



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.

24 January 2020

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

By Email

Dear Royal Commissioners

The EveryAGE Counts Campaign appreciates the opportunity to comment on the recently released Consultation Paper 1, *Aged Care Program Redesign: Services for the Future*. Our brief comments here follow on from our detailed submission on the operation of ageism within aged care, lodged with your inquiry on 2 August 2019. We believe that submission contains many important concepts,

principles and recommendations of deep relevance to the discussion of system design, and commend it to you once again in the context of the Consultation Paper.

We congratulate the Royal Commission for the direct approach you have taken in the Consultation Paper to the crucial issue of redesign of aged care for the future, and your explicit acknowledgement of many of the current system design faults. We also welcome the way in which you have attempted to place people – system users and their carers and families – more centrally within systemic design. However, we feel there is much more that could be done in this regard, using person, or human-centred design thinking and incorporating relational care approaches more fully. We take this up below in our point on co-design.

EveryAGE Counts will leave detailed critiques of the proposed model to those with deeper understanding of the technical operation of aged care, and will instead comment on whether the proposal adequately acknowledges and addresses underlying ageism in the system, and whether it offers older people quality of life and a real alternative to current practices. To that end we mostly address the proposed principles, general structure and process of redesign.

Response to the proposal in the Consultation Paper

1. The pivotal issue of ageism that underpins so many of the existing problems in aged care (and in many other settings) is inexplicably missing as a focus, concept, frame, or even as a word, in the Consultation Paper.

The Royal Commission *Interim Report* last year acknowledged in its Introduction the existence and impact of ‘ageist mindsets’ in aged care. While we were dismayed that you did not directly recommend action to address this crucial issue, we anticipate that the Royal Commission will do so in its Final Report. Similarly, in the Consultation Paper you do not name the problem of ageism, let alone directly tackle it. This is despite widespread acknowledgment of the role played by ageism as a barrier to safety, positive outcomes and quality of life for older Australians in aged care.

We welcome the proposed principles set out in the Consultation Paper, and particularly acknowledge the starting principle that focuses on the rights of older people. We believe this would be strengthened and made more meaningful by clarifying that this is as much directed towards the rights to personal autonomy in decision-making across all aspects of daily life as to rights to safety and quality care.

We also acknowledge the inclusion of other crucial principles around maximising independence and functioning, but feel that a missing piece at the principle level is committing the system to flexible operation around rehabilitation and reablement. It is essential that aged care does not place people on a one-way conveyor belt, but rather, responds to the realities of people’s complex journeys through illness and impairment in older age and partners with older people around illness prevention and to maximise health and function improvements and recovery.

Further, we welcome the elevation of quality of life into the principles statement, but strongly recommend that you lift it out as a stand-alone principle. Coupling principles of quality of life and independence with physical functioning alone – and not with other equally important rights – is a worrying aspect of the current principles statement.

Related to this, is the absence of a principle around co-design. While it appears in other parts of the paper as a method for delivering care, EveryAGE Counts views it as much more than that. The necessity of a system designed and delivered around the centrality of the voice of those using it is surely one of the great lessons to emerge from the Royal Commission so far.

Our overall point in regard to the principles is that ageism in our society broadly and within the aged care system specifically, creates a major barrier to success in embedding and enacting these principles. The positive intent of the principles will not somehow 'trickle down' to dilute the underpinning of negativity towards and stigma attached to older age and older people in our society, and upon which so many of the problems in aged care rest. Conversely, the oppressive foundation of ageism is likely to render the principles meaningless rhetoric. In addition, as you move forward with refining the design process and proposals we strongly encourage you to map the logic of translation of those principles into the structure, implementable delivery strategies and measurable outcomes.

2. EveryAGE Counts is concerned that despite strong acknowledgement of the principle of co-design in the proposal, this crucial first stage of system redesign is a top-down consultation exercise, rather than a meaningful, open, bottom-up co-design process.

In our view this is reflected in the limited model proposed which, while offering an improvement on current arrangements, is not the transformation to aged care we believe is urgently needed. Such a transformation requires all ages, but especially current older people, to come together to reimagine the possibilities for living and care arrangements in later life. We are confident that such a process would:

- generate an emphasis on quality of life, rather than mostly on quality of care (as important as this is);
- stress strengths and growth in later life (including allowing for the potential for recovery and rehabilitation from illness, injury and impairment at various stages of later life) rather than largely focus on a medical model of decline and impairment; and
- flesh out real meaning in the operation of relational and person-centred care, rather than a continued over-emphasis on transactional, market-based interactions.

We understand the imperative faced by the Royal Commission to improve the system and support the positive intent to generate change as quickly as possible. To that end, we suggest that running alongside the program improvement offered in the present proposal, a commitment be made to a concurrent, longer term, evidence-based process of transformation of support for older Australians. This should be driven by citizen and consumer-expressed vision and need, and engage providers and their staff, researchers and governments at all levels in leadership of innovation to transform the system.

3. Regarding the proposed structure, resting essentially on three streams of care, and the interactions between parts of the system, we ask the following questions:

- How will the new structure avoid system silos, and instead ensure nuanced, non-linear, person-centred continuums of care across different assessment points and funding pools?
- (While we welcome the intent to improve face to face support in accessing and navigating the system and the recognition of variable need for assistance) how will the

individual preferences, choice and agency of the older person be safeguarded without explicit recognition of the need to counter ageist assumptions, stereotypes and behaviours in interactions between system assessment, case management and navigation staff on the one hand and aged care consumers on the other?

- (While we welcome the motivation of the proposal to provide in-reach multi-disciplinary, clinical care within residential care environments in the interest of resident safety, comfort and clinical support) given the poor record of attracting medical and allied health staff into residential care, what safeguards will there be against the creation of a separate, second-class, rationed healthcare response in residential aged care?

Conclusion

In summary, the existence of ageism needs to be explicit, articulated and tackled with very real, meaningful strategies in redesign of the aged care system – otherwise the important principles outlined in the current program improvement proposal become rhetoric that can be too easily ignored. It is essential to uncover, give shape to and find ways to eliminate the ubiquitous, but largely invisible force of negativity towards older age, older people and especially older people with cognitive or physical impairment.

If we redesign the system based on existing ageist assumptions and stereotypes, and the devaluing of older people and this stage of life, we are largely tinkering at the edges but leaving the foundations in place. In so doing, the ongoing impact of ageism will continue to sabotage improvements and change in aged care and undermine quality of life for older Australians.

We attach our set of recommendations from the EveryAGE Counts submission to the Royal Commission in August 2019, which we believe are especially relevant to the discussion of system redesign. We believe that the adoption of these recommendations will lead to the transformational changes so urgently needed and expected.

We are of course very willing to discuss this in further detail with you in person and thank you for invitation to participate in the upcoming Design Roundtable and Workshop. We would also welcome any other opportunity to discuss the issue of ageism further with you as Commissioners.

Yours faithfully



Robert Tickner
Co-Chair
EveryAGE Counts Campaign



Kirsty Nowlan
Co-Chair
EveryAGE Counts Campaign

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

The EveryAGE Counts Campaigns 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
 - 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.