation and Associate Dean, Research at the Queensland University of Technology, stated that while platforms 'embrace features of the on-demand economy such as incentivising responsiveness and worker flexibility', there are also a 'range of direct and indirect costs of doing business [that] are apportioned to workers and also clients by digital platforms'. Professor McDonald concluded that the apportioning of these costs of the labour process to the worker, in addition to the lack of paid leave, superannuation contributions and 'other protections in Australian employment regulation, suggests an inevitable erosion of the hourly rate of pay set by the worker'.[302] Similarly, Professor Stewart identified that the challenge for workers without an employer is that they are not automatically entitled to the range of benefits and protections available to employees.[303]

Professor Stewart also told us that:

> 'if you are trying…to ensure that service providers have to have certain and discharge certain responsibilities about the care and quality of services that they provide, allowing them to minimise their direction and control over their workers, to me doesn't make a lot of sense'.[304]

Section 96-4 of the Aged Care Act provides that 'a reference in this Act to an approved provider providing care includes a reference to the provision of that care by another person, on the approved provider's behalf, under a contract or arrangement entered into between the approved providers and the other person'.

Although there is no contract between an approved provider and an independent contractor sourced through arrangements provided by businesses such as Mable's, Ms Amy Laffan, Assistant Secretary, Aged Care Reform and Compliance, Australian Department of Health, considered it was clear that section 96-4 would deem services provided by an independent contractor to be services provided on behalf of the approved provider in such situations.[305] Ms Laffan conceded 'some separation' of responsibility for quality and safety with the ability to direct and control the care provided.[306] Ms Laffan said that there is 'the connection of payment', as 'to access the Commonwealth funds, that person, selected by the care recipient, would need to get those funds from the home care provider'.[307] Mable submitted that it generates invoices on behalf of the support workers for payment collection.[308]

In a post-hearing submission, and with reference to section 96-4 of the Aged Care Act, the Australian Government submitted that 'these obligations on approved home care providers extend to home care services provided on behalf of the approved provider under a subcontract or other arrangement'.[309] The Australian Government submitted that it would support 'clarifying the obligation in a situation in which an approved provider is providing home care services through a "digital labour platform" scenario' and 'the development of guidelines…and further information for approved providers who use digital labour platforms and about the obligations on those approved providers'.[310]

Mable submitted that 'Mable is not an aged care provider' and is 'not funded to provide services'.[311] Mable explained that 'Mable's duty of care relates to duties as the builder and operator of the platform, which incorporate all of the safeguards that form part of the platform'.[312]

While we specifically inquired into issues with the mode of engagement of workers in the home care context, we consider that many of the issues are also relevant in the residential care context.

12.7.4 Requirement to employ care workers

During Sydney Hearing 4, Counsel Assisting tested with witnesses a proposition that 'providers should be required to deliver a set percentage of their care hours through the care workers they employ directly'. While there was support for the idea that high quality care was more likely to be delivered by employees rather than by contractors, there was little support for a legal requirement in these terms. For example, Professor Stewart described it as 'too arbitrary an approach'.[313]

Professor Stewart did support what he described as a 'general rule', subject to exceptions, that 'workers who are performing services on behalf of providers, whether they are engaged directly or not, should be employees'.[314] Such an approach could be justified, he considered, because it was 'far more compatible with achievement of objectives relating to achievement of quality standards in relation to care'. This is because 'an employee is necessarily somebody who can be closely directed in the work they do'.[315] Professor Stewart considered such an approach would also advance 'the more general objective of improving wages, working conditions…training and career paths for care workers'. [316]

Recommendation 87: Employment status and related labour standards as enforceable standards

Commissioner Briggs

1. **By 1 January 2022, the Australian Government should require as an ongoing condition of holding an approval to provide aged care services that**
   a. **approved providers: have policies and procedures that preference the direct employment of workers engaged to provide personal care and nursing services on their behalf**
   b. **where personal care or nursing work is contracted to another entity, that entity has policies and procedures that preference direct employment of workers for work performed under that contract.**
2. **From 1 January 2022, quality reviews conducted by the Quality Regulator must include assessing compliance with those policies and procedures and record the extent of use of independent contractors.**

We consider employment as a mode of engagement of the workforce is more compatible with achievement of our broad objectives of developing a well led, skilled, career-based, stable and engaged workforce providing high quality aged care. Employees are, by definition, required contractually to comply with any lawful and reasonable directions they are given about the performance of their work.[317] If a provider directs an employed care worker to provide care through a relationship-based model of care, for example, the employee is required to do so. Where the care worker is engaged by an older person directly via a platform, this is necessarily more difficult, if not impossible, for the provider to control.

We heard that under some models, it is possible that employment-related responsibilities could fall on the either a third party platform provider or the older person themselves. Mr Brian Corley, Chief Executive Officer of aged care provider Community Options ACT, told us that:

> Community Options has commenced using online platforms to source workers in our HCP [Home Care Package] and NDIS [National Disability Insurance Scheme] service areas, where our clients request us to do so. In these cases we seek to advise clients that the support workers that they engage through the platform are not employees of the platform and that they may be seen as the employer; and that the platform is not responsible for the quality of care or for any acts or omissions of the support worker. Not all clients fully understand the possible implications of this arrangement.[318]

Unless an older person willingly takes on the role of an employer and is fully informed about the implications, we consider it is undesirable for an older person to risk being deemed an employer because of their use of online platforms to select their own workers.

We received submissions supporting direct employment as the preferred mode of engagement for the aged care workforce.[319]

Commissioner Briggs proposes that approved providers be required to have policies and procedures in place that support and preference the direct employment of workers. The COVID-19 pandemic has reinforced the importance of a directly employed and stable workforce in aged care. She considers that direct employment is the model that is best adapted to achieving the objectives of the suite of workforce reforms proposed, including professionalising and building the skills of the aged care workforce. Now is the time for a trained, stable and cohesive workforce, with the right terms and conditions of employment, rather than a fractured, disparate and ill-supported workforce.

Commissioner Pagone has sympathy with this view but does not believe it appropriate to require direct employment when the required standards of high quality care can be achieved by other models with appropriate controls and checks. The Quality Regulator, in Commissioner Pagone's view, will need to be vigilant to ensure that flexibility of worker engagement promotes, and does not detract from, the provision of high quality care.

Rather than a 'general rule' that would be difficult to enforce, Commissioner Pagone has concluded that the best way to encourage approved providers, and contractors engaged by approved providers, to employ care workers is by means of the statutory general duty outlined in Recommendation 14.[320] Approved providers will be required to comply with this duty whether they directly employ the care workers or not. We anticipate that they will find it easier to comply with that duty if they are legally able to direct the way in which care work is performed through an employment relationship.

12.8 Leadership and culture

To support and drive the reforms we envisage, consistent and confident leadership at all levels of aged care organisations is essential. While this is reinforced through strategies, policies, practices and behaviours, it begins with a genuine commitment to the core values and philosophies on which high quality and safe care are built.

The intent of our aged care workforce recommendations is to improve the workforce's ability to deliver high quality care to older people. The success of these measures and the overall performance of approved providers is contingent on them having leaders and managers who understand that people are their most critical resource.

Good workplace leaders get the best out of others as a result of their own behaviour. In this sense, everyone should consider themselves to have leadership responsibilities. However, those who are formally appointed to managerial and strategic leadership positions in aged care organisations exercise profound influence over the thoughts and behaviour of others

and, in turn, the culture of the workplace and care environment. They must represent the organisation's values and model these to others through their behaviour.

As Dr Veronique Boscart, of Schlegel Villages in Canada, explained:

> if you invest in a team, which is a costly investment from an organisational perspective, this leads to better care, therefore it does lead to better care outcomes…But if you don't have a staff team that is going to exemplify that practice, you will not get to better care outcomes because change in care is not going to happen by one specific group. It needs to be a team approach.[321]

Ms Hills said the difference between an approved provider organisation that is struggling, is providing substandard care, and is poorly staffed, and an approved provider organisation that is well-managed and providing a terrific service is culture.[322]

We heard evidence about the impact of poor leadership and workplace culture and climate. Dr Duncan McKellar, Head of Unit, Older Persons' Mental Health Service, Northern Adelaide Local Health Network, identified poor workplace culture as one of the principal causes of the events that led to the closure of the Oakden Older Persons Mental Health Service. He emphasised that a 'cultural failing' of the 'organisation and…the people that worked within it' was 'at the core of what went wrong'.[323] Dr McKellar said that organisational support is important because commitment is required 'from the CEO level right through to the…grass roots delivery of care'.[324]

In contrast to the failures at Oakden, Mr Bryan Lipmann AM, Chief Executive Officer of Wintringham, told us about the importance of culture and of valuing his staff:

> I tell them that they are special people doing special work and they will go home and they will feel they've done something that very few people ever will…So for these staff to be doing that in such often difficult circumstances fills me with great pride. I—I am enormously proud of my staff, they are really very special people.[325]

Ms Jennene Buckley, Chief Executive Officer of Feros Care, illustrated why communicating and promoting her organisation's values helped to keep her workforce stable. She described Feros Care's mission as to help people 'grow bold' by staying independent, socially connected and living the best life they can.[326] She added that 'our company values are based on that and that's what keeps our staff with us, because they know that that aspiration of ours is genuine'.[327]

In our view, good leadership and culture provides a necessary foundation for workforce development and growth—to being an employer of choice. Some providers offer a range of training, education and career development opportunities to their staff, seeing this as an investment in attracting and retaining their workforce.[328] Other providers highlighted that great culture lays the foundation for staff commitment. Mr Lipmann exemplified this when he said that a by-product of positive culture and rewarding staff members for their long service at Wintringham is staff loyalty.[329]

Dr Boscart explained to us how a retention strategy can be founded on making work meaningful. She said that when leaders encourage staff members to see meaning in their jobs, it is easier for them, and their supervisors, to help them to develop their career aspirations in aged care.[330] Dr Trigg described the importance of instilling good leadership to enable staff members to build relationships with residents.[331]

Leaders in aged care have a shared responsibility to help the sector emerge from what Professor Pollaers described as a state of 'adolescence'.[332] We agree with his observation that the sector's leadership capability has not kept pace with the growing size and complexity of organisations within it.[333]

The challenge for strategic and operational leaders and managers within aged care organisations will be to lead their organisations through the reform process in the years to come with confidence. Ms Kerri Rivett, then Chief Executive Officer of Shepparton Retirement Villages, offered simple guidance for effective communication during periods of change. She highlighted the importance of 'open disclosure and listening and hearing the truth, hearing warts and all about what is actually happening'.[334]

12.8.1 The Government Workforce | Commissioner Pagone

We both agree that the Australian Department of Health needs to revitalise its workforce and engagement with the aged care sector whichever system governance model is adopted. If the Commission model I recommend is adopted, it will require substantial development of the workforce within the Australian Aged Care Commission to ensure it is able to meet the requirements of leading and guiding the aged care sector effectively. That will be a substantial undertaking. If the Government Leadership model Commissioner Briggs proposes is adopted, that additional development will need to be made within the relevant parts of the Australian Department of Health and Aged Care.

12.8.2 The Government Workforce | Commissioner Briggs

The Australian Department of Health and Aged Care will need to step up to the requirements of a major hands-on service delivery agency if it is to lead and guide the aged care sector effectively. Its approach and its workforce should be akin to that which we see in the States and Territories, which run large service delivery arrangements for health and welfare. This will necessarily require a fundamental change in the culture, leadership and management arrangements of the Department as it transitions to one of the two governance models we suggest.

Government workers are essential both to the delivery of care and to the management and oversight of the aged care system.

As at 30 June 2019, the Australian Department of Health's core aged care workforce comprised approximately 583 full-time equivalent employees.[335] In addition, there are many other Australian Government-funded workers who are in direct and daily contact with older people and with approved providers as part of the aged care system. This workforce directly influences how care is delivered and the timing of access to care. My Aged Care contact centre staff, Regional Assessment Services assessors and Aged Care Assessment Teams assessors are the 'gatekeepers' to the aged care system, deciding, as they do, whether a person is eligible to receive aged care services. They are often the first point of contact for many people with the aged care system. I know from the evidence we have received that, more often than not, that first interaction with the aged care system is during an anxious or crisis time in a person's life.

The Australian Government aged care workforce is therefore a critical conduit between older people and their families and their access to care. The nature of the interactions between people receiving care and Government aged care employees can play an important role in determining the quality of that care. It is therefore essential that the Government workforce has the experience, knowledge and skills to ensure that it plays its part in guaranteeing that the care provided by the aged care system is high quality and safe.

The evidence and information we received in our inquiry suggests that there are too few highly skilled and knowledgeable Government aged care workers and too much reliance on external contractors.

Ms Natasha Chadwick, founder and Chief Executive Officer of approved provider New Directions Belmere Pty Ltd, told us that in her experience, some Aged Care Quality and Safety Commission 'assessors have no aged care background or residential aged care background. You know, it's pretty hard to assess something that you've not had any experience of'.[336]

Ms Maree McCabe, Chief Executive Officer, Dementia Australia Limited, said that often Aged Care Assessment Team assessors are not well versed in dementia and the complexities that dementia can present.[337] The Australian Medical Association submitted that Aged Care Assessment Team and Regional Assessment Service assessment workers often have no health knowledge and the skills mix in teams varies.[338] While a bachelor's degree in a clinical or 'specialist area' is required to be an Aged Care Assessment Team assessor, tertiary qualifications are not mandatory for Regional Assessment Service assessors.[339]

Many of the issues that affect the broader aged care workforce also affect the Government aged care workforce. These issues include a lack of adequate training, a lack of necessary skills, overuse of, and over-reliance on, contractors and consultants, dissatisfaction with opportunities for career progression, high turnover of staff and a lack of resources to deal with the volume of work.[340]

I acknowledge that many of the concerns that have been identified in the evidence about the Government aged care workforce beset the entire Australian public service. In 2019, the Australian Government conducted a review into the Australian Public Service. The Report of the Review is entitled *Our Public Service, Our Future. Independent Review of the Australian Public Service*, also referred to as the Thodey Review. It identified a decline in capability over the past decade across the entire Australian Public Service:

> The greatest concern has focused on the hollowing out of strategic policy skills—the ability to understand the forces at play in the world, what is needed to position the nation to meet challenges and opportunities, and to develop, analyse and provide incisive advice to the Government.[341]

The Thodey Review attributed this decline to the prioritisation of short-term responsiveness at the expense of long-term thinking; employees' potential not always being realised; staffing-level caps that have made it difficult for agency heads to retain some functions or to maintain them at the same size and strength as previous years; and labour contractors and consultants increasingly being used to perform work that has previously been core in-house capability.[342]

Government staff engaged in gateway services must be able to deliver services to all people competently, including to those with diverse needs. This may include people with culturally and linguistically diverse backgrounds, people who identify as LGBTI, care leavers, Aboriginal and Torres Strait Islander people, veterans, and people who are homeless or at risk of homelessness.

The Thodey Review made a similar recommendation at its Recommendation 25.[343] This is imperative for the Government aged care workforce. It is also important that workers engaging with the public in any way have effective cultural awareness and trauma-informed care training. We have made recommendations on this matter in the chapter on aged care for Aboriginal and Torres Strait Islander people and the chapter on quality and safety.

According to Professor Pollaers, 'The Government needs to be more transparent and acknowledge that workforce training and development is as important for the Department of Ageing and all government agencies involved and take necessary steps to either develop or upgrade capability and practises accordingly.'[344]

The Australian Department of Health agrees in principle that the Australian Government must continue to invest in the workforce, which supports and interacts with providers, people receiving care, and State and Territory Governments.[345]

The Thodey Review identified insufficient structured support for career development in the Australian Public Service, which it said affects retention and contributes to a loss of expertise.[346] Not only does there appear to be a lack of nationally consistent training, there also appears to be a lack of induction training for the Government workforce. At Adelaide Hearing 2, BE said that there is no actual program of training given to assessors in what was then the Approved Provider Program Section of the Australian Department of Health.[347] She said that training is 'very ad hoc'.[348] From what we have heard, it appears to me that there is a heavy reliance on training manuals in lieu of training.[349]

The Aged Care Workforce Taskforce considered that a:

> thorough review is needed of induction resources and processes for government workforces so that they gain the required understanding needed of the industry, the impact of changing consumer demand and their roles in the continuum of care and consumer journeys.[350]

Throughout this Final Report, we make a number of recommendations which will impact the Australian Government workforce. Some of these will have a direct impact, such as the introduction of thousands of care finders, the expansion and integration of the single assessment service, and reforms to the My Aged Care and access to information services. Other impacts will be as a result the new and expanded institutional models, including the System Governor, Quality Regulator, Prudential Regulator, the Pricing Authority and the Inspector-General for Aged Care. The Australian Government workforce will also feel the impact of increased access to aged care and the revision of programs and streams of aged care services.

All this will require a professional cadre of public servants, sensitively recruited, trained and educated to meet the needs of vulnerable older people.

12.9 Conclusion

We reflect on the words of the late Commissioner Tracey, following evidence given by four aged care workers:

> We are enormously grateful to you for bringing us stories from the coalface and giving us a better understanding of what it is like to provide quality care to the aged in this community. And the dedication that you display on a day-to-day basis is something that this community must be exceedingly grateful for.[351]

We agree. Gratitude must mean something in real terms. It must mean that the work of caring for older people is valued.

This will require strategic leadership by the Australian Government on aged care workforce planning. It will require collaboration between employee representatives, sector and the Australian Government to improve pay. These steps will contribute to the provision of high quality and safe care for older people. So, too, will a robust registration scheme for aged care workers, fit-for-purpose education and training courses, and the right number and mix of staff caring for older people.

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ISBN: 978-1-921091-69-8 (print)
ISBN: 978-1-921091-70-4 (online)

Published February 2021