EveryAGE Counts (https://www.everyagecounts.org.au/) is led by a broad-based national coalition (including in the aged care field, providers such as The Benevolent Society and ECH, peak bodies such as ACSA, staff representatives such as United Workers Union and consumer representatives such as COTA Australia and National Seniors) to tackle ageism. While ageism can affect anyone of any age, the particular focus of the EveryAGE Counts campaign is older people. Our campaign vision is a society where every person is valued, connected and respected regardless of age and functional ability.

We define ageism as stereotyping, discrimination and mistreatment based solely upon age. Ageism against older people comes from negative attitudes and beliefs about what it means to be older. It impacts on our confidence, quality of life, job prospects, health and control over life decisions.

Ageism is neither benign nor harmless. It is a pervasive but sometimes hidden form of discrimination with three key aspects:

- prejudicial attitudes towards older people, including some attitudes held by older people themselves;
- discriminatory practices against older people, for instance in employment, aged care or health care; and
- institutional practices and policies which perpetuate stereotypes and undermine dignity.

In ageism's 'benevolent' form (with positive intentions towards older people), narrow assumptions and stereotypes about older age can often lead to an overprotective, controlling response built into processes, systems and behaviours towards older people. This can undermine the dignity, capability and quality of life of older people, because it removes their sense of personal agency, control and independence over their own lives. They become treated more as dependent, small children than sovereign adults.

At the other extreme, a more 'malevolent' form of ageism can and does lead to neglect and abuse. It incorporates negativity and fear towards, and assigns diminished value to older life and impairment. The worst examples involve criminal activity and should be treated as such.

29 June 2020

The Honourable Tony Pagone QC and Ms Lynelle Briggs AO
Royal Commissioners
Royal Commission into Aged Care Quality and Safety

By Email: ACRCenquiries@royalcommission.gov.au

Dear Royal Commissioners

The EveryAGE Counts campaign appreciates the opportunity to comment on the impact of COVID-19 on the Australian aged care system. Our comments here follow on from our detailed submission on the operation of ageism within aged care (lodged with your inquiry on 2 August 2019) and our submission on aged care program redesign (lodged in January 2020).

In our August 2019 submission to you, we argued that ageism is a key driver of failures in safety, quality of care and quality of life within the Australian aged care system, and proposed a series of recommendations to directly challenge ageism and mitigate the impact of ageist norms in aged care.

In our January 2020 submission on aged care redesign we welcomed the way in which your consultation paper attempted to place people – system users and their carers and families – more centrally within systemic design. However, we noted that there was much more that could be done in this regard, using person, or human-centred design thinking and incorporating relational care approaches more fully.

In this submission we build on our earlier arguments, highlighting some of the ways in which we think that the ageist underpinnings in the age care system have played a key role during COVID-19 pandemic.

Introduction

The EveryAGE Counts campaign is relieved that Australia has been so successful in containing the spread of COVID-19. We are also deeply saddened at the loss of life both here and internationally. We are particularly grieved by the concentrated outbreaks of the virus in a small number of residential aged care facilities in Australia to date. Our sympathies go to the families and friends of those whose have died, their carers and other residents. We further acknowledge the distress caused by the implementation of strict physical isolation on residents, friends and families, and at the same time, the efforts made by frontline carers, health professionals and administrators to do everything possible to keep older people safe in home based and residential aged care.

However, EveryAGE Counts believes that fault lines created by ageism at the heart of the aged care system have been exposed by the stresses of the pandemic – not only at the point of service delivery but also at the level of design, policy, funding arrangements, crisis management and integration with the healthcare system. This submission will focus on those fault lines, those cracks in the aged care system exposed by COVID-19.

In our August 2019 submission to the Royal Commission, we argued that ageism is an underpinning of the following issues:

- impact of the 'economic and social burden narrative' on aged care;
- the stigmatising of older age, older people and impairment in older age;
- the absence of a vision of a 'good life' in older age with impairment;
- the absence of a vision for a good end-of-life experience and death;
- unchallenged institutionalisation and segregation of people experiencing impairment in older age;
- lack of awareness of ageism and its impacts in aged care;
- the lack of safeguards against neglect and elder abuse; and
- the absence of a human rights approach and framework in aged care.

In our discussion below we draw on these pre-existing, systemic and cultural issues to highlight some of the ways in which ageism has played out in aged care during the pandemic to date. In particular, we highlight the role of:

- infantilising, stigmatising stereotypes of total dependency of older people in aged care;

- the loss of personhood status and the denial of personal agency to older people in decision-making about their own lives in care situations;
- compromise of the human rights of aged care residents in accessing healthcare on the same terms as those in the broader community;
- the missing imperative to give quality of life the same weight as quality of care in aged care;
- the reliance on the simplistic marker of chronological age to designate risk in the pandemic;
- the need for workforce transformation to support new service models and deliver appropriate care and support to older people in aged care.

Key Issues

1. The absence of personal agency and voice of older people in residential age care decision-making during the pandemic

It is striking to EveryAGE Counts that during the COVID-19 pandemic the voices of older people in residential aged care have largely been absent from the public debates. This has been the case even on key issues such as visitor policies, resident relocation and the location of medical treatment of COVID-positive residents.

Within individual facilities we understand anecdotally that there was considerable variation in approaches to engaging residents, from no consultation through to significant levels of participatory decision making. We acknowledge that this engagement is not always easy with those residents who are the most frail and ill. However, the invisibility of older people in public debates, and the absence of evidence from providers or government that residents were being engaged at the local level, has deeply concerned us.

The struggle over visitors to residential care, for example, played out in media largely between aged care provider peak bodies on the one hand and government on the other. Families of residents were a presence in these discussions in a limited way – largely around issues associated with the failure of information flows – and consumer groups clearly worked hard to represent the rights and needs of aged care service users in policy and practice responses.

However, the absence of older people's voices in public debates about how best to balance safety and wellbeing is a clear violation of the sovereignty of older people in the context of care. It is symptomatic of the infantilising stereotypes of total vulnerability and dependency in which older people become the object of care and not agents of either individual or collective decision making. We are also deeply concerned that the silence of residents creates a feedback loop, further entrenching public sentiment that it is appropriate to make decisions for and about older people in the residential care setting without their active engagement.

EveryAGE Counts asks the Royal Commission to review the recommendations in our original submission, which we believe have a great deal to offer on shifting norms in residential care around individual resident agency and decision-making. The suite of recommendations from our first submission to the Royal Commission are included at the end of this document, and we particularly draw your attention to Recommendations 1, 4, 6, 7, 9, 10, 11 and 13 as especially relevant here.

Fault line

The absence of older people in public debates about how best to balance safety and wellbeing is a clear violation of the sovereignty of older people in the context of care. It is symptomatic of the infantilising stereotypes of total vulnerability and dependency in which

> older people become the object of care and not agents of either individual or collective decision making.

2. The adequacy and appropriateness of containment pathways in COVID-19 outbreaks in residential aged care.

In our original submission we argued that the negative social norms around older age and disability and/or impairment contribute to continued social acceptance of a segregated system of care for older people, constructed as a one-way journey. We believe this narrow, linear and rigid view of aged care limited and skewed the decision-making around the best way to contain COVID-19 outbreaks in residential aged care, making it difficult to think through alternative options for managing infection. At least some Australian jurisdictions seemed unable to conceive of any alternative to tighter, quarantined in-place segregation as the only containment strategy available.

In Europe, where the deaths of older people in residential care and nursing homes are thought to account for around half of all COVID-19-related deaths, the Council of Europe's Human Rights Commissioner, Dunja Mijatovic, issued an urgent wake-up call on the care of older people in the pandemic and beyond.[1] She called for other countries to learn the lesson of Europe and repeated the call from the WHO[2] for residents with COVID-19 to be cared for in a health facility.

We ask the Royal Commission to investigate the assumptions and values behind and efficacy of state-by-state approaches – and variation internally within in some states and territories – to containment of COVID outbreaks in residential aged care facilities in Australia. In particular we ask you to examine how widespread the practice was of not moving COVID-19 infected residents to hospital from residential care, the reasons given for this and why WHO advice on this issue was not heeded. Equally importantly, we ask the Royal Commission to assess the impact on infection and mortality rates of placing responsibility for critical care and infection control on staff members in an aged care environment apparently not established to provide it under such extreme circumstances.

Aged care provider peak organisation, ACSA, reiterates this point in its important recent paper on the interface between aged care and the healthcare system during the pandemic.[3]

> Residential aged care is not an acute setting and has never been funded in such a way to enable clinical care to be delivered. Comparing the funding provided for acute hospital care versus residential aged care illustrates this – the average national cost for acute hospital care per day is $1,300, compared to an average aged care bed cost per day of just over $300.
>
> Residential aged care facilities are homes, not acute medical facilities. They provide a home-like environment to their residents, and do not have the medical resources required to deliver acute care, such as doctors and other clinicians, medical equipment or sufficient levels of personal protective equipment to cope with a significant outbreak.[4]

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[1] https://www.coe.int/en/web/commissioner/-/lessons-to-be-drawn-from-the-ravages-of-the-covid-19-pandemic-in-long-term-care-facilities

[2] https://apps.who.int/iris/bitstream/handle/10665/331508/WHO-2019-nCoV-IPC_long_term_care-2020.1-eng.pdf (P3)

[3] EveryAGE Counts welcomes and supports ACSA's strong framing around ageism in this paper.

[4] https://acsa.asn.au/ACSA/media/General/Documents/ACSA-Policy-Paper-A-Framework-for-the-Aged-Care-and-Healthcare-Interface-during-COVID-19-FINAL.pdf (P4)

The apparent decision taken by NSW Health, for example, to isolate those diagnosed with COVID in place at Newmarch House, rather than admit them to hospital and/or evacuate uninfected residents, is of deep concern. In our view it demonstrates, at best, a mistaken view that residential care is somehow able to transform itself into an extension of the critical care infrastructure in the tertiary health system. At worst, the decision to quarantine all residents in place at Newmarch House, can be interpreted as denying the right to proper medical treatment and protection against infection to an entire community of older people.

Clearly, there was enormous and dedicated effort from staff at Newmarch (who themselves braved and were widely infected by COVID-19) to care adequately for sick residents and stem the spread of infection. However, we ask the Commission to examine closely whether they had the specialised training, skills, equipment, numbers and other support to do this job. (See our discussion of workforce issues below.)

Placing the responsibility on aged care staff is particularly hard to understand while hospitals with intensive care units, palliative care capability, highly trained staff and the capacity for infection management were available nearby. Why and for whom were the hospital beds being saved? Why were aged care residents, on a collective basis, not deemed suitable for medical treatment in hospitals on an individual basis, available to other older people and other ages in the broader community?

AGE Platform Europe, a European network of non-profit organisations of and for people aged 50+, has also highlighted this deep concern. AGE Secretary-General, Anne-Sophie Parent has publicly argued that aged care lockdown measures in Europe did not aim to save older persons' lives. Instead, she argued, the actual purpose of those measures was to enable the health systems to regain their capacity to cope with the pandemic and in the longer term to save the economic fabric.

> "When we look at the number of people who lost their lives because of COVID-19, half of them were older persons who were never brought to hospital. So, it was not to save those lives that the lockdown measures were introduced".[5]

A common response made in defence of not relocating those with COVID-19 from aged care facilities to hospital, has been that residents themselves wanted to remain in their home – the aged care facility – and many did not want to receive what they perceived as futile care in hospital. EveryAGE Counts understands and defends the right of residents to choose the former in circumstances that do not endanger others, and the latter in all circumstances. We also acknowledge that moving very ill and frail people to hospital contains its own serious risks. However, the Royal Commission should assure itself and the community:

- (by reference to the evidence in the form of advance care directives and other records and discussion with residents and their families) that *individual residents themselves* did indeed choose this path, with the option of hospitalisation being freely available to them as an alternative;
- whether the dual role of residential facilities as a home-like environment meeting high care needs and, when required, operating as a critical care facility is feasible, fair, realistic or effective;
- that the quarantine approach itself, when used, did not exacerbate the spread of the virus among a congregated, highly susceptible group of people; and

[5] https://www.age-platform.eu/policy-work/news/liberties-lockdown-webinar-age-highlights-intergenerational-challenges

- that the right to healthcare of the type and quality available to those in the broader community (for example, quality palliative care and life saving treatments) were not denied to residents in quarantine who may have benefited from them and chosen them.

EveryAGE Counts supports the call from ACSA for federal, state and territory governments to develop and adopt clear protocols for the management of the interface between the aged care system and the health system, particularly residential aged care and hospitals, during the COVID-19 situation.[6] We view this common sense, obvious, essential guidance as urgent to achieve.

Fault line

Ageist assumptions about who should receive critical hospital care in the pandemic, with aged care residents on a collective rather than individual basis deemed not suitable for medical treatment in hospital, available to other older people and other ages in the community on an individual basis, does not meet the rights test.

3. Impact of physical isolation on residents

EveryAGE Counts fully acknowledges that the issue of visitors in residential aged care and the presence of carers in the home during the pandemic presents difficult dilemmas and complex decisions for all involved.

At its most distressing, those dying in residential aged care have largely been unable to have family with them because of fears of contagion. We acknowledge that this is not specific to aged care facilities, as we have all seen the sad footage from overseas hospitals where patients were unable to have family or friends with them at the end of their lives. However, for all aged care residents where facilities have issued blanket bans on visitors, the cost to mental health and wellbeing is widely accepted as having been great.

The recent ABC episode of 4 Corners, which followed the experience of a number of Newmarch residents and their families during the lock-down period gave us a window into the extreme experience and impact of isolation over a number of weeks. The lived experience of isolation in individual rooms depicted by the show was distressing enough to view, and was clearly deeply difficult to live through for many residents.

EveryAGE Counts supports recent comments from Anglicare Australia that there needs to be a much broader and deeper conversation about balancing mental wellbeing, social connectedness, quality of life and the rights of older people with public health responses that rely on isolation as the key protective measure. This conversation needs to be forward looking, and based around possible COVID-19 outbreak scenarios going forward in this pandemic and beyond.[7]

Anglicare Australia acknowledges that there is no question that older people want to be properly protected from a virus that may well kill them; but they also wish to live as full a life as possible in their later years, knowing their time is likely to be limited and is precious. EveryAGE Counts agrees with Anglicare Australia that there is a complex set of rights to balance – particularly in any close, communal environment such as aged care – where the rights and wishes of one individual have to

[6] https://acsa.asn.au/ACSA/media/General/Documents/ACSA-Policy-Paper-A-Framework-for-the-Aged-Care-and-Healthcare-Interface-during-COVID-19-FINAL.pdf (P4)

[7] Anglicare Australia is a member of the EveryAGE Counts coalition and provided these comments from their own draft submission to the Royal Commission, with permission for quotation given to EveryAGE Counts

be balanced against a collective approach. But this "conversation is urgent in order to safeguard choice and rights, and it must have individual older people at the heart of it."[8]

We accept that residential care providers will have considered the complexities of the visitor issue, and have not taken isolation steps lightly. However, we urge the Royal Commission to examine it through the eyes of individual residents, and not just from the standpoint of a facility, where considerations of risk mitigation and efficiency are necessarily part of the response.

EveryAGE Counts is looking to the Royal Commission to:

- examine the evidence of the sources of infection in residential care before and after widespread visitor bans, to better understand the risk and response profile and reassure residents and the community more broadly of the evidence base for the quarantine path, or recommend a shift in direction;
- directly ask residents
    - whether they would have been and are willing to have visitors and under what conditions and circumstances during the pandemic
    - whether their views were ever sought on isolation policies and practices;
- investigate if any innovative ways of enabling safe personal contact between residents and visitors have been introduced by any facilities to date and what would be needed to replicate these more broadly;
- identify specific impacts of isolation policies and practices on residents as a whole and on particular groups of residents, including how these impacts were addressed and what can be learned from this
    - in particular, how those in mainstream care whose first language is not English were impacted when the absence of family and friend visitors removed their interpreters and only outlet for verbal communication, and how communication was facilitated in their absence; and
- assess the readiness of the home based care system to continue safe delivery of its services during the pandemic.

Fault line

The lack of discussion – with older people themselves at the centre of it – which balances the rights and choices of older people to be properly protected from the virus but also to live as full a life as possible in their later years has been a failure of the pandemic response.

4. Exposing the absence of quality of life at the centre of design of the aged care system

EveryAGE Counts raised a number of issues in our January 2020 submission to the Royal Commission on the redesign of the aged care system in Australia that are pertinent to the way in which the COVID-19 pandemic has played out in aged care.

The pandemic has once again demonstrated the serious and fundamental risks associated with communicable disease in the context of large institutional, communal living environments. This practical issue also arises every influenza season and presents an ongoing challenge to the residential care model.

[8] ibid

In his recent article,[9] Mike Rungie argued that the increasing trend of older people 'voting with their feet' to leave, or avoid entry to, the residential aged care system has been boosted further by the pandemic. While EveryAGE Counts recognises that there is likely to continue to be a need for some form of congregate living for older people within the Australian system of care, we support Rungie's analysis that the absence of quality of life and human dignity as a priority at the heart of the current communal system is increasingly unacceptable to a growing body of older consumers.

Further, Rungie is a prominent voice arguing that ageism has allowed our society to redefine quality of life as it applies to older people; elevating quality of care as the only important factor and normalising institutions as the best place for older frail people to live.

Added to this, many older people have further lost confidence in the safety of the aged care system during the pandemic. Rungie argues that the current pandemic has fast tracked a consumer led disruption to aged care service models, and asks us all to consider "…how could we build a residential facility that's not a petri dish and lets people live the way they want to. Can't imagine it? Well try some co-invention with consumers…".[10]

In the pandemic context, EveryAGE Counts strongly encourages the Royal Commission to look for ways to 'design out' as much infection risk in aged care as possible, without resorting to strict and prolonged physical and social isolation. If it is possible at all to achieve in institutionalised situations such as residential facilities, change will require clever design thinking, reframing the 'wicked' problem of infection control in aged care in human-centric ways, focusing on what is most important for service users.

We also include here two further, more detailed points in regard to system design, highlighted by the pandemic.

<u>Communications capability</u>

The pandemic has demonstrated the need for residential aged care facilities to undertake technological upgrades in a number of ways to improve the quality of life of residents. Just one of these is communications capability.

Increasingly, reliable internet access and device availability are viewed as essential services within our society. Anecdotally, we understand that the pandemic lock-down demonstrated that some aged care facilities remain outposts of the age-based digital divide, at the level of individual residents, with internet access available in some facilities only in the common, public areas.

We acknowledge that low levels of digital literacy and physical and cognitive health problems among some aged care residents present challenges for connectivity. However, the pandemic demonstrated that self-directed and staff-assisted digital and mobile connection with family and friends, enabled by 21st Century digital technical capability, is crucial to maintaining the social inclusion and human rights of aged care residents in the face of resident isolation.

This has likely been particularly important for people from culturally and linguistically diverse backgrounds in mainstream residential care during the lock-down period. As we noted above, unless the facility employs staff members who can speak their language, it is often family members who provide language assistance to staff. Were alternative, technology-based communication options available and used consistently to ensure the safety and welfare of residents whose English language skills are not strong?

[9] Mike Rungie, *Coronavirus highlights the strengths and weaknesses of aged care,* Aged Care Insite, May 4 2020
[10] ibid

The growing role of telehealth and 'hospital-in-the-home' also makes mobile and digital access crucial in residential care. While we recognise that it is very early days, it would be timely for the Royal Commission to begin to review how effectively telehealth has been deployed to date in both residential and home-based aged care (compared with usage in the broader community), in terms of coverage, equity, quality of care and health outcomes.

We acknowledge the essential work on ICT in aged care currently underway by the Aged Care Industry Technology Council (AIITC)[11], and urge the Royal Commission to promote this important development in the sector as a priority.

Funding flexibility

EveryAGE Counts also notes that one particular government action in the funding realm during the pandemic points the way forward for greater responsiveness to meet the specific needs of individuals and their communities.

We understand from some of the aged care providers among our campaign members that funding flexibility provisions invoked by government in the crisis have opened important opportunities for better responsiveness. For example, we understand that funding flexibility enabled service delivery to Indigenous communities and individual older Indigenous Australians to be more agile and responsive. The capacity to shift resources to the regions where they were most required in order to meet the needs of elders (as communities and individuals) has been an important feature of funding during the pandemic, and is something to learn from.

Fault line

Institutional living, increasing size of aged care facilities and the lack of fit-for-purpose technologies and funding design mitigate against both quality of life and safe, quality of care.

5. The necessity and opportunity for reform of the aged care workforce

A large part of the Australian aged care workforce has gone above and beyond the call of duty during the pandemic in its efforts to care for and protect residents, often operating within significant resource and information constraints and straining beyond the usual, already demanding scope and volume of work and required skill set. Yet, the public response to this workforce has remained ambivalent during the pandemic.

The pandemic has shone a light on a workforce whose contribution is habitually diminished, stigmatised, underpaid and underplayed in our society. We argue that this is intricately linked to the low social value placed on aged care, older lives and working with older people. Further, the aged care workforce is older than the average in most other industries and sectors, introducing the additional dynamics of ageist, negative perceptions of older workers. It is also a female dominated industry, adding the deep, historical and recalcitrant undervaluing of the work women do in our society, especially when it is associated with caring roles.

Aged care workers are central players in the ability of the aged care system to transform itself to offer contemporary, person-centred, relational care and quality of life to older people. But overall to date, particularly in the residential care setting, the potential for aged care staff to be change

[11] https://www.aciitc.com.au/it-vision/

makers, collaborating with service users to build good lives with aged care, has gone largely unrealised.

Dr Hans Henri P. Kluge, WHO Regional Director for Europe, argues that the top three ways to build sustainable, person-centred, long term aged care in the wake of the COVID pandemic are:

1. empower care workers;
2. change how long-term care facilities operate;
3. build systems that prioritise people's needs.[12]

EveryAGE Counts argued in our first submission to the Royal Commission that the institutionalised paradigm guiding residential aged care disempowers everyone within it, including staff. We expect the Commission will unearth numerous examples during the pandemic where staff in residential care were stymied from speaking up and safeguarding the health and rights of residents because the culture and operation in their facility disempowered them from doing so.

We view Kluge's three priorities above as inextricably linked. However, we would add a fourth, drawing on the pandemic experience:

4. clarify the currently opaque and ill-defined role of residential care in relation to the broader health and social care system.

Without this, the role definition and associated training, qualifications and career paths of aged care workers cannot adequately be specified and delivered, and older people in aged care cannot expect to receive the care and support they require.

EveryAGE Counts would then place these four priorities within the context of ageism. We argue that ageism permeates our society and is carried over into aged care through system design and culture and in the minds of all those involved, including staff members and older people themselves.

Many reports over recent years have chronicled significant issues regarding the aged care workforce, and the reforms required for its sustainability. We have the opportunity to 'build back better' in aged care coming out of the pandemic. Workforce transformation will be a key aspect to support a pivot in service models towards greater dignity, control, choice and rights for aged care service users.

There is still much to be done, and some of it is urgently needed. EveryAGE Counts requests that the Royal Commission refers back to our August 2019 submission, particularly Recommendations 10, 11, 12, 13 addressing ageism and the aged care workforce, and once again we advocate for their adoption as part of a broader workforce reform response.

In addition, we ask you to recommend to Government that it urgently provides a pandemic recovery stimulus package to transform the aged care workforce that:

- promotes the value proposition of working in the aged care industry;
- boosts employment opportunities and addresses workforce pressures; and
- embeds a forward looking skills agenda for new service models and paradigms.

Regarding a stimulus package, we join the chorus of voices that has challenged the Government's focus to date on providing post-COVID stimulus packages to male-dominated secondary industries, rather than female-dominated tertiary service industries.

[12] https://www.euro.who.int/en/about-us/regional-director/statements/statement-invest-in-the-overlooked-and-unsung-build-sustainable-people-centred-long-term-care-in-the-wake-of-covid-19

Fault line

The pandemic has shone a light on a workforce whose contribution is habitually diminished, stigmatised, underpaid and underplayed in our society. This is intricately linked to the low social value placed on aged care, older lives and working with older people.

Conclusion

In summary, the COVID-19 pandemic has created extraordinary circumstances and challenges right across society and throughout healthcare, aged care and other social care systems. The particular susceptibility of older and ill people to the worst impacts of this very infectious virus, along with the design of the aged care system, has ensured that residential care facilities are at the frontline of the pandemic.

It is timely and valuable for the Royal Commission to review the way in which the aged care system has responded to the pandemic to date, and to identify adjustments and even wholesale changes in direction going forward, while the pandemic continues. This review is also crucial for embedding learnings into transforming the aged care system going forward.

In addition to your review of safety and protection factors, we encourage the Royal Commission to examine whether the human rights of people in the aged care system have been safeguarded during the pandemic. We acknowledge the very real danger to the lives of older people presented by the virus and the extraordinary efforts of aged care staff and managers, policy makers and individual Australians of all ages to support those most susceptible to its worst effects. However, your current review offers a powerful opportunity to open the conversation as to whether the particular protection path chosen was the most effective at stemming outbreaks in aged care and saving older people's lives.

Importantly, you also have the opportunity to examine whether unthinkingly the COVID-19 response was at the cost of the human rights of older people in the aged care system. The capacity to balance both the protection of rights and safety is owed to older people in the aged care system.

In particular, we encourage you to consider:

- whether the quality and type of health care available to those in the broader community was restricted or limited for those in residential aged care and if so, why;
- whether free and informed consent was sought from residents in aged care (to the extent that individuals were able to exercise this right assisted or independently) regarding medical treatment decisions;
- the degree to which a COVID-19 response decision-making framework in aged care incorporated principles and practices around safeguarding human dignity, personal agency and the equality of aged care residents with other Australians;
- the degree to which actors at all levels of the system fulfilled their duty of care in respect of residents and the aged care workforce.

We attach our set of recommendations from the EveryAGE Counts submission to the Royal Commission in August 2019, which we believe remain relevant to your current deliberations.

We are of course very willing to discuss our contribution in this submission in further detail with you in person.

Yours faithfully

Robert Tickner
Co-Chair
EveryAGE Counts

Kirsty Nowlan
Co-Chair
EveryAGE Counts

ATTACHMENT 1: EveryAGE Counts recommendations to the Royal Commission on Aged Care Quality and Safety – from submission lodged 2 August 2019

The EveryAGE Counts campaign calls for:

Recommendation 1:
Political leadership at all levels of government build a new narrative about the opportunities of longevity, the strengths and opportunities for innovation and the value of lives at all life stages.

Recommendation 2:
The Productivity Commission research the economic and social contribution made by older Australians within families, communities, the workforce and as tax payers, to:

- provide balance to its inquiries and projects over the past decade which have focused on the costs and challenges of an ageing society;
- contribute more complete evidence to inform public debate and narratives.

Recommendation 3:
The federal Treasury include greater balance in its next-in-series Intergenerational Report by expanding its data coverage and analysis of the economic and social contributions made by older people to our society as well as the costs associated with an ageing society. Further, data and its analysis should be disaggregated by age, on a decade by decade basis over 65.

Recommendation 4:
The Minister for Aged Care and Senior Australians commission research in community and residential aged care:

- to identify the forms of conscious and unconscious ageism and understand their impact within aged care;
- support a 'what works' program of action research to build evidence based approaches to addressing ageism in aged care settings.

Recommendation 5:
The Minister for Aged Care and Senior Australians review aged care funding models to ensure they support reablement as well as providing appropriate clinical care when needed.

Recommendation 6:
The Minister for Aged Care and Senior Australians review and redirect (as required) policy, regulation and funding arrangements in aged care towards actively supporting good lives with frailty and impairment:

- as defined by older people in an ongoing collaborative process with aged care staff, families and the broader community;
- drawing on and expanding the body of research on this issue;
- developing an outcomes framework that enables continuous improvement in service delivery and facilitates transparent reporting to those using or selecting aged care services.

Recommendation 7:
Establishment of a collaborative Ministerial Taskforce through COAG engaging governments, aged care providers, advocates, aged care users and broader communities in the creation of a new initiative, New Models of Living Arrangements and Care for Older Australians to:

- explore, pilot, test and invest in initiatives that offer contemporary, integrated alternatives to segregated, institutionalised aged care;

- shift government funding models to expand new, evidence-based models of living and care for older Australians.

Recommendation 8:
The Australian Institute for Health and Welfare (AIHW) lead the development of an ongoing, deeper, more comprehensive picture of the diversity of Australia's older population taking into account cultural and linguistic background, Aboriginality, sexual and gender diversity, place and socio economic status:

- in collaboration with all levels of government and relevant NGOs;
- drawing on and developing both quantitative and qualitative data sets to provide a full view of lived experience;
- providing a comprehensive data source for exploration of the impact of and way in which
    - multiple forms of marginalisation, disadvantage or discrimination can overlap or intersect in older age, and
    - the opportunities and strengths available to older people from their (often multiple) identities and identifications;
- contributing to policy, research and service models that reflect and respond to the diverse older population and are therefore fit for purpose.

Recommendation 9:
A broad, sustained Commonwealth government-funded public awareness and education campaign on ageism and its impacts, which:

- aims to shift social norms on ageing and being older to recognise both opportunity and diversity of experience;
- builds on recent government campaigns such as Long Live You;
- recognises all elements of the lifecycle including the possibility of needing, accessing and navigating care and support.

Recommendation 10:
Aged Care providers, with government resource support, develop collaborative, localised responses co-designed between staff, aged care recipients, families and carers to understand:

- ageism (in both its benevolent and malevolent forms) within specific aged care settings;
- the operation of unconscious bias towards older age and its impacts;
- the ways to reduce the impact of ageism on the quality and safety of aged care for all involved;
- how to move more towards a culture involving a 'dignity of risk' approach (while not abrogating the duty of care), recognising the importance of this for autonomy, identity, a good quality of life and the success of Choice and Control Reforms, person-centred care, reablement and other health strategies.

Recommendation 11:
Explicit support in the Aged Care Workforce Strategy for inclusion of learning goals, assessable elements and performance criteria explicitly on ageism (what it is, how it operates within aged care, what its impacts are, how to change ageist attitudes, behaviours, practices, processes and policies) within:

- national training certificates, diplomas, degrees and Continuing Professional Development programs in community services, nursing, allied health and aged care and support (building on the existing units of competency related to facilitating the interests, rights and empowerment of clients).

Recommendation 12:

Governments maintain effort and resourcing to implement the five priority areas in the *National Plan of Action to Respond to the Abuse of Older Australians (Elder Abuse) 2019- 2023*. In particular, that *Priority Area Five: Strengthening safeguards for vulnerable older adults*, goes beyond its current focus on safeguarding in the aged care regulatory framework to also incorporate the necessary components of:

- awareness raising and education about ageism and its impacts in the community and within the aged care system;
- promotion of a human rights approach to underpin the aged care system.

Recommendation 13:
A stronger, explicit, funded human rights approach within all aspects of the aged care system, which has at its core the inherent value of every human life; is aspirational in relation to the fulfilment of the full complement of human rights; is in line with the World Health Organization principles of human rights and health and the UN Principles of Older Persons (especially Principle 14); and is reflected in aged care policy and program design, implementation and accountability measures. As an important underpinning for this approach we call for:

- review of the package of federal Aged Care legislation (beginning with the Primary Legislation – the Aged Care Act 1997)
    - introducing a coherent, rights-based approach to the purpose, principles and application of the legislation
    - introducing the rights-based principle that society should make living conditions available for people who have impairments that are as close as possible to those without impairments
    - examining whether continued separate aged-based care legislation is consistent with a human rights approach;
- Australian Government support for the creation of a UN Convention on the Rights of Older Persons, and its eventual ratification by Australia noting that
    - there is no binding international instrument dedicated to the human rights of older people, and o a Convention ratified by Australia would provide a stimulus, encouragement and authority for a much stronger human rights framework in Australian aged care;
- greater use and awareness of the existing provisions and objects of the Australian Age Discrimination Act to improve outcomes in aged care
    - given the explicit inclusion of changing negative stereotypes about older people within the Act's objects;
- a government-funded education program across aged care (including residents and families as well as provider organisations and staff) about
    - the new Charter of Aged Care Rights
    - the broader context of human rights of aged care recipients
    - the way in which ageist norms around older people operate in aged care and undermine human and consumer rights
    - a range of ideas about co-creating living environments with and for those in receipt of aged care that reflect the sort of opportunities available to older people not using aged care
    - the *National Plan of Action to Respond to the Abuse of Older Australians (Elder Abuse) 2019-2023* and the role of ageism in elder abuse.