A Principles-Based Framework to Guide System Change

Submission Purpose

The Australian Association of Gerontology (AAG) strongly supports the Commissioners' ambition for systemic change to the arrangements for caring for older people[1].

AAG's membership has identified a wide range of important areas for inquiry and reform of services and supports for older people. All of these areas are important and informed by a significant body of research, practice knowledge and personal experience. Because of the number and complexity of these issues, it is important that the Royal Commission is guided by a conceptual framework to strategically structure and prioritise thinking, discussion and action for the reform of services and other support for older people.

The basis for AAG's submission is that systemic, transformative change is necessary to address safety and quality issues: substantive, on-going and sustainable improvements cannot be adequately addressed through ad hoc or piecemeal change. Most importantly, systemic reform must address the underlying ageism that has resulted in a discriminatory and frequently second-tier 'aged care system'. Ageism is defined by the World Health Organization (WHO) as:

"…the stereotyping, prejudice, and discrimination against people on the basis of their age… ageism is everywhere, yet it is the most socially "normalized" of any prejudice, and is not widely countered – like racism or sexism. These attitudes lead to the marginalisation of older people within our communities and have negative impacts on their health and well-being[2]."

Marginalisation of older people in a second-tier 'aged care' system is apparent in:

- professional and community expectations that all older people have significant levels of disability (particularly cognitive impairment) leading to disrespectful interactions
- mainstream health and other services (e.g. financial, hospitality, housing etc) not being aware of, designed for, or operated to appropriately support older people
- 'warehousing' of older people in residential aged care, where residents are separated from their communities with an expectation that they will not return to their communities (with an accompanying lack of appropriate services for integration or reablement)
- differentiating care pathways for health and community services based on age rather than other more relevant factors such as their health and social care needs
- marginalisation of the workforce in health and social care who provide services to older adults, reflected by comparatively low salaries, and low levels of education, training and on-going professional development opportunities in gerontology.

EveryAGE Counts found that 33% of survey participants identified aged care as an important area in which to address ageism (following behind only the workplace and healthcare in importance)[3]. The AAG endorses the EveryAGE Counts Royal Commission submission on ageism and aged care through its contribution as a member of the Coalition Steering Group.

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[1] *"The Royal Commission is a once-in-a-lifetime opportunity to come together as a nation to consider how we can create a better system of care for elderly Australians that better aligns with the expectations of the Australian people"* (Commissioner Tracey 18/1/19)

[2] WHO Ageing and Life Course: Ageism, https://www.who.int/ageing/ageism/en/

[3] The Benevolent Society, The Drivers of Ageism. September 2017. p.19, https://www.everyagecounts.org.au/research

A fundamental re-conceptualisation may be required to address the underlying ageism inherent in the concept of a separate aged care system to ensure safe and high quality services and support. The system of services and support for older people should be responsive to the needs of those it is designed to serve (requiring a holistic view of the person and their needs) and rigorous in promoting best use of public resources.

This submission presents a principles-based, conceptual framework to strategically structure and prioritise thinking, discussion and action to guide transformational change of services and other support for older people. The framework comprises the following principles:

- Principle 1: Informed by evidence
- Principle 2: Recognising the whole person
- Principle 3: Ensuring equity of access and outcomes.

These principles are discussed further below.

The value of this principles-based framework to the Royal Commission is that it is:

- universal: applicable across the range of reform areas
- strategic: can be used as a filter to focus on the most important issues
- pragmatic: guides system design, service delivery and accountability.

The framework reflects AAG's purpose to improve the experience of ageing through connecting research, policy and practice. AAG's distinctive value to the Royal Commission's investigation (and to on-going system and service improvement) is by being:

- independent: AAG is not obligated to serve the interests of any particular profession, institution, service sector or interest group
- collaborative: since 1964, AAG has connected professionals with an interest in gerontology to help them collaborate and exchange information on ageing. Currently, AAG brings together over 1,450 members to share knowledge, influence policy and inform practice by bringing the evidence base and knowledge on ageing to wider forums
- multidisciplinary: AAG's members include researchers, geriatricians, nurses, allied health professionals, aged care practitioners (including personal care workers, managers and other aged care workers), policy makers, consultants and other gerontology specialists.

This submission should be read in conjunction with AAG's ATSIAAG (Aboriginal and Torres Strait Islander Ageing Advisory Group) submission to the Royal Commission into Aged Care – dated 12 August 2019.

Principle 1: Informed by evidence

System reform and service delivery should be based on research, practice knowledge and the experience of older people

Priority areas for action include:

- *improving coordination to better utilise existing information, and to identify and address information gaps*
- *broadening the scope, quality, volume and type of research and to incorporate multidisciplinary and cross-sectoral approaches, wider sources of information, and co-design with older people from the outset*
- *improving the translation of evidence to inform better practice and policy*
- *embedding rigorous design and outcomes measurement principles in program monitoring and reporting to track implementation and inform future directions*

This principle highlights the importance of broadly conceiving 'evidence' to incorporate multiple sources, including the lived experiences of older people, carers and communities; the practice of individual professionals; the experience of provider organisations and administrators; models of care; high quality research; and learnings from policy implementations and directions.

In its submission to the Medical Research Future Fund, the AAG drew attention to three critical aspects of ageing research.

Firstly, effective research and evidence about ageing should recognise the multi-factorial causality of age-related health issues. Ageing research is poorly served by the dominant bio-medical, single-disease research model and needs to incorporate specialist gerontological knowledge. Ageing research has experienced significant funding neglect over many decades with the consequence of a substantial shortfall in evidence and research capacity. Therefore, ageing research requires a multidisciplinary and cross-sectoral approach that builds research capacity and collaboration across relevant areas (such as medical, psychosocial, nursing, allied health, organisational, disability, technology, design and policy), including international collaboration where relevant[4].

Secondly, just 'doing the research' is not enough. A greater emphasis is needed on mechanisms to (i) support knowledge transfer, (ii) translate ageing research into policy and practice, and (iii) evaluate effectiveness and uptake into policy and practice through an on-going feedback cycle. Changes to regulations, resourcing and organisational culture are required to support effective research and implementation of evidence to generate practice improvements and opportunities for efficiency gains and the potential for commercialisation[5].

Thirdly, ageing research requires a greater share of Australian research funding and should (i) be of sufficient quality, scale and continuity to bring together collaborative, multidisciplinary teams; and (ii) incorporate budgets and mechanisms for engagement of policy makers, practitioners and older people themselves throughout the research process, and dissemination and translation of findings to increase uptake and application of knowledge[6].

[4] AAG, Medical Research Future Fund (MRFF) Submission, 2018, p.7, https://www.aag.asn.au/news-publications/aag-submissions/2018-08-aag-mrff-submission

[5] AAG, MRFF Submission, 2018, p.9

[6] AAG, MRFF Submission, 2018, p.8

Examples of the successful application of this principle are:

1. AAG Research Trust – Strategic Research Grants[7]: these grants support the development and translation of the evidence base, through facilitating dynamic and responsive research to improve research impact by contributing to research programs and research translation. AAG's Research Trust strongly encourages applications from early to mid-career researchers, and practitioners engaged in research. The grants program is informed by the following principles:
   - emphasising policy and/or practice implications of research, supporting strategic and applied research and research translation
   - promoting multidisciplinary and cross-sector collaboration
   - responding to evidence needs while remaining independent
   - addressing areas of need that are neglected by large scale funding priorities
   - providing equity of access.

2. Unpacking reablement: AAG is playing a lead role in unpacking the different research and policy perspectives, through working towards a consistent and coherent framework for wellness and reablement. It is doing this through the development of fact sheets and videos regarding terminology, current practices and case studies, international guidance documents and supporting evidence, all guided by a broadly-based expert reference group[8].

Principle 2: Recognising the whole person

The experience of ageing will be improved by supporting the physical, mental and psychosocial well-being of the person and recognising the interactions between all aspects of older people's lives and environments

Priority areas for action include:

- *utilising biopsychosocial and person-centred approaches in the design and delivery of services*
- *increasing inter-professional collaboration and co-design within and across systems*
- *increasing system and organisational capacity to offer flexible, tailored services to meet individuals' preferences as their needs vary across the life course*
- *embedding awareness of the implications of an ageing population across all disciplines – from health planning to city planning and financial planning*

This principle is consistent with, and supports the achievement of, the WHO's definition of health: *"Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"*[9]

The corollary to this broad conception of health is the growing international recognition of the profound influence of social determinants of health throughout an individual's life, impacting and resulting in variation in individual needs and preferences for services through diversity of life experience and personal circumstances.

It is therefore important to consider a range of factors to promote and support a holistic, realistic and appropriate conception of good health, including recognising that:

- all relevant determinants of health, including biological, psychological, economic, social and environmental factors, need to be considered to promote improved health and care outcomes

[7] https://www.aag.asn.au/education/strategic-research-grants
[8] https://www.aag.asn.au/news/unpacking-reablement
[9] *WHO, 1946 Preamble to WHO Constitution,* https://www.who.int/about/who-we-are/constitution

- biological processes increase the likely need for specialised services and support for people as they age
- approaches to reablement that promote a cultural shift from 'doing for' the person to 'doing with', through shared decision-making, maximise independence and autonomy
- individuals have different needs, life goals and risk appetite irrespective of their age
- individuals interact with multiple systems (e.g. health, community, housing, economic and political participation, recreation etc).

Examples of the successful application of this principle include:

1. AAG's research on older women experiencing, or at risk of, homelessness[10]: illustrates the value of a 'whole person' perspective. The research recognised the diverse lives and needs of women experiencing, or at risk of, homelessness, and the various economic and social risk factors that are more likely to contribute to homelessness for older women when compared to older men. AAG's recommendations highlight the need to expand and develop services appropriate for older women, including considering changes required in the broader service system (e.g. better integration across aged care, homelessness, health, social service and disability systems); and that the lower socio-economic status of women when compared to men must underpin attempts to address risk factors for homelessness for older women.

2. WHO 10 Priorities: Towards a Decade of Healthy Ageing[11]: identifies that physical, social and economic environments are important determinants of capacity and functional ability over a person's life course and into older age and are powerful influences on the experience of ageing and the opportunities that ageing affords and recommend implementing processes to prevent, slow or reverse decline. They acknowledge the failure of health systems to address complex and chronic needs through a focus on acute conditions.

3. Specialised village style living arrangements for aged care[12]: Hogeway is a Dutch aged care facility for people with dementia that imitates a village lifestyle while being a secure dementia unit. While this approach is too recent to provide a strong evidence base it demonstrates innovation based on evidence. There are also a diversity of quality models of residential and community care that are available in Australia, the best of which need to be documented so as to avoid reinventing the wheel.

Principle 3: Ensuring equity of access and outcomes

Equity of access and outcomes will be ensured by applying human rights-based approaches to the design, delivery and monitoring of services and support for older people

Priority areas for action include:

- *promoting inclusion and responding to the diverse characteristics of older people*
- *addressing ageism to ensure needs-based resource allocation for older people*
- *addressing barriers to ensure equity of access and outcomes for individual older people*
- *applying a more sophisticated approach to funding than the current health and disability funding model that is linked to age or place of residence, to recognise preventive services and early intervention to promote health and well-being across the life course*

[10] AAG, Older Women Who Are Experiencing, Or At Risk Of, Homelessness – Position Paper and Background Paper, August 2018. https://www.aag.asn.au/news-publications/policy-papers/aag-collaborative-project-on-older-women-experiencing-or-at-risk-of-homelessness

[11] WHO 2019 10 Priorities: Towards a Decade of Healthy Ageing esp pp 8 and 12, https://www.who.int/ageing/WHO-ALC-10-priorities.pdf?ua=1

[12] https://www.theatlantic.com/health/archive/2014/11/the-dutch-village-where-everyone-has-dementia/382195/

The WHO has identified that a human rights-based approach to health provides a set of clear principles for setting and evaluating health policy and service delivery and targeting discriminatory practices by promoting services and supports that are non-discriminatory, available, accessible, acceptable, at appropriate quality, accountable and universal[13].

Australia has already ratified a wide range of human rights frameworks that contain provisions relevant to service provision for older people. Human rights frameworks, such as those developed by the National Aged Care Alliance, the United Nations' Madrid Statement, and the Global Alliance on the Rights of the Older Person, are particularly relevant to the circumstances of older people.

"The aged care sector has long been concerned with equitable access to services and participation. However, sector policy tends to speak in terms of priorities and goals rather than in terms of rights. The application of a human rights approach will assure a strengthened focus on a people-centred approach to aged care and the requirement for meaningful participation by older Australians[14]."

A human rights-based approach provides a practical framework to support Commonwealth, State and local governments, and for service providers to establish and monitor arrangements for effective and appropriate policies, programs and resource allocation methods to meet the service and support needs for older people. For example, the principles developed by the Australian Human Rights Commission[15] illustrate how incorporating a human rights approach to the delivery of services and support for older people can promote more person-centred decision-making and real change in organisational culture through:

- Non-discriminatory policy design and service delivery: respects difference and diversity, recognising that discrimination is multi-dimensional, based not only on age but also gender, Aboriginal and Torres Strait Islander or ethnic origin, rural location, disability, poverty, sexuality and gender, literacy levels etc.
- Available, accessible, appropriate and quality services and supports: of sufficient quantity should be made progressively available as needs change. Services and support should be both economically and physically accessible; the service system should promote workforce awareness and on-going training to identify and address access barriers; and there should be appropriate and timely access to health and other personal information.
- Progressive realisation: it is recognised that fundamental change to the current aged care system will need to be implemented gradually and transparently. Progressive realisation recognises the impracticality of demanding immediate implementation. Instead it requires that effective action is taken to progressively work towards the implementation of reform.
- Participation: active and informed participation in decision-making is an essential element in a human rights-based approach to service provision and care. Active and informed participation relies in part on other rights such as the right to seek, receive and impart health-related information, the right to express views freely and the right to basic health education.

[13] refer to the WHO Human Rights and Health, https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health

[14] Australian Human Rights Commission, Respect and Choice: A Human Rights Approach for Ageing and Health, 2012, p.3, https://www.humanrights.gov.au/our-work/age-discrimination/publications/human-rights-approach-ageing-and-health-respect-and-choice

[15] Australian Human Rights Commission, Respect and Choice: A Human Rights Approach for Ageing and Health, 2012

- Monitoring and accountability: monitoring reform implementation and on-going service delivery will require a range of measures in relation to access and equity, quality and sustainability and efficiency and cost effectiveness. A human rights approach to indicators requires additional features to service access and quality measures, particularly in relation to including sex, race, ethnicity, sexuality, rural/urban/remote locality and socio-economic status and to ensure the rights of service users are protected and their decisions respected.

AAG's emphasis on prevention and a life course perspective highlights the inequity of applying an arbitrary age to determine eligibility for aged care, as well as other health and community services. The selection of 65 years of age for the majority of the population reflects nineteenth century life expectancies and does not reflect current (or likely future) life expectancies and age-related capacity. Nor does it reflect variations in individual needs and abilities.

Importantly, current societal narratives about age and ageing do not value the contribution and participation of older people. The dominant focus is on diminishing capacity and the associated societal cost related to ageing.

A human rights-based approach shifts the narrative from an arbitrary age and singular focus on costs to an agreed and easily understood set of principles. These principles provide a consistent, fair and robust framework to inform the development and evaluation of policies, programs and services. Importantly, a human rights perspective effectively addresses ageism by recognising that fundamental human rights do not diminish with age or varying ability.

Examples of the successful application of this principle include:

1. Intergenerational Living[16]: there is qualitative evidence about the benefits of intergenerational living. Humanitas is an example of a move away from closed off aged care facilities. It has six students and 160 older people as residents. Non-residents are also welcome, including individuals with disabilities needing daily support to live independently. It is important that the potential use of international models should be carefully adopted and adapted to ensure they work in the Australian system.

2. Revised funding models: The proposed Australian National Aged Care Classification system (AN-ACC) is an example of a model that attempts to improve resource allocation by adopting a new method for assessing consumer need. The model has been built up from evidence about the drivers of relative care costs in residential aged care, both at the resident and facility level.

[16] Arentshorst ME, Kloet RR, Peine A. Intergenerational housing: The case of Humanitas Netherlands. Journal of Housing For the Elderly. 2019;33(3), 244-256, https://www.tandfonline.com/doi/full/10.1080/02763893.2018.1561592

Conclusion

"*…one of the hallmarks of older age is a great diversity of health and functioning. Since this is often a consequence of the cumulative impacts of advantage or disadvantage across people's lives, policy responses need to be crafted in ways that overcome, rather than reinforce, these inequities*[17]."

Ultimately the goal for AAG is consistent with that of the Royal Commission, Commonwealth, State and local governments, service providers, workers, researchers, and older people and their communities: to improve the experience of ageing by ensuring equitable access to, and outcomes from, quality services and supports for older people that are timely, appropriate, acceptable and respectful.

AAG has proposed the application of a principles-based framework based on research, practice knowledge and the views of older people to guide transformational change at both the systemic and operational levels:

i. guiding system design and policy funding development
ii. supporting organisations and individuals involved in the delivery and improvement of care and services
iii. providing a foundation for communities and governments to consider and discuss issues related to ageing.

Substantive, sustainable improvements to the system of services and support to older people must be grounded in an understanding of ageing as an integral part of an individual's life course, this includes:

- recognising the physical, mental, and social aspects and implications of ageing (i.e. not limited to medical care and treatment of older persons)
- valuing and respecting the contribution of older people in society generally and in the co-design and evaluation of policies, services and support in particular
- multidisciplinary collaboration and investigation including the sciences, humanities, economics, public policy, medicine, and health and community services
- recognising an explicit human rights approach to promote 'people-centred' decision-making and respect for older people.

[17] WHO, 10 Priorities: Towards a Decade of Healthy Ageing, 2019, https://www.who.int/ageing/10-priorities/en/