# Table of Contents

1. **Tell us about you**
   - What is your full name? ................................................................. 2
   - What stakeholder category do you most identify with? ......................... 2
   - Are you providing a submission as an individual or on behalf of an organisation? ..... 2
   - Do you identify with any special needs groups? ..................................... 2
   - What is your organisation’s name? ...................................................... 2
   - Which category does your organisation most identify with? ...................... 2
   - Do we have your permission to publish parts of your response that are not personally identifiable? ................................................................. 2

2. **Response to Criteria in the Legislation**
   - Whether unmet demand for residential and home care places has been reduced..... 4
   - Whether the number and mix of places for residential care and home care should continue to be controlled................................................................. 5
   - Whether further steps could be taken to change key aged care services from a supply driven model to a consumer demand driven model ........................................... 5
   - The effectiveness of means testing arrangements for aged care services, including an assessment of the alignment of charges across residential care and home care services .......... 8
   - The effectiveness of arrangements for regulating prices for aged care accommodation ................................................................. 9
   - The effectiveness of arrangements for protecting equity of access to aged care services for different population groups .................................................. 9
   - The effectiveness of workforce strategies in aged care services, including strategies for the education, recruitment, retention and funding of aged care workers ................. 10
   - The effectiveness of arrangements for protecting refundable deposits and accommodation bonds ................................................................. 14
   - The effectiveness of arrangements for facilitating access to aged care services ....... 15

3. **Other comments** ..................................................................................... 16
1. Tell us about you

1.1 What is your full name?
-

1.2 What stakeholder category do you most identify with?
Consumer Organisation

1.3 Are you providing a submission as an individual or on behalf of an organisation?
Organisation

1.4 Do you identify with any special needs groups?
Nil

1.5 What is your organisation’s name?
Health Care Consumers’ Association

1.6 Which category does your organisation most identify with?
-

1.7 Do we have your permission to publish parts of your response that are not personally identifiable?
Yes, publish all parts of my response except my name and email address

The Health Care Consumers’ Association (HCCA) is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:
- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is a member based organisation. We have a Health of Older People Consumer Reference Group. This group has a very strong interest in health of older people. While much of the activity relates to consumer access to affordable and responsive primary health care and hospital care there is also an interest in home based care, and access to rehabilitation and primary care for those consumers in residential care. In preparing our response we have drawn heavily from the lived experience and insight of members of the Consumer Reference Group. We have considered the strategic Roadmap for Aged Care in framing our response. We have also worked with members who are also contributing to the COTA ACT response.

Much of our attention in this response is on residential care. The transition to aged care can be an extremely challenging time for families. The system is complex and can be overwhelming. It needs to be improved.

It is disappointing that quality of care has not seemed to be a driver for these reforms. The reforms instead are very focussed on processes rather than quality of care that is delivered. We are strongly of the view that this needs to be rebalanced. Quality of life and quality of care are fundamental elements of aged care reforms.
In 2013 Alzheimer’s Australia released a report\(^1\) that detailed cases of residents of nursing homes with Alzheimer’s being physically restrained, assaulted and sedated without consent. We have heard similar stories from people in our membership of family members, residents of nursing homes, left in urine-soaked beds (or worse). We need to have visibility on the quality of care that the services provide, including on basic requirements such as providing hydration, nutrition, cleanliness and safety.

Our membership holds a variety of views regarding the value of market forces in improving the supply and quality of care. While some commented that they welcome the introduction of market forces to set standards and prices through competition, the majority of our members are deeply concerned by this and fear the consequences of market driven supply and market failure.

2. Response to Criteria in the Legislation

2.1 Whether unmet demand for residential and home care places has been reduced

<table>
<thead>
<tr>
<th>Refer to Section 4(2)(a) in the Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>In this context, unmet demand means:</td>
</tr>
<tr>
<td>• a person who needs aged care services is unable to access the service they are eligible for</td>
</tr>
<tr>
<td>e.g. a person with an Aged Care Assessment Team / Service (ACAT or ACAS) approval for residential care is</td>
</tr>
<tr>
<td>unable to find an available place; or</td>
</tr>
<tr>
<td>• a person who needs home care services is able to access care, but not the level of care they need</td>
</tr>
<tr>
<td>e.g. the person is eligible for a level 4 package but can only access a level 2 package.</td>
</tr>
</tbody>
</table>

Response provided:

**Shortage of Residential Places**

ACT has a shortage of residential care places. This shortage was identified in the Department of Social Services’ Stocktake of Australian Government Subsidised Aged Care Places and Ratios as at 30 June 2015 which showed the ACT ranked second last of all Australian jurisdictions using the Department’s own planning measure. In the ACT we have 73.1 residential care places for 1,000 people aged 70 and over. Against this measure, the ACT had a ratio of 73.1. While this represented an improvement on the previous year’s ratio of 70.6, it was still well short of the national average of 81.1 and well short of the target ratio of 78 places per 1,000 people aged 70 and over (Aged Care Finance Authority Report 2016, p. 189). The ACT’s residential care occupancy rate was 94.5%, the highest nationally.

The shortage of residential care places has had negative flow-on effects in the ACT’s public hospitals, where there is a backlog of patients awaiting discharge to residential aged care. The ACT’s public hospitals rate poorly nationally against the performance benchmark of bed days per thousand occupied by these patients. The hospitals are experiencing increased pressure on their inpatient beds with older people awaiting nursing home placement.

Not only are residential care place numbers limited. In the ACT, the level of accommodation deposits required represents an additional barrier to entry to residential aged care. (See comments against 2.4). The pricing behaviour of aged care suppliers in the ACT provides a real world commentary on some of the assumptions built into the Roadmap.

**Aged Care Packages**

In terms of Commonwealth-funded home care packages for people 70 and over, the ACT was relatively well supplied in terms of current needs. There were 17.1 high care (level 3 and 4) packages for every 1000 Territory residents in that age group, compared with a national average of 7.7. However, according to consumers at a recent ACT forum on Consumer Directed Care, the cost of the new Home Care Packages is too high. Some consumers found it was cheaper to access private level 3 or 4 packages than through the Government. This was also raised as a key issue by service providers attending the Forum, who indicated the cost of home care services was driving some consumers to residential aged care.

We note that the rate of supply for home care packages will need to increase over the next 10 years to keep pace with the growing proportion of ACT residents aged 70 and over, as the post-war generation ages. The Intergenerational Report provides a projection of the increase in the number of people aged 70 years and over expected to almost triple over the next 40 years, reaching around 7 million people by 2055, Australia is facing a significant shortage in the aged care workforce².

**ACAT**

The ACAT is a critical pathway to accessing appropriate levels of support. As such it is important for the community to monitor the performance of this.

---

The ACT Government has a quarterly report on the performance of public health services that is tabled in the Legislative Assembly. This has traditionally included data on access to ACAT. More recently the ACT Government has not reported publicly on this. It is an important measure for our communities and we would like to see uniform reporting on the time it takes for consumers to access these assessments.

2.2 Whether the number and mix of places for residential care and home care should continue to be controlled

<table>
<thead>
<tr>
<th>Refers to Section 4(2)(b) in the Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>In this context:</td>
</tr>
<tr>
<td>• the <strong>number and mix of packages and places</strong> refers to the number and location of residential aged care places and the number and level of home care packages allocated by Government; and</td>
</tr>
<tr>
<td>• <strong>controlled</strong> means the process by which the government sets the number of residential care places or home care packages available.</td>
</tr>
</tbody>
</table>

Response provided:

**The role of Government**

We support the continued control of residential care and home care by Government. This needs to be driven by consumer demand but we see that aged care needs to be heavily regulated and coordinated by Government. If the mix of places is not adequate then ultimately it is the Governments of Australia and the tax payers who are left with putting the pieces together, often through long term admissions to our public hospitals.

2.3 Whether further steps could be taken to change key aged care services from a supply driven model to a consumer demand driven model

<table>
<thead>
<tr>
<th>Refers to Section 4(2)(c) in the Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>In this context:</td>
</tr>
<tr>
<td>• a <strong>supply driven model</strong> refers to the current system where the government controls the number, funding level and location of residential aged care places and the number and level of home care packages;</td>
</tr>
<tr>
<td>• a <strong>consumer demand driven model</strong> refers to a model where once a consumer is assessed as needing care, they will receive appropriate funding, and can choose services from a provider of their choice and also choose how, where and what services will be delivered.</td>
</tr>
</tbody>
</table>

Response provided:

Clearly the supply driven model is not working. We support the concept of consumer demand driven model and that care and support is provided based on assessed need. Consumer control and choice is rhetoric that we hear with great regularity but to make this a reality is extremely challenging. We have to learn the lessons of the National Disability Insurance Scheme.

**Quality of care**

For a consumer demand driven model to work properly in the way described, a number of conditions would need to be satisfied. These include access by consumers to full and accurate information about the nature and quality of services offered by providers, effective complaints management processes and a capacity on the part of consumers to switch easily from one supplier to another if not satisfied.

Equity of access is an issue of concern for many consumers. We need a system for aged care that is based on need and not our ability to pay. Need for aged care is not discretionary, it is a necessity.
Our reading of the Roadmap suggests that it is intended to shift the primary responsibility for funding aged care from Government to consumers, while uncapping the prices that providers can charge. These prices will be expected to cover the development, maintenance and replacement of capital stock, paid for by borrowings from the financial markets. Government assistance will be restricted to consumers who meet a tightened means test, and will reflect an efficient price sufficient to make service provision viable. The expectation is that this mix of funding will stimulate competition at all levels of the market. We find this concerning.

While it may be the case that supply has to date been artificially restricted by the limits of Government’s willingness or capacity to fund aged care, it does not follow that supply to all consumers can be guaranteed by uncapping prices and providing efficient price funding to those without means.

Government appears to have no wish to provide the services itself. This means that approved service providers, particularly the bigger players in the industry, wield significant market power. This power of bigger existing players will be expanded under the Roadmap scenario, due to the emergence of barriers to entry resulting from increased reliance on service revenues to fund the development of capital stock.

In an environment where supply is limited, uncapping the prices that suppliers can charge may prompt suppliers to compete to attract those who can pay the highest charges, with diminishing competition as the amount offered reduces. We are concerned that this model will encourage cherry picking. As one consumer commented: “We need to make sure that we don’t end up having a system that only caters to the rich and the people who have low care needs”

Any planned movement towards a ‘consumer demand driven model’ must ensure service accessibility and quality assurance for those older consumers who have little or no means of support other than the age pension. These consumers will continue to represent a significant proportion of the market, given the time required to address the reality of broken work patterns and financial illiteracy in large sectors of the population.

Another of our consumers commented:

“The risk is that older consumers who are totally dependent on Government funding will receive inferior quality service from staff with a lower level of education and training. These older people must be assured of access to the services that they have been assessed as needing, which must be provided to an adequate standard of quality and safety”.

The importance of information in guiding consumer choice

The Roadmap sees a paramount role for aged care clients in driving service improvement by exercising their consumer sovereignty. It recognises that to play this role, these older consumers will need full information about competing available services. This is important, because people who are old, ill and needing care are already at a disadvantage in educating themselves about their options. However there is reason to question whether the measures outlined in the Roadmap will meet the informational needs of these clients.

Clearly, aged care clients do not have the mobility of choice enjoyed by purchasers those who are buying property or committing to telecommunication contracts. Once an 85 year old moves into a residential aged care service, they are not nearly as able to relocate. This is a high stakes decision that has significant consequences. While clients of home care services do not have the same physical constraints on changing suppliers, anxiety about negotiating and changing to an unknown supplier is a significant factor. And for people with cognitive impairment the impact of the change is very serious and can have a harmful effect on their health.
The Roadmap envisages that ‘Government will establish and maintain consumer protections (including accreditation against core standards, compliance and complaints mechanisms) and encourage quality improvement by registration category’. This includes mandating consumer involvement in the quality assurance process across end-to-end aged care; and ensuring reporting against standards is transparent and publicly available.’ The Roadmap also states that ‘differentiated performance information on a single set of core standards and quality indicators will be published on the service finder in My Aged Care’. Consumers must be involved in the co-creation of these protections.

These are fine intentions, but they will not be served by the Roadmap’s proposal that Government should consider the private sourcing of accreditation services. This seems to us to open the door to a form of industry self-regulation. While industry ‘in-house’ accreditation bodies certainly have a part to play in lifting standards of service, their assessment processes tend to focus on praising and publicising selected positive aspects of a service rather than being comprehensive and exacting. If entrusted with the function of assuring that care providers satisfied minimum standards of safety and quality, we believe they would tend to find excuses for service providers who fell short of meeting the standards, rather than render them liable to compliance action by Government. HCCA believes the accreditation function should remain the principal responsibility of Government.

Elsewhere, the Roadmap proposes that the My Aged Care website be enhanced to include information from a range of different sources and envisages that ‘providers will become more sophisticated in terms of how they market the quality of services to consumers, including via My Aged Care’. These statements raise concerns about the reliability and independence of service quality information that will appear on MyAgedCare. In our view it is not appropriate for Government websites to include ‘advertorial’ content.

Central to this is consumer empowerment. We want control and choice but need opportunities to develop our understanding on how to effectively navigate the system. We need sound accurate and timely information to base these important decisions on. The emotional aspects of decision making around aged care services is inadequately addressed.

As one consumer commented:

“Most of us don’t want to think about aged care while we’re still active and relatively healthy. It is only once our independence is compromised that we have to deal with it. This often happens after some crisis; we tend to leave it until an emergency forces us – or our family – to make decisions. And this is often when we are emotional and unprepared”.

---

2.4 The effectiveness of means testing arrangements for aged care services, including an assessment of the alignment of charges across residential care and home care services

Refers to Section 4(2)(d) in the Act

In this context:
- **means testing arrangements** means the assessment process where:
  - the capacity of a person to contribute to their care or accommodation is assessed (their assessable income and assets are determined); and
  - the contribution that they should make to their care or accommodation is decided (their means or income tested care fee, and any accommodation payment or contribution is determined).

Response provided:

**The Roadmap plan for a user pays approach is a radical change**

Basic care services which have previously been funded wholly by Government are now to be wholly funded by consumers, with Government assistance restricted to consumers with limited means. Residential care consumers are expected to become ‘primarily responsible for their accommodation and everyday living costs, as they have been throughout their lives’\(^4\). In the case of home care, the position appears similar - Government contributions will be set according to ‘the consumer’s ability to pay’.

At the same time, the Roadmap proposes to uncap the prices that service providers can charge. ‘Government will not regulate provider prices or what consumers choose to pay for care and support’\(^5\). Again, the Government budget is intended to be a beneficiary of this approach, because ‘providers’ prices will take account of the costs of maintaining, renewing and expanding their capital stock’. Rather than continuing to fund the provision of services and capital expenditure by the industry, Government will assist only in circumstances ‘where there is a service need and insufficient market response’. From our perspective, the effect of these changes would be comparable to replacing Medicare funding of hospital services with a regime of means tested assistance, while at the same time privatising public hospitals.

**An alternative approach**

Any changes to means testing arrangements needs to be done in keeping with the principles underpinning progressive income taxation. There is potentially inequity between city, metropolitan and regional areas. It would not be fair to expect an older pensioner in a rural location to use up the entirety of their home equity to pay for a given set of basic care services, when a city pensioner with a similar house happens to be worth ten times as much, might be able to pay the same amount with 90 per cent of their equity untouched.

**Alignment of charges across residential and home care services**

The Roadmap’s objective of making aged care funding ‘agnostic’ with regard to the location of the recipient accords with the wishes of the majority of older people to receive care in their own homes rather in a residential facility. Provision of care in the home setting rather than in residential care might result in some savings to Government as a consequence of reduced need to subsidise accommodation costs, but expectations here should be realistic. It needs to be recognised that the alternative of home care is not feasible for many consumers such as those with high care needs and single consumers who have no children to assist with their care.

---

\(^4\) Aged Care Roadmap (2016) p.11

\(^5\) Ibid.
2.5 The effectiveness of arrangements for regulating prices for aged care accommodation

Refer to Section 4(2)(e) in the Act

In this context:

- regulating prices for aged care accommodation means the legislation that controls how a residential aged care provider advertises their accommodation prices.

Response provided:

The current arrangements for regulating prices for Aged Care Accommodation in the ACT are clearly ineffective. When comparisons are made with NSW and Victoria, there can be no credible cost-based rationale for the ACT’s accommodation deposit levels.

This comment applies to all levels of accommodation pricing in the ACT beyond the 5th percentile, where a symbolic effort appears to have been made to help a minority of battlers by offering entry to residential care for low accommodation deposits.

The Aged Care Financing Authority’s 2016 report on the Funding and Financing of the Aged Care Sector clearly states the significant business that is aged care. Accommodation deposits in 2014-15 were $18.2 billion, up from $15.6 billion in 2013-14. This report shows the national average deposit paid by residents entering care as at 30 June 2015 was $342,000. The ACT was ahead of all other jurisdictions with an average of $426,000. Significantly, the national median deposit was $325,000, indicating most new places were available for deposits lower than the national average. In the ACT however, the median deposit was higher than the local average, at $450,000 – this indicates most new places required a deposit higher than the average. At the top end, agreed accommodation deposits at the 95th percentile in the ACT averaged $659,000, compared with $625,00 for NSW and $600,00 for Victoria. This is a significant barrier for many people with lesser means and reduces choice for some consumers.

There does not appear to be adequate discussion of financial arrangements during ACAT. To allow informed choice some basic information needs to be provided. There is a lack of affordable financial advisors who have expertise in aged care. Subsequent to this, the cost of using a financial adviser can be prohibitive – especially for the part funded retiree cohort.

We need to have plain language explanations of quite complex financial concepts and processes eg, Refundable Accommodation Deposits (RADS) and Daily Accommodation Payments (DAPs).

The resident agreement outlines the costs for aged care and is a legal agreement you sign when you enter a residential centre. It’s important that you and your family fully understand the costs and care arrangements, so you may want to consult a financial adviser, lawyer and family before you sign.

2.6 The effectiveness of arrangements for protecting equity of access to aged care services for different population groups

Refer to Section 4(2)(f) in the Act

In this context equity of access means that regardless of cultural or linguistic background, sexuality, life circumstance or location, consumers can access the care and support they need.

In this context different population groups could include:

- people from Aboriginal and/or Torres Strait Islander communities;
- people from culturally and linguistically diverse (CALD) backgrounds;
- people who live in rural or remote areas;
- people who are financially or socially disadvantaged;
- people who are veterans of the Australian Defence Force or an allied defence force including the spouse, widow or widower of a veteran;
- people who are homeless, or at risk of becoming homeless;
- people who are care leavers (which includes Forgotten Australians, Former Child Migrants and Stolen Generations);
• parents separated from their children by forced adoption or removal; and/or
• people from lesbian, gay, bisexual, trans/transgender and intersex (LGBTI) communities.

Response provided:

HCCA fully supports efforts to ensure consumers from all different population groups can access the care and support they need.

Since 1 July 2014 providers have been able to accept lump sum refundable deposits from all residents, regardless of the level of care they need. This was a significant change. Many in our membership are concerned that this opens the door to a two tiered systems where those people who can afford to pay receive better quality of care.

The experience of people in our membership is that residential care facilities do not want to accept clients with a lower level of care because it attracts less funding. RACF are giving priority to clients with high physical needs because it attracts more funding as opposed to those with high psychological needs. The way aged care advertises needs to be transparent with many worked examples, and to get real people to explain not ex hotel managers as they employed at Goodwin Services in Canberra, nor the ex-real estate agents at Anglican Homes in Eastern Sydney.

Social Determinants of Health

In terms of health, it is important that the Inquiry considers services in line with the World Health Organization definition of health, and taking into account the Social determinants – this then encompasses many of the other human services especially (but not limited to) education, including early childhood education and child care, which then takes us into child protection and family programs, generally NGO funded who work with vulnerable families, which then leads to affordable housing, and social security. Vulnerable consumer groups need to be considered in this inquiry, not just Aged and Disability Services, but Refugee, Migrant, Aboriginal and Torres Strait Islander health and links to other human services.

2.7 The effectiveness of workforce strategies in aged care services, including strategies for the education, recruitment, retention and funding of aged care workers

Response provided:

Government policy is geared toward keeping people healthy and in their own homes for longer. This means that we will see an increase in the complexity of the health of people living in residential care. This means people require more clinical services to address their medical conditions and cognitive impairment. Adequate coverage by Registered Nurses, pharmacists, Nurse Practitioners and general practitioners (GPs) is essential. Often the focus is on nursing ratios and 24/7 attendance but the role of general practitioners (GPs), pharmacists and nurse practitioners as part of the aged care workforce is often overlooked. The role of all health professionals need to be considered as they are complementary.

We know from our members that it is increasingly difficult to get GPs to attend nursing homes. In Canberra to provide treatment for medical issues such as chronic pain, dizziness, urinary tract infections, depression and anxiety, falls and rashes. Access to health care for residents of RACFs has to be improved. While there has been an increase in Nurse Practitioner Registrations in the ACT there is still insufficient numbers in aged care to deliver the care that is needed.

The ACT Government recognised this as an issue when they introduced the GP Aged Day Service (GPADS). We supported GPADS which provided short term, episodic GP in-hours support to RACF residents and for the homebound in the community. It was disappointing that the program did not receive ongoing funding. This service
provided an in-hours locum to support people who are homebound or in residential aged care facilities when their regular GP is unable to make a house call. The service provided care to frail or aged patients who need prompt attention and might otherwise have ended up in hospital. GPADS operated from Monday to Friday, 8am–6pm (excluding public holidays). Patients were handed back to their usual general practice after the isolated episode. The GPADS program filled a gap in services that otherwise remained unmet for consumers who are homebound or RACF residents.

The Federal Government’s freeze on Medicare Benefits Schedule (MBS) rebates for consumers makes this even more challenging to provide care to older people.

As is the case nationally, the ACT requires more and better trained aged care workers, and demand will grow in pace with the ACT’s ageing population. The age demography of the ACT is close to the national average.

The Department of Social Services recently undertook a stocktake and analysis of Commonwealth-funded aged care workforce programmes.

The stocktake report noted that the aged care workforce will be required to nearly triple from 352,145 people, to 827,100 people by 2050 (Stocktake and analysis of Commonwealth-funded aged care workforce activities, 2015, p. 2). The report further indicated that leadership development, succession planning, and regional, rural and remote service provision were identified as future priorities p.7. Future workforce strategies would need to focus on building a multi skilled, dynamic and flexible workforce to meet this surge in demand and meet the needs of sick residents.

Inadequate staffing and the resulting substandard care has been a recurring theme over the years.

We support the establishment of minimum staffing ratios and want the Commonwealth Government to require nursing homes to publish information about their staffing skills on the ‘My Aged Care’ website.

**Staffing mix and skills**

The sector is also undergoing a shift in staffing and skill mix where the number of registered (RN) and enrolled nurses (EN) working in aged care is decreasing while the number of unregulated care workers is expanding. This shift is occurring at the same time as increasing acuity and care needs for those elderly Australians requiring residential aged care.

We support the introduction of mandated minimum staffing and skill mix requirements for nursing services in the aged care sector. This goal includes the mandated requirement for a 24 hour registered nurse presence for all aged care facilities where there are residents with high care needs and medication management by registered and enrolled nurses only.

Our members have expressed concerns about the current composition of the health age care workforce, expressing alarm at the shortage of well qualified staff working in age care services. Of particular concern is that Assistants in Nursing are working with minimal clinical supervision and are often asked to work outside their scope. This presents a patient safety issue and needs to be addressed.

We have anecdotal evidence about lack of access of quality primary care in age care which leads to the unnecessary physical and emotional deterioration in care. This often leads to admission to hospital (acute care). One of our members commented:

“Then there is the continuous complaint about staffing being untrained or only having the basic Certificate requirement and also the use of staff who have little English and/or very heavy accents. Older people need staff who are easy to understand as they have not always had contact with people from other nationalities. There is the continuous problem for the facilities of having sufficient staff daily as required and this is particularly so on weekends and holidays. How does this affect the implementation of the Consumer Centred Care as required since 1 July 2015 as per the Aged Care reforms? (The Commonwealth Aged Care Act of 1997 and the 2013 Amendments to that Act).”
**Diverse Workforce**

One of the areas currently being investigated by the HCCA Consumer Reference Group on the Health of Older People is how we can ensure culturally and linguistically diverse (CALD) staff members working in health and aged care are better supported. The increase in the number of staff with diverse backgrounds warrants consideration of how best to adequately support them to provide safe and quality care.

We know that within ACT Health over 30% of their clinical staff are from CALD backgrounds. We have anecdotal evidence to suggest that this proportion is greater in aged care services. This is important to investigate as we know that the inadequate workforce in age care is a challenge to the sustainability of the system and that willing compassionate workers are needed. There is some concern from our membership that 457 visa are being used inappropriately which leads to unskilled workers entering Australia with certificates in age care that do not meet the level of quality that we, as a community, require.

Language and cultural barriers have also been identified by our membership as a barrier to receiving appropriate care. We want to be assured that there is consistent language and cultural training and support provided in age care across Australia. For example, one member commented:

“I guess time has moved on and we have a whole range of nurses with different cultural backgrounds and that’s a barrier and can have issues. I mean they have subservient behaviours and a hierarchy that we don’t follow. That’s not good...As an example of that and one particular incident in the next bed, there was this little Greek man next to us and he did not have very good English. He was old and unwell and an Indian nurse came in and said to him "You are getting dia-sis" and he said “what? No I don’t get any of dia-sis” and I had to step in and say “she means dialysis!” and he said “Oh yes I definitely get that.” That patient had no idea what she was saying because her English was not that understandable”.

**Care around the clock**

We are concerned with the loss of requirements to have registered nurses in age care facilities 24/7. We believe this has a dramatic impact on the quality and safety of care delivered. Funding for age care facilities to support registered nursing roles in high acuity age care. We are aware that that the acuity level of many residents is rising and we want to see more money to fund that care.

The Aged Care Act lists the minimum care and services that needs to be provided to care recipients. Schedule 1, Part 3 - Care Services of the Aged Care Act does not specify the requirement for 24 hour RN onsite coverage 7 days per week. We are of the view that this requires change.

One consumer commented:

“I think my concerns were the cutting back on the requirement for a Registered Nurse to be available 24/7 and that the workload for the RN is excessive in a number of facilities. Whenever there is discussion about this it is always raised. Also in NSW apparently they are talking about this not being a necessary requirement. However this is important as in the RACF’s the older people frequently have falls or skin tears and the normal staff are not allowed to do dressings etc. Therefore when dressings need to be changed on the wounds an RN is required to do it and dressings are not changed as often as they should be”. – HCCA Member

If there is inadequate trained people in nursing homes they will have no choice but to transfer residents to already overwhelmed hospital emergency departments for basic treatment if there wasn’t a nurse on duty.

It is in the best interest of residents to support care in their RACF home, where possible. But the issue is in the definition of what can happen in RACF. The experience of many families is seeing their loved ones moving between the Nursing Home and public hospital. "In the last year of her life my grandmother bounced between her nursing home and the local public hospital. This was for things like cellulitis, which could have been treated in her nursing home. But there seemed a real reluctance of the nursing home staff to step up." HCCA Member

One advantage of registered nurses is their ability to prevent unnecessary hospital transfers. People become unwell at predictable times and do not confine our deterioration to business hours. Quite simple, if there is no RN on duty the enrolled nurse or assistant in nursing on duty may have no option but to send the person to hospital as it may well be outside their scope of practice. Our experience suggests that enrolled nurses and personal care workers may be more inclined to call an ambulance.
The Terms of Reference of NSW Parliamentary Inquiry into Registered Nurses in New South Wales Nursing Homes (2015) included the requirement for a registered nurse to be on duty in a nursing home at all times, as compared with requirements in aged care hospital wards (1b). This requirement is set out in NSW Public Health Act 2010. They also looked at the adequacy of nurse to patient ratios in nursing homes and other aged care facilities with residents who require a high level of care (3). The responses from large aged care providers are most telling. We remain concerned that they will put profits before people.

In their submission to the NSW Parliamentary Inquiry into registered nurses in New South Wales nursing homes (2015) Bupa stated their opposition to the requirement for 24/7 registered nurses. In their submission they stated that to "pre-determined or fixed inputs to care, like nurse to patient ratios" do not provide the flexibility of having a workforce that will meet the range of residents needs. They described it as "a costly requirement which will be ineffective in delivering improvements in the quality of life and care for residents".6

In their submission to the NSW Parliamentary Inquiry Uniting Care Ageing NSW ACT described legislative requirement for a 24 hour a day 7 day a week (24/7) onsite Registered Nurse as "out-dated" and "ill-considered". Uniting Care oppose the requirement for a 24/7 nurses and said the cost impost could lead to closures.

UnitingCare Ageing NSW ACT stated that they thought it was not the role of state governments to legislate these requirements for 24/7 coverage of Registered Nurse in Commonwealth-funded RACFs. They also stated that "the Australian Aged Care Quality Agency (AACQA) is the most appropriate organisation to assess the quality of the overall provision of care and appropriate staffing for individual services". This demonstrates one of the critical issues - the complication the intersection of state and territory governments with the Federal Government. The Commonwealth is responsible for aged care and the States are responsible for acute health care. If the Federal Government requirements are inadequate, or not enforced, the state and territory governments are the default through public hospitals.

We want enrolled nurses and assistants in nursing work under the supervision of a registered nurse in all residential aged care facilities to ensure quality care and protection of the public.

Palliative Care Access to palliative care in residential aged care facilities is a cause for concern. Older people facing death in aged care facilities often find it difficult to access appropriate palliative care medicines and care.

Consumer Story

This is the experience of one of our members which demonstrates some of the difficulties in obtaining good palliative care services in residential aged care facilities (RACF) in Canberra.

The care and nursing staff of the RACF did the best they could with the severe lack of resourcing and training that they have on dealing with anything other than very basic care situations. John’s family has been involved with this facility over a period of 6 years with both of their parents receiving end of life palliative care following deterioration and complication resulting from their primary diagnosis of Parkinson’s disease. Marie’s (Mum’s) palliative care journey at this RACF 3 years ago was characterised by family members having to fill prescriptions on weekends (twice) for morphine because RACF had run out (family was given the option on both occasions of going to the pharmacy themselves or sending their mother to hospital). Similarly, John’s (dad’s) journey was characterised by a lack of nursing staff to administer breakthrough shots of morphine (prescribed for every 4 hours if needed). This RACF does not have a nurse on site after 5pm so during this time agency nurses were called in resulting in long waits whilst John was in distress. On one occasion the nurse was called in from Bungendore and this took one hour. On another occasion a nurse was called in but the wait was an hour due to the fact that 3 residents in the RACF were receiving end of life care - despite the facility knowing this they did not roster a nurse on between the hours of 5pm and 7am). The nurse during the daytime was wonderful but was under huge

---

amounts of pressure which also resulted in stressful delays because of the number of end of life residents she was dealing with in addition to the 100 or so other residents at the facility. The care staff overnight were caring but untrained to deal with the situation which resulted in John being repositioned inappropriately and being in great distress during the last hour of his life whilst we waited for a nurse to come and show them how to correctly position him so he was not on his back groaning and lurching forward whilst he appeared to drown in his own fluid. The trained nurse had repositioned him on his side during the previous visit and had shown care staff how to do this but there was only minimal care staff on during the early hours of the morning and despite many attempts of pushing, pulling, and rolling (during which time John was moaning and groaning loudly in response) the two carers could not get him on his side.

**Palliative care - Consumer Story**

Another of our members shared a positive experience of palliative care in a nursing home in Toowoomba:

*My father in law died earlier this year in a Nursing home in Toowoomba. While his death was confronting, he had fallen and suffered a brain bleed, we were very pleased with the care from the staff. The RNs were there, around the clock. The personal care workers were well trained and there was a genuine feeling that they were working as a team. There was an Advance Care Plan in place and my father-in-law and all the family accepted that a good death was the best outcome. I mentioned this to the Nurse Manager and this worker was reallocated. The nursing staff understood palliative care and had support from a GP who made regular visits. This level of good care may be given to all residents but we did think that one of the reasons our family received such good care was that my father in law was known to the staff. He had lived in the independent living units and regularly visited residents. The nursing staff knew him as a person rather than an old person with a challenging head injury.*

HCCA is strongly of the view that aged care workforce planning and training should be made a priority focus area.

### 2.8 The effectiveness of arrangements for protecting refundable deposits and accommodation bonds

<table>
<thead>
<tr>
<th>Refers to Section 4(2)(h) in the Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>In this context:</td>
</tr>
<tr>
<td>• arrangements for protecting refundable deposits and accommodation bonds means the operation of the Aged Care Accommodation Bond Guarantee Scheme.</td>
</tr>
</tbody>
</table>

**Response provided:**

What service providers do with their revenue, and how they are faring financially, can end up affecting quality of care. If providers of residential care are funnelling their revenue into the development of attached retirement villages, or if they are simply incompetent or greedy, they will cut costs by hiring unqualified staff or neglecting basic services. It can take a long time for this to be identified and remedied via a complaints and quality monitoring system, no matter how good it is. The present complaints system has been ineffective in identifying the majority of quality of care issues, let alone resolving them.

In worst case scenarios, providers suffer financial collapse, homes close and residents are forced to find alternative accommodation quickly. The stress of this search and relocation, and anxiety about the refund of accommodation bonds, is not what elderly residents and their families want.

This has long been recognised by the Department of Health which has maintained a prudential infrastructure to monitor residential care providers’ use of government grants and accommodation bonds paid by consumers. Providers have been required to submit regular General Purpose Financial Reports. These enable the Department to assess their exposure to debt, their capacity to repay bonds from liquid assets, and their overall profitability. With this information, the Department is then able to identify service providers of concern, for closer monitoring of service quality. They are also able to closely monitor those providers whose financial activities are exposing them to the risk of collapse, and encourage them to change course.

It is known that, at times, half the service providers identified by the Department as presenting the highest category of risk have been accorded that status primarily because of their financial situation.
If the changes envisaged under the Roadmap are seen to reduce government’s financial responsibility for aged care, there may be less justification for prudential monitoring of care providers’ financial operations. The incentive then would be for the Department of Health to reduce its administrative costs by winding down its monitoring operation, which would no longer be able to provide advice informing the targeting of providers presenting service quality or financial risk. Without this alert mechanism, aged care residents would in turn be placed at increased risk of poor quality service or the stress of a sudden need to relocate.

The function of prudential monitoring must continue to be performed by government, and to an extent that supports precautionary monitoring of service quality risk. If provider financial information is deemed too sensitive for consumers to access, the information must remain with government, or an independent body with sufficient resources to maintain it. But, given the additional payment responsibilities that consumers are likely to assume, a way must be found to alert genuine prospective care recipients if the financial state of a particular service is considered to raise risks.

Public consultation undertaken as part of the legislated aged care review must allow the issues surrounding provider financial information to be raised and properly considered.

Nowhere are the financial stakes for older consumers of aged care services likely to be higher than in the ACT. Median accommodation bonds required of entrants to residential care in Canberra are easily the highest in the country, and there is no reason to expect this pricing behaviour will change.

2.9 The effectiveness of arrangements for facilitating access to aged care services

<table>
<thead>
<tr>
<th>Refers to Section 4(2)(i) in the Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>In this context access to aged care services means:</td>
</tr>
<tr>
<td>• how aged care information is accessed; and</td>
</tr>
<tr>
<td>• how consumers access aged care services through the aged care assessment process.</td>
</tr>
</tbody>
</table>

Response provided:

People in our membership have articulated concerns that MyAgeCare portal and NDIS do not have clear processes that set out what is covered by each. With the significant changes it is no longer clear what is covered in Health and Community Care services funded by the ACT Government and the NDIS. One of our members provided a specific example:

The NDIS has “bad interface with MyAgedCare” (example - oxygen and sleep apnoea equipment come from separate funding) – need for clear assessment processes and protocols for the interface between the NDIS and the aged care system. There is a problematic interface with ACT Health over the range of issues, including getting health reports from ACT Health, getting ongoing services and identifying which matters are the responsibility of the NDIS or the health sector – HCCA Member

We are also hearing feedback on the difficulties of carers in accessing appropriate respite care. There is a series of phone calls to other call centres. It is a disjointed process that needs to be improved. There needs to be greater recognition of carers in the aged care reforms.
3. Other comments

Response provided:

There are a number of specific issues we have identified from our membership and from the issues paper that we think are particularly important in considering improving outcomes in the health sector – some may also have more broad applicability to other human services. These include:

- Quality of Care
- Data
- Systemic and individual advocacy
- Informed consumer choice and health literacy
- Consumer participation
- Complaints

Quality of care

We are disappointed that there was no explicit mention of quality of care.

The Quality of Care Principles 2014 set out the responsibilities of approved residential aged care providers. The principles specify the care and services that residential aged care providers must provide. (Source: Quality of Care Principles 2014, Explanatory Statement. The Quality Care Principles also set out responsibilities of approved providers in providing care and services for home care.) The principles state that certain medical procedures such as establishing and supervising complex pain management or palliative care, inserting intravenous and nasogastric tubes, and establishing and reviewing a catheter care program, can only be carried out by a nurse practitioner, registered nurse, enrolled nurse, or other professional appropriate to the service, acting within their scope of practice.

The Australian Aged Care Quality Agency (Quality Agency) is an accreditation and monitoring agency established by the Australian Aged Care Quality Agency Act 2013 (Cth). The agency began operations on 1 January 2014 when it assumed the functions previously performed by the Aged Care Standards and Accreditation Agency. The Quality Agency’s functions include responsibility for accrediting residential aged care facilities by ensuring compliance with the Accreditation Standards.

How is quality being monitored in Australian residential aged care facilities? “Quality of Care” is a difficult concept to measure, particularly within the context of residential aged care, which involves lifestyle issues as much as health issues. We need a structured and comprehensive quality monitoring system with public reporting. Our members have expressed concern that the existing standards are insufficient and too easy to pass. This needs to be changed and we see this as a priority. As one of our members said: “We need a system with teeth that will protect people from poor care and mismanagement”

Many new aged care facilities shine with their stylish architecture and delightful décor, carefully stage managed tours to prospective residents and masterful marketing collateral. What really matters is the quality of care. We need to improve the way we report this in a meaningful way so people can make informed decisions about their future care options. We need to know about extra services fees or additional services fees. We need informed financial consent. We need to know about the types of residents, the mix and skills of staff, the nutritional quality of meals, the activity schedule, access to primary care and rehabilitation services.

Concerns about quality within residential aged care facilities are regularly raised in the media as questionable care practices or carer behaviour are exposed, but monitoring quality in this context remains problematic and poorly addressed. The United States has introduced, and continued to refine, a compulsory system of assessment within its nursing homes, aimed at monitoring quality of care and clinical outcomes.

---

Residential aged care is a complex environment. It is a place for people to live as well as rehabilitate and receive the clinical services they need, such as wound dressing and medication. Consumer perceptions of what constitutes quality of care encompasses broader issues than in mainstream health care services such as hospitals and rehabilitation centres as it also includes quality of life. Indicators for quality of life in residential care could include general health, functional status, mental health, comfort, emotional wellbeing, privacy, choice, and autonomy.\(^8\)

One member recounted a story of finding a place for her mother. Her mother had fallen and broken her hip and needed nursing home care as she could not return home. The family was under significant pressure from nursing staff to find a place and accept the offers. But the family were reluctant to take the first offer as they wanted to know things like – what is the general health of other residents? How long do people generally live at each facility? Is the quality of life good? Do they have access to health care? Does the facility have arrangements for general practitioners or nurse practitioners to visit? And what about dental care? How many complaints has the facility received and what were the issues of concern? How active is the resident and family advisory group?

The National Aged Care Quality Indicator Program is voluntary for aged care service providers. We want to see mandated quality indicators that are publicly reported.

**Data**

Data quality is an important issue for consumers, as the data obtained from health services can be used to shape future service delivery and detect quality and safety issues. Good quality data can help us to identify areas for improvement and reform, as well as providing a strong evidence base for policy and decision-making. We emphasise that data collection should be both accurate and relevant, and that it be accessible to the public as well as service providers. The engagement of consumers in collecting and reviewing data is important in order to achieve the best possible outcomes. Outcome and quality data collection across all human services remains generally process and business focussed, rather than looking at the needs of service users and the quality and respectfulness of the services provided.

**Systemic and Individual Advocacy**

Both systemic and individual advocacy is important to consumers in human services. Individual advocacy involves supporting and representing individuals, such as to access a service, or to ensure their health rights are met. Systemic advocacy takes a broader view and helps consumers to make systems change. For example, this may be where a policy, system or law is amended to improve a service so that everyone can benefit. There needs to be further attention given to this role of advocacy.

**Informed Consumer Choice and Systems Literacy**

While welcoming the philosophy of increased consumer choice, the process for ensuring that consumers have all the relevant information and support to make decisions about their ongoing care needs to be very carefully structured and communicated. A consumer commented:

“The capacity to make informed choices depends on consumers being able to readily access all the relevant information and to be resourced and supported in the decision making process. This cannot be just words. If we are to facilitate informed user choice there will need to be a strong and ongoing commitment to supporting consumers in their role”.

The provision of useful and appropriate information for consumers is important, whether it is about the services available or the likely outcomes of services and what other options there might be. In health care as in many other areas, the information available on outcomes is often of poor quality and low reliability. Service providers can often skew the information to their benefit, without improving the outcomes for service users.

---

\(^8\) [https://eprints.qut.edu.au/9495/1/9495.pdf](https://eprints.qut.edu.au/9495/1/9495.pdf)
**Consumer participation**

HCCA suggests that there be a consumer panel of five consumers, drawn from all sectors, with direct access to the Minister, who can quickly and reasonably assess the capacity of the care providers to meet the needs of consumers and can step in when a service is found wanting. Without some such input the market will be able to do as it wishes and most likely provide good care to those who can afford it and lower quality or none to the rest. One can’t help wondering what will happen in rural areas where there may not be many older people requiring care and an inadequate number of providers.

**Complaints**

As an organisation that advocates for consumer rights in accessing health care we are very familiar with the barriers people experience in making complaints. Making a complaint takes time and energy. There is an emotional cost too. As consumers of health services – and disability or aged care services – we are often unwell or struggling with our health and capacity. And fear of repercussions as a result of our complaint is very real. And we know that for many they do not make complaints because of this, or they are too busy dealing with what life presents – such as caring responsibilities, or recovering from illness.

The Aged Care Complaints Commissioner reported that 81% of the complaints they received in 2015-2016 were about residential aged care. This was 1,746 complaints. They received 276 complaints about home care packages (13%), 114 (five per cent) were about Commonwealth Home Support Programme and 17 (one per cent) were about flexible and community care services. Complaints about home care services across Australia have almost doubled in that period. The Commissioner noted that complaints about home care packages and the Commonwealth Home Support Programme accounted for 18% of all complaints in 2015-6 and this was an increased on the previous year (12%). The Commissioner initiated 29 resolution processes and this included the examination of 51 issues. Most issues related to health or personal care, including behaviour management, continence management, oral hygiene, answering call bells in a timely way. The Commissioner reported that second most common are issues related to communication, including involving the family and guardians in decision making and being kept informed of what is happening. Cleanliness of facilities and service and staff behaviour and the numbers of staff were also issues of concern.

Given this trend we see that there needs to be more focus on reporting on quality of care and making this information publicly available to increase accountability of providers and help consumers and families make informed decisions about care. We can only drive change in the new market if we have the information to take action.

In a recent interview the Aged Care Complaints Commissioner said complaints about home care are still small compared to complaints about residential care, which number 780 for the first three months of 2016, but the increase has been “quite significant.”

**A comment on the ‘market’**

The issues paper fails to address the potential trade-offs in the use of market mechanisms in the delivery of human services. For example, Figure 2 provides a “framework” rather than a list of “factors” that could be used to guide decision-making. Some of the “factors” listed under “Scope for improving outcomes” inevitably involve trade-offs, for example - improving “equity” is likely to mean reducing “responsiveness”. Figure 2 also focussed on identifying “practical barriers to implementation” of market mechanisms in each human services area.

**Access to healthcare**

As a consumer organisation, HCCA’s prime focus is to ensure that the consumer voice is heard. Our consumers tell us that they particularly value Australia’s universal access to safe, quality health care and the opportunity to be in control of their own care. They want care to be integrated and multidisciplinary and for out of pocket expenses to be contained as much as possible.

Consumers are concerned that there are ever-increasing moves towards the privatisation of health care. This is evident in the shifting out of pocket costs to consumers, the outsourcing of some services, particularly into the private sector, which is creating an increasingly tiered health system that disadvantages many of the most vulnerable in our community.

Concern about changes to our universal healthcare system was a primary issue in the recent Federal election. The importance of protecting the most vulnerable and maintaining universal access to quality health care should be at the forefront of this or any future reviews of the human services.

The value of existing publicly available audit reports

There are publicly available audit reports available but they are not easy to find. Also because of the cycle of audits they are not necessarily relevant.

As an example I use the Ginninderra Gardens Nursing Home, now called Bill McKenzie Gardens. This is located in Page, ACT.

In 2012 there were significant concerns about Ginninderra Gardens Nursing Home in Page ACT. This is outlined in the Canberra Times10. The concerns were significant, including failure to ensure residents' nutritional needs were met and to provide terminally ill residents with dignified care. In 2013 Anglicare sold this facility. It was purchased by RSL LifeCare and is now called Bill McKenzie Gardens.

Change in ownership and name is not an uncommon occurrence. How can people track the changes when looking at previous audits? There has to be more transparency.

How can we make informed decisions on out-dated information?

The audit reports need to be timely. For example, on 27 November 2016 we accessed the most recent audit11 of Ginninderra Gardens (ACT) on the Australian Aged Care Quality Agency (AACQA) website. The decision was made on 10 July 2013. The audit was conducted on 18 June 2013 to 19 June 2013. While there is a reference that there may be site visits it is not clear if these have been undertaken. So if a consumer or carer was making a decision about an offer of a residential care place at this facility there would be no recent information to draw on.

And the content of the audit reports needs to be improved. For example, the profile on staffing in these audit reports has raw numbers. If a service lists a dietician it would be useful to know if this person is full time or part time.