THE UNIVERSITY OF QUEENSLAND
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CREATE CHANGE

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Table of Contents

Introduction

For more than a century, The University of Queensland (UQ) has maintained a global reputation for delivering knowledge leadership for a better world.

The most prestigious and widely recognised rankings of world universities consistently place UQ among the world's top universities.

UQ has won more national teaching awards than any other Australian university. This commitment to quality teaching empowers our 52,000 current students, who study across UQ's three campuses, to create positive change for society.

Our research has global impact, delivered by an interdisciplinary research community of more than 1500 researchers at our six faculties, eight research institutes and more than 100 research centres.

The Centre for Health Services Research, Faculty of Medicine aspires to be a world class Centre of innovation and excellence in research that advances health services and systems. The Centre conducts specialised research programs, with particular focus on ageing and geriatric medicine, kidney medicine and telehealth, and includes a team of experts in the fields of biostatistics, health economics, behavioural science and health informatics who are dedicated to improving health systems and care.

The Centre for the Business and Economics of Health researches innovative, effective and cost-effective healthcare solutions, and the economic and social benefits of health and healthcare. It informs policy and practice through a combination of investigator-led and commercial research projects designed to improve health and wellbeing for Australians.

The Health and Behavioural Sciences Faculty is at the forefront of health education and research in Australia, with global research leaders in disciplines such as brain science and mental health, social services and policy, and healthy ageing.

The Queensland Brain Institute is an international leader in the research of fundamental neuroscience focusing on discovering the mechanisms that underpin brain function, disease and repair.

The School of Psychology has built a reputation on outstanding research, teaching, and service to the community. UQ psychology research received the highest ranking of 5—well above world standard in the 2015 Excellence in Research for Australia, with expertise including biological, clinical, cognitive, developmental, health, organisational, and social psychology.

Summary and recommendations

Australia is in the grip of an aged care crisis – and it will impact us all.

Aged care in Australia is a community issue and something we should all think about. If we are lucky, we will all get old and the reality is that more than 40 per cent of Australians who live over the age of 65 will spend at least some time in a Residential Aged Care Facility (RACF). It would be a disconnect to think that all Australians are not involved in resolving issues in the sector – we all have a responsibility – both for older Australians now and the generations that follow. Protection of the public should be an over-arching component of the actions flowing from this Commission's work.

Too often, RACFs are viewed as 'places for dying'. As the population grows and Australians live longer, we need to ensure that older Australians receive premium care – both medical expertise and community support – to ensure they are comfortable with a high quality of life. Rather than places for dying, aged care facilities should be facilities to 'live longer and die feeling young'.

In our submission, we hope to highlight some of the many ways that care for older people can be improved on a practical level, for the ageing population, their families and the people who care for them. We stress the need for sound policy planning around the *needs* of older Australians rather than the *supply* of particular infrastructure or professionals. We thank the Royal Commission for accepting our submission and giving due consideration to our recommendations.

Recommendations outlined in this document are:

1. Change the funding model for older Australians in aged care. Rather than the current 'deficit model' that provides payment for people with on-going illness and ailments, move to a social model to provide standard funding to meet individuals' needs, across the entire environment of Aged Care, and additional funding if their needs require additional care or interventions. Funding should 'follow the individual', be person-centred and be subject to regular input from families.

2. The governance of RACFs should be broadened to provide residents and their relatives more oversight of the facility, its programs and available care. This could be achieved through:
    - A Board or Committee consisting of residents' relatives, providing oversight of the facility and an avenue for relatives and guardians to raise issues with the RACF.
    - Identified liaison officers at every RACF, independent to the Director, so relatives have a consistent person with whom to discuss care, treatment and concerns regarding residents. These liaison officers would actively seek family and guardian engagement with the facility.

3. The design, environment and culture of aged care centres must be improved to reduce barriers to incidental exercise and enable more time outside. Enough staff should be available to encourage people with dementia to undertake exercise.

4. Occupational therapist's roles in RACF and home care should be broadened to support older adults to participate in meaningful activities.

5. Admission to aged care should not occur until after community alternatives are fully explored.

6. There should be improved conditions within aged care facilities and better training for staff to improve culture within facilities, making them attractive to live in and to work in. Staff continuing education should be mandated and the time to take it should be compensated.

7. The appointment of Care Coordinators should be required; the aged care system is vast and complex, and navigating it with efficiency would improve care outcomes.

8. Systemic structural issues within the broader aged care system must be addressed. These include:
    - increased availability, and decreased waiting times for My Aged Care packages

- targeted policy changes enabling older adults to reside for longer in the community (e.g. ability to modify rental housing to enable staying longer at home)
- enhancing consumer-directed, family inclusive policies, and embracing improved technological care outreach (e.g. telehealth) to benefit all sectors including regional, rural and remote areas.

9. Australian families and wider communities need to be part of the system, not on the outside.

10. Establishment of mandated Family Advisory Care Committees would help integrate family knowledge and family-inclusive care into RACFs. Physical, social and symbolic 'space' needs to be created to facilitate such an endeavour.

11. The principles of shared decision-making (SDM) should be implemented within aged care facilities.

12. General Practitioners should be required to record when and why they veto a medical or allied health care professional's health care recommendation.

13. Family-inclusive involvement would assist in reducing the hierarchical, medical-model system with one which was more focused on appropriate, timely care.

14. We put forward the following suggestions for sustainability of care services for older people, from an economic perspective:

- Principle 1: Funding should reflect the needs of patient populations and be responsive to changes in those needs, not the capacity or supply of provider organisations.
- Principle 2: Services need to be provided based on 'teams' of providers working collaboratively in ways that utilise the full scope of practice of the health and social care workforce based on skills and training, not job titles and guild-type barriers to care delivery.
- Principle 3: Regulation of the sector (providers and institutions) needs to be based on public interest principles that include reducing risks of harm, maximising patient well-being and ensuring effective and efficient use of public resources.
- Principle 4: The RACF sector is one part of a continuum of care or care pathway, and hence planning, management and funding should be integrated with that of other services aimed at providing seamless transitions in care pathways as individual needs change. Transitions between care locations should reflect the care needs and functional capacities of people not the revenue needs and capacities to provide care of suppliers/institutions.

Terms of reference

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

Funding for aged care in Australia encourages, in effect, a 'deficit model' whereby RACF providers receive additional funding for unwell people, without incentives to work towards rehabilitation or improving function. This model, when combined with a significant increase in the number of for-profit providers, has led to an aged care service that disincentivises quality care and improving the health and wellbeing of older Australians.

Furthermore, care for older people in Australia is currently organised around a medical model. This model treats the unwell, when it could more productively be organised around a broader social model, expanding its scope to the overall environmental context which people inhabit and the care pathways they follow.

Finally, it is a system organised around the supply of units of care, or beds, or professional staff in various disciplines, rather than around the holistic needs of individuals.

For example, if a patient with dementia in aged care is designated as having a significant behavioural problem such as aggression, extra funding is received (unit of care). The most common outcome here is that *behavioural strategies* and *reducing environmental triggers* are not pursued, while *chemical restraint*, in the form of antipsychotic medications (another unit of care), are given, in the name of 'safety'. The extra funding remains in place as nothing has changed the root cause(s) of the behaviours – in sum, the person's needs have not been met. In fact, they may never have been examined carefully in the first place.

While the current funding model is well meaning – to provide additional resources for those who need them the most – it has unintended negative consequences. Instead, mandated 'core funding' that benefits all (e.g. better overall care environments to promote positive well-being and facility-wide programs) should be coupled with mandated key top-up funding to 'follow the individual' in an attempt to improve or supplement an individual's unique care needs. Moreover, the 'top-up' funding should be linked to family or guardian input. This input is a key missing link in the care of older people – families have no official advisory route to influence care standards and care delivery.

Regardless of the education and capacity of staff at RACFs, treatment of people in care will not significantly improve until the funding model enables all people to receive funding despite, or indeed perhaps because of, improvement. A funding model should encourage and reward better person-centred outcomes, and better addressing of all needs (medical, emotional, social) for RACF residents; families and residents should play a key role here.

Recommendation:

1. Change the funding model for older Australians in aged care. Rather than the current 'deficit model' that provides payment for people with on-going illness and ailments, move to a social model to provide standard funding to meet individuals' needs, across the entire environment of Aged Care, and additional funding if their needs require additional care or interventions. Funding should 'follow the individual', be person-centred and be subject to regular input from families.

2. The governance of RACFs should be broadened to provide residents and their relatives more oversight of the facility, its programs and available care. This could be achieved through:
    - A Board or Committee consisting of residents' relatives, providing oversight of the facility and an avenue for relatives and guardians to raise issues with the RACF.
    - Identified liaison officers at every RACF, independent to the Director, so relatives have a consistent person with whom to discuss care, treatment and concerns regarding residents. These liaison officers would actively seek family and guardian engagement with the facility.

b. How best to deliver aged care services to:

I. People with disabilities residing in aged care facilities, including younger people;

No response provided

II. The increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services.

The number of people living with dementia will nearly double every 20 years in the years to come[i] and the percentage of persons within nursing homes with dementia, currently at 50-80 per cent, has been increasing steadily[ii]. Despite the cost, RACFs need a stronger focus on the development of a caring environment that supports mobility and interaction (e.g. soft furnishings in common areas to aide hearing), and staff being given the time to discuss patient needs and to include families.

RACFs need to see a huge shift in their culture, which will come through a shift in management structure and personnel, staff education levels and staff support (ratios, time with patients and levels of professional development). Management needs to change to reflect best practice in other countries – witness the mandated shared management structure of nursing-home-trained physician, nurse and psychiatrist triad in all Dutch nursing homes[iii].

Culture is hugely important. The best intentioned care staff or family can be stymied by the entrenched culture within aged care. People will stay in an RACF if it is a good community with a family feel. Such facilities can also better retain good staff. Continuing education should be paid for – even a small amount paid – because knowledge is advancing so there must be provision for professional development within their work. There should be transdisciplinary career paths for highly skilled personnel within RACFs.

Importantly, the Australian Government should appoint mandated Care Coordinators to oversee the health of individuals and to assist them to navigate government processes. Similar to cancer care coordinators, these coordinators would be able to act as a liaison between care staff, outside consultants and families, and be a reassuring conduit of information for people within RACF.

There is currently no cure for dementia and trials for treating the progression of dementias such as Alzheimer's disease have not been successful. However, researchers have identified that exercising can slow progression of cognitive decline more generally, and dementia specifically. Increasing exercise has benefits even in persons who have moderate to severe dementia, as evidenced in a Cochrane Review[iv]. Indeed, the recent WHO guidelines recommended a minimum 150 minutes of moderate-intensity exercise to reduce cognitive decline[v]. However, in RACF residents are often encouraged to sit, watch television and stay in their room to reduce falls risks, limit wandering and reduce the number of staff required.

In order to reduce dementia decline – and promote all round wellbeing – the design, environment and culture in RACFs must be improved to reduce barriers to incidental exercise and enable more time outside and participation in meaningful/enjoyed activities. For example, exercise sessions such as tai chi (which can be conducted by people in a wheel chair, or who have sensory deficits) should be held routinely and occupational therapists could support participation in meaningful activities.

Improved movement, along with providing purposeful engagement in meaningful activities for RACF residents, would provide older Australians with more opportunities for interaction, greater feelings of being valued and offer opportunities for increased awareness of other health issues.

Finally, persons with complex physical and emotional needs, or with a diagnosis of dementia, are often admitted to Aged Care when a closer examination of available options might have allowed them to live for longer at home. Well-designed, easily accessible home care packages, as well as better support for primary caregivers, would alleviate premature admissions to aged care, and significant improvements in well-being and have economic savings at personal, government and societal levels.

Recommendation:

3. The design, environment and culture of aged care centres must be improved to reduce barriers to incidental exercise and enable more time outside. Enough staff should be available to encourage people with dementia to undertake exercise.
4. Occupational therapist's roles in RACF and home care should be broadened to support older adults to participate in meaningful activities.
5. Admission to aged care should not occur until after community alternatives are fully explored.
6. There should be improved conditions within aged care facilities and better training for staff to improve culture within facilities, making them attractive to live in and to work in. Staff continuing education should be mandated and the time to take it should be compensated.
7. The appointment of Care Coordinators should be required; the aged care system is vast and complex, and navigating it with efficiency would improve care outcomes.

c. The future challenges and opportunities for delivering accessible, affordable and high quality aged care services in Australia, including:

I. In the context of changing demographics and preferences, in particular people's desire to remain living at home as they age;

There is currently a strong sentiment, in the press as well perhaps in the national psyche, of the 'rising tsunami' picture of a rapidly ageing population creating unsustainable demands on health care systems. This is a misleading picture that ignores the cohort effects on health arising from the future elderly population having experienced different social, economic and physical environments during their lifetimes. For example populations now entering normal retirement age groups had no lifetime exposure to the conditions of the 1930s depression and the second world war as was the case for previous cohorts. Allowing for cohort effects on health suggests that the tsunami Australia and other countries will face is one of rapidly increasing numbers of healthy, active and functioning older people[vi]. Some of these changes can already be observed using data from the Household, Income and Labour Dynamics in Australia Surveys. For example in 2017 59 per cent of the population aged 85 or over reported their health as good or better compared to 46 per cent of the same age group in 2001. Similarly, within the same age group the percentage reporting no restrictions on their activities increased from 16 to 25.

Thus, while the *absolute numbers* of old sick people will increase the *rates of prevalence* are expected to fall[vii] (as they have over most time periods) and hence within each older age group, we can expect a lower *rate* of sickness/disability than observed at present. There is therefore no reason to believe we shall not have the fiscal capacity to fund these needs[viii].

However, while currently the number of Australians wanting to stay at home (supported by their families) is increasing, their actual ability to do so is decreasing, reflecting systemic structural issues including:

- Pace of government assessment and availability of My Aged Care packages, including excessive waiting times
- Waitlists to access suitable facilities
- Lack of response to needs while older adults are still living in the community actually places a paradoxical pressure on older adults to exit the community, in many cases prematurely.

Improved care packages would take into consideration:

- pension and housing limitations. For example, as private tenants cannot modify their housing, they can be forced into aged care unnecessarily. This is particularly important given the rising number of older Australians who will be renters in the future.
- the current consumer directed care model, which enables older Australians to choose low levels of care – such as cleaning and domestic help – rather than more targeted and expensive medical care. Again, more timely provision of care packages could decrease premature moves to RACFs.

II. In remote, rural and regional Australia.

Older people, particularly in rural communities, can have strong community relationships, adding to the fact that telehealth can be a suitable alternative to face-to-face appointments. Telehealth is most successful when there is someone present who knows the person and their medical history. Older people in rural areas have poorer health, less access to aged care services and specialist services.

Recommendation:

8. Systemic structural issues within the broader aged care system must be addressed. These include:

- increased availability, and decreased waiting times for My Aged Care packages
- targeted policy changes enabling older adults to reside for longer in the community (e.g. ability to modify rental housing to enable staying longer at home)
- enhancing consumer-directed, family inclusive policies, and embracing improved technological care outreach (e.g. telehealth) to benefit all sectors including regional, rural and remote areas.

d. What the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe.

Family Advisory Care Committees

For many older Australians, there is no place like home – and, ultimately, home is where you find family. However, in many aged care facilities, families are often seen as 'part of the problem'. Research[ix] has found that Australian families find it difficult to engage with RACFs. There is a need to make 'space' (literally and figuratively) for families within aged care policy and practice. This is because often families notice first that something is wrong, and it is families who bring what they observe to the attention of the authorities.

Many facilities seek to empower residents through committees, however, the success of these groups is often dependent on the residents' health – as residents age and become more frail, their voice within aged care settings diminishes, when it need not. In contrast, dedicated family members are often an under-utilised resource. They often have a strong desire to be involved in the welfare of loved ones and should be encouraged to join RACF Family Committees. Similarly to School P&C Associations, Family Advisory Care Committees would provide families a voice to ensure appropriate care of loved ones, and a protected relational 'space' in which to work together with RACFs to improve care provision. The 'space' of family involvement includes dedicated physical space for meetings, social space to recognise the relationships between families, carers and the facility, and symbolic space within regulation and policy, to help attenuate risks and improve markers of care.

Shared decision-making

Research is clear that people with dementia have the ability to express preferences through to the end stages of their disease. However, the 'paternalistic' approach typical in many RACFs runs contrary to the principles of shared decision-making which require the active involvement of persons and their families in care and treatment decisions[x].

Finally, it should be remembered that people with dementia have a voice. While dementia may reduce capacity, RACF residents should still be engaged and heard – not just by families but aged care providers themselves.

Recommendation:

9. Australian families and wider communities need to be part of the system, not on the outside.
10. Establishment of mandated Family Advisory Care Committees would help integrate family knowledge and family-inclusive care into RACFs. Physical, social and symbolic 'space' needs to be created to facilitate such an endeavour.
11. The principles of shared decision-making (SDM) should be implemented within aged care facilities.

e. How to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters.

Caring for older people involves more than health care – it includes social care, family and community inclusion, and clear communication paths among others. It should be less a hierarchy and more of a group process. Yet it should be noted that 'models of care' is medical speak – and caring for older people requires us to look past such rigid hierarchical frameworks to embrace more innovative, evidence-based 'whole-of-person care'. Even though the system has become medicalised, there are many cases of aged care not undertaking simple medical care well. Thus, the system needs to move to a social system of care reflecting the needs of those within it.

The increasing number of medical specialists involved in the care of older Australians has led to the medicalisation of aged care in recent years. While gains with respect to the involvement of allied care professionals such as psychologists and occupational therapists have made some inroads, care remains firmly rooted in a medical model, with many aspects of care funneled through the GP.

The importance placed on GP assessments in the care of people can result in unreasonable bottle-necks to the provision of timely care with respect to simple care needs (e.g. removal of ear wax), or timely review of medications. Recommendations made by medical specialists are all too often ignored by resident GPs, who are placed at the top of the care 'hierarchy' and who often have the ultimate veto power over specialists, without any requirement to justify their decisions. No right of reply exists for other medical or allied health professionals, or indeed the families involved.

Such an approach is not only overwhelming but also often confusing for older Australians and their families – and urgently needs to be addressed. There needs to be a stronger continuum of care, breaking down barriers and duplication of services across disciplines, which are currently still largely entrenched in silos, where communication and addressing the real needs of people is restricted.

Where a medical specialist has made a recommendation and it has been overruled by a GP, there should be a record of this decision with reasoning provided. This would lead to better collaboration and understanding of care decisions. If other recommendations such as a Family Advisory Care Committee were in existence, and if GPs were required to explain and justify their decisions to such a committee, instances of blockage and frustration would diminish.

Recommendation:

12. General Practitioners should be required to record when and why they veto a medical or allied health care professional's health care recommendation.

13. Family-inclusive involvement would assist in reducing the hierarchical, medical-model system with one which was more focused on appropriate, timely care.

f. How best to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure.

As mentioned above, given the trends for improved health in the Australian population as a whole, sustainability in services to address the needs of older adults should be within reach[xi]. One way to improve the sustainable servicing of needs is to stop using age as a proxy indicator of risks to health, needs for health care and capacities to function (i.e., basing the planning, management and evaluation of care and support programs on 'old' models of demography). US economist Victor Fuchs argued over 30 years ago that we should redefine our notion of 'the elderly' by a fixed number of years from expected age of death[xii]. Under that approach, if we arbitrarily took 1969 (50 years ago) as a baseline for 65 years as the threshold for old age, in Australia in 2019 old age would begin at age 77. An alternative 'new economic demography' view would recognise that 65 (or any other age, or age group) defines one thing only, and that is date of birth. A 65 year old with dementia has, on average, the same problems, challenges and care and support needs as a 54 year old with dementia, but very different problems, challenges and care and support needs from a 65 year old with full cognition. In this absence of adopting this new economic demography, the needs of younger persons with dementia, and indeed the resources and contributions of healthy persons over 65, are not met, nor at times even acknowledged.

Our fascination with age, when thinking about public services/policies, has distracted us from better meeting the needs of the population. As a result, much more attention within the planning of health services for older people needs to be given to cohort analyses that use the outcomes of different lifetime experiences to inform the levels of need.

Recommendation:

14. We put forward the following suggestions for sustainability of care services for older people, from an economic perspective:

- Principle 1: *Funding should reflect the needs of patient populations* and be responsive to changes in those needs, not the capacity or supply of provider organisations.
- Principle 2: Services need to be provided based on 'teams' of providers working collaboratively in ways that *utilise the full scope of practice of the health and social care workforce* based on skills and training, not job titles and guild-type barriers to care delivery.
- Principle 3: Regulation of the sector (providers and institutions) needs to be based on *public interest* principles that include *reducing risks of harm, maximising patient well-being and ensuring effective and efficient use of public resources*.
- Principle 4: The RACF sector is one part of a *continuum of care* or care pathway, and hence planning, management and funding should be integrated with that of other services aimed at providing seamless transitions in care pathways as individual needs change. Transitions between care locations should reflect the care needs and functional capacities of people not the revenue needs and capacities to provide care of suppliers/institutions.

g. Any matter reasonably incidental to a matter referred to in paragraphs (a) to (f) or that [the Commissioners] believe is reasonably relevant to the inquiry.

No response provided

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Endnotes

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