

EveryAGE Counts Ageism and Aged Care



The EveryAGE Counts Campaign appreciates the opportunity to provide a submission to the Royal Commission into Aged Care Quality and Safety.

EveryAGE Counts is a campaign led by a broad-based national coalition (including aged care providers, peak bodies, staff and consumer representatives) to tackle ageism (see our membership list at Appendix 1). 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 or health care; and
- institutional practices and policies which perpetuate stereotypes and undermine dignity.

Dedication

EveryAGE Counts acknowledges and supports the efforts by a range of individuals (and their families and carers) using aged care services, aged care providers, staff members (and their representatives) and consumer groups, who are working hard for change and improvement in aged care. We also acknowledge that there are some excellent aged care services pursuing best practice and dedicated to the care of older people. We offer this contribution on ageism in aged care in support of those pursuing improvement in the lives of older people and as an additional voice calling for change to the Australian aged care paradigm and how older age is viewed.

Introduction - what is the problem?

This submission argues that ageism is a key driver of failures in safety, quality of care and quality of life within the Australian aged care system and proposes a series of recommendations to directly challenge ageism and mitigate the impact of ageist norms in aged care. We contend that the proliferation of negative social views about ageing and older people are inevitably carried into aged care by the workforce, family members, decision makers and older people themselves, reflecting values and attitudes in the broader Australian community.

Throughout this submission we are focusing on both main aspects of the formal system of regulated, government-funded care specifically for older people:

- care and support delivered in a person's own home through CHSP, Home Care Packages by professional carers; and/or
- fulltime, complex care and support delivered by professionals in residential facilities, on either an ongoing or respite basis.

Practices and processes across this entire aged care system are often unconsciously designed and implemented on the basis of ageist perspectives, which may limit the wellbeing of older Australians accessing these services. While this is true both of community and residential aged care, we propose that the dynamics of institutional care especially reinforce and amplify the impact of ageism within the residential care setting. Therefore in this submission we more often highlight issues within or use examples from residential care.

Ageist norms operate across our society, attaching a lower value and greater stigma to older life than any other part of the life course. The dual, entwined impact of age stigma and stigma attached to disability is especially powerful in negative ways for those in older life who experience cognitive and/or physical impairment. Ageism limits choice, drives poorer outcomes and undermines rights and self-esteem for older people from late middle age onwards, in crucial areas affecting wellbeing such as employment and healthcare, and through into our systems of aged care.

Contemporary ageism in Australia rests heavily on two dominant and conflicting stereotypes of older people, both of which are corrosive and neither of which reflect the reality for most older people. The first stereotype is older people economically and socially draining our society (giving rise to the prominent 'burden narrative') and the second is the affluent, selfish Baby Boomer living a glamorous life (fuelling intergenerational conflict).

We address the first of these in some detail below regarding its impact in aged care. The latter trope though is equally important. It establishes an image of older life in the popular discourse which most older people do not and cannot experience, resulting in a sense of angst and failure for many who feel their lives do not "match up" financially or in other ways to the stereotype. In addition, this stereotype gives permission to society to dismiss older people and ignore ageism because it views older people as having significant advantages over other age groups and nothing to complain about. Not only does this ignore the reality

of economic diversity among older people but it also misses the point that ageism touches the lives of all older people, whatever their circumstances.

We know a great deal now about how ageism operates in employment and health care but there has been less research into and public discussion about its specific impact in aged care, despite its obvious imprint on the design and operation of the system and the relationships with in it. To understand how ageism operates in aged care it is necessary to see it as part of an evolving experience and narrative that begins earlier in older age and accumulates and solidifies across the life course.

Ageism's impacts on individuals and our society accumulates from our 50s when our productivity and rights to employment are questioned, and age-based discrimination in recruitment and promotion soars.¹ So embedded are ageist norms in employment, that the incidence of employers (knowingly or unknowingly) breaking employment discrimination laws is widespread, with around 30% admitting to reluctance to recruit people over around the age of 50.² This undermines our economic security, health and personal confidence in mid-life and affects our standard of living and wellbeing into later life.

Into our 60s and beyond, as major consumers of healthcare many of us experience ageist stereotypes and discrimination in personal interactions with healthcare professionals, access to preventative health measures and age-biased clinical decision-making in diagnosis and treatment.³

Studies repeatedly find that the communication style adopted with older patients by healthcare professionals is often patronising, and older patients are included less frequently in decision-making about their healthcare than younger patients. The same research goes on to demonstrate that these factors can lead to demonstrable negative health outcomes for the older person.⁴

Nursing studies have also often shown negative attitudes towards older people expressed in shorter, more superficial, more task-oriented conversations; less use of humour; more detached treatment; and low expectations of rehabilitation. Importantly, studies also show that there is a link between the functional and health status of an older person and the activation of ageist responses from health professionals – negativity increases when the older person is ill or experiencing impairment.⁵

¹ See for example, Australian Human Rights Commission, *Willing to Work: National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability*, (Australian Human Rights Commission 2016)

² Australian HR Institute (AHRI) and Australian Human Rights Commission, *Employing Older Workers*, (Australian Human Rights Commission and AHRI, October 2018), 5.

³ Mary F Wyman, Sharon Shiovitz-Ezra, Jurgen Bengel, "Ageism in the Health Care System: Providers, Patients, and Systems" in *Contemporary Perspectives on Ageism. International Perspectives on Aging*, edited by L. Ayalon and C. Tesch-Römer (Springer, 2018), 193-212

⁴ Ibid.

⁵ Ibid.

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In our 70s, 80s and 90s when accessing aged care becomes more common (although not universal), many of us carry the accumulated, internalised impact of ageism in other environments into a separate, segregated system of aged care, itself bounded by limited and constraining beliefs around older age.

The age-bias within the healthcare system has a particularly strong impact on aged care, given the interface between medical professionals and models of care between the systems. Even at the policy level, aged care (policy, programs and funding) is firmly situated within the health portfolio at the federal level (despite a short period in recent years where it was placed with Social Services).

Despite a large, long-running, positive aged care reform agenda in Australia⁶, EveryAGE Counts believes that:

- the field and systems of aged care (and its very separation from other systems of care) are largely still constructed around limiting, stereotyped and damaging views of older age;
- our aged care system is the key institutionalised form of social norms about the 'otherness' of older people; and
- ageism permeates the design and delivery of care to older people (often as an unconscious bias) and can lead to (the often unintended consequences of) damage to the autonomy and wellbeing of older people, and to poorer quality service.

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 staff behaviours towards older people accessing care. This approach can undermine the dignity, capability and quality of life of residents and home care service users, 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.

There are many examples of the way in which extreme risk-averse rules and operational practice in residential aged care constrain the lives and choices of residents, ranging from issues with food preparation to the extremely serious use of physical and chemical restraint. These actions are generally motivated by a desire to protect residents (for example from the risk of contaminated food, or the possibility of falling from bed or a chair) but they also result in a range of indignities and losses for them.

In some instances there can also be a conflict between the preference or decision of the older person receiving care and accepted clinical practice. An example of this relating to wound management was shared with EveryAGE Counts by a home care provider. They reported an example of a client wanting different treatment for a wound than the accepted clinical approach and the subsequent difficulty of negotiating an outcome. While there is no question in this example that the best intentions (bringing to bear technical knowledge and skill, and a duty of care) are motivating the provider, if informed consent from the client is absent, should there be any question about the course of action?

⁶ See <https://agedcare.health.gov.au/aged-care-reform>

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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. There is a powerful combination between negative social norms that evaluate some lives as mattering less than others and the power imbalance between carer and care recipient. While the worst examples involve criminal activity and should be treated as such, it is also important to be attentive to the ways in which attitudes, power and resource constraints can create the fertile ground in which abuse and neglect become possible. Importantly, EveryAGE Counts believes that ageism within the aged care system has contributed to the high profile examples of neglect and abuse that have led to a Royal Commission into Aged Care Quality and Safety.

In this submission we do not undertake a resource analysis of aged care, but we do refer to resource constraints occasionally. Our comments on resources are based on our concern about a number of factors that we touch on in the submission, such as:

- the financial constraints placed on reablement, rehabilitation and recovery activity in aged care by rigidity in the funding instrument;⁷
- the ongoing contestation about staffing ratios in residential care;⁸
- the inadequate access to crucial health services within parts of residential aged care such as GP primary health care, dental and oral care and mental health care;⁹
- the significant waiting list for Home Care Packages at the approved level
 - around 125,000 people in December 2018 (comprising people who had been offered a package at a lower level than that for which they were approved and people who had not been offered a package at or below their approved level).¹⁰

EveryAGE Counts recognises that resource issues are not the only reason for poor quality and safety in parts of the aged care system – two aged care facilities may receive identical resources and one will deliver exceptional person-centred care and the other will be quite substandard. Nonetheless, resource availability does form an important part of the picture,

⁷ Chris Mamarelis, “How can we heal aged care when funding relies on us staying sick?” *The Sydney Morning Herald*, April 4, 2019

⁸ see Parliament of the Commonwealth of Australia, *Advisory Report on the Aged Care Amendment (Staffing Ratio Disclosure) Bill 2018* (Canberra: House of Representatives Standing Committee on Health, Aged Care and Sport, December 2018)

⁹ Bronwyn Hemsley, Andrew Georgiou, Joanne Steel, Susan Balandin, “The shocking state of oral health in our nursing homes, and how family members can help,” *The Conversation*, 22 May 2017 AND Linda Slack-Smith, Angela Durey, Clair Scrine, *Successful Ageing and Oral Health: Incorporating dental professionals into aged care facilities* (Australian National University and University of Western Australia, July 2016), 12. AND

Doug Hendrie, “Government announces almost \$100 million in new funding for GP aged care visits”, *NewsGP*, 17 December 2018 AND

Australian Government Department of Health, *Psychological Treatment Services for people with mental illness in Residential Aged Care Facilities* (Canberra: Australian Government Department of Health, 2018) 7.

¹⁰ Australian Government Department of Health, *Home Care Packages Program Data Report 2nd Quarter 2018-19, 1 October – 31 December 2018* (Canberra: Australian Government Department of Health, 2018), 3.

as recent Australian research into GP attitudes towards visiting residential aged care facilities demonstrates.¹¹

In this submission we offer an outline of the main ways we see ageism playing out within aged care and what needs to be done to change this. We explore these through a number of perspectives below:

- 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.

We propose a series of recommendations to the Royal Commission in this submission to reduce ageism in aged care and/or mitigate its impacts. These recommendations fall into three broad categories:

- seeking to change the broader social and political norms about older people, in order to address the problem at its source;
- reforms to legislation, policy and research to ensure that the design of the aged care system is informed by rights based principles and responsive to the full diversity of older Australians; and
- recommendations for aged care providers to strengthen efforts to focus on supporting the wellbeing of aged care users/consumers.

In addition, we subscribe to the principle of working with and through the voice of older people. This principle underpins all the recommendations we make below. While our recommendations here largely focus on the policy sphere, EveryAGE Counts is also actively supporting the mobilisation of older people themselves (and those at other ages who see the importance of these issues) to challenge ageism in aged care and elsewhere.

The Issues – what are the impacts of ageism in the aged care system?

In our view, there a number of main ways in which ageism is played out within our aged care environment. We introduce these briefly below, starting with the negative social norms which permeate our society and by extension aged care and then reflecting on the ways in which these play out within the design and delivery of the aged care system.

¹¹ Russell W. Pearson, Judy Mullan, Eniko Ujvary, Andrew D. Bonney, Bridget R. Dijkmans-Hadley, “Australian general practitioner attitudes to residential aged care facility visiting,” *Health and Social Care in the Community*, 26 (4), e497-e504. Doi 10.1111/hsc.12561

Impact of the ‘economic and social burden narrative’ on aged care

Australia needs to shake off the ‘doomsday’ problem narrative around ageing and reframe longevity as a triumph for humanity....[and] a natural population transition that, for a rich country like Australia, can be managed constructively – without scapegoating older people or applying policies that inflict social deprivation on disadvantaged groups or future generations.¹²

EveryAGE Counts believes that ageism is a key component of a dominant theme within policy, media and public narratives of recent years in Australia – that increased longevity and an ageing population is a burden on society, the economy, younger people and families. While this narrative has operated for decades in one form or another, its prominence in Australia appears to have increased and intensified alongside growing popular recognition of demographic change, and with the five yearly release of the federal government Intergenerational Reports.¹³

The ‘burden narrative’ sets the scene and gives permission for a thread of callousness and disinterest in society towards the needs, experiences and rights of older people. It rests heavily on the assumption of illness, decline, impairment and dependency in older age, with all older people (generally spanning ages 65 through to end of life) viewed as a homogeneous group, needing costly care and support and ‘not pulling their weight’ economically or contributing to society.

As individuals and as a community, many of us have internalised beliefs and attitudes that tightly couple getting older with declining health, autonomy and independence and vilify those attributes as a burden on others. Therefore, the idea of the inevitability of ‘becoming a burden’ hardens into a pervasive social norm. EveryAGE Counts argues that rendering older age in this way is egregious on three key counts.

Firstly, the length of time that an individual is subject to the burden narrative, by virtue simply of their chronological age and social assignment to the category of older person, bears no relation to their individual circumstances.

Secondly, the burden narrative radically understates the actual economic and social contributions made by older people over their lifetime and as a group, partly because many of these (such as partner and grandchild care) do not occur in the public sphere and are not assigned a monetary value (not unlike women’s contributions more generally).

Thirdly, and most importantly for this submission, EveryAGE Counts rejects the value system sitting at the heart of the burden narrative, that views vulnerability (at any time of life) as a deficit with unacceptable costs to society. We support the challenge to this proposition,

¹² Hal Kendig, “Not there yet: A gerontologist’s lament,” *Australasian Journal on Ageing* Vol 37, Issue 3 (Sept 2018): 165-166.

¹³ See <https://treasury.gov.au/intergenerational-report>

prominent in the discussion around dementia, that calls for resistance to the value and meaning of our lives being reduced to economics.¹⁴

EveryAGE Counts argues that the burden narrative especially impacts on the status and perceived value and role of the aged care system, because taken to its logical extension, the most vulnerable older people – those in need and receipt of aged care – could be viewed as representing the biggest ‘burden’.

Most of us cannot imagine our future selves. Some of us deny or dread getting older – we look away. The language of ‘putting’ someone into aged care reinforces this idea of ‘putting’ an older person to one side because they are no longer a productive member of society, they have nothing further to contribute and hence they, and the care they require, are a burden.

EveryAGE Counts also contends that this narrative spills over to under-valuing the care given to older people and a willingness to-date to look away from the many examples of neglect and abuse within the over-stretched system.

We acknowledge that, with increased longevity and declining birth rates, there is a complex debate to be had around issues such as ‘dependency ratios’, tax treatment of people over 65, housing wealth, later life employment and much more. Demographic ageing will transform our society, and we have the opportunity in our policy and cultural debates to ensure that the resulting realignments meet our needs across the entire life course and for future populations.

However, it is not inevitable that the debate be conducted through a lens of crisis and negativity about and towards older people and older age. In fact, it is the least valuable and most destructive approach to take to the demographic circumstances in which we now find ourselves. Indeed, a compelling reason to oppose the burden narrative at any age is that it makes our society less hospitable and cohesive for everyone.

Changing demographics requires innovative thinking and action in how economic and social systems function, for all ages, to meet the needs of our contemporary and future population.

None of us want to be cast as a burden – to our family, our community or our economy. We want to be members of a society where every person is valued, connected and respected regardless of age and functional ability, or where we live. The burden narrative positions any given cohort of older people as ‘other’, failing to recognise that we are all on a course across a life span and, if we are lucky, we will all experience older age. When we are at that stage, we will all want respect, empathy, independence, meaningful relationships, decent living standards, safety and appropriate care (if and when it is needed), just as we want those things at earlier life stages.

¹⁴ Gaynor MacDonald and Jane Mears (eds), *Dementia as Social Experience: Valuing Life and Care* (UK: Routledge, 2019)

The prominence and broad acceptance of the burden narrative also provokes an urgent requirement for a national discussion of societal values and a wake-up call to reconsider and redesign our systems of support for older people to match the reality of a much larger proportion of the population living much longer. This will need to be accompanied by a broad community conversation about purpose within longer lives.

In order to limit the existence and impact of ageism in aged care we need to fundamentally change Australian attitudes and beliefs about ageing and older people. Our recommendations on this point address the imperative for political leadership to disrupt the 'burden narrative' and its impact.

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.

The stigmatising of older age, older people and impairment in older age

A range of international studies have explored the stigmatisation of older people in health and aged care settings.¹⁵ In this submission we will highlight a small number of the most powerful ways ageist stigmatisation is expressed in Australian aged care settings, defining stigma as the assignment of negative worth on the basis of devalued group or individual characteristics.¹⁶

Studies of stigma suggest it has three interrelated components: cultural beliefs linking undesirable characteristics to labelled people; labelled people are placed into distinct categories so as to separate 'them' from 'us'; and the labelled person experiences loss and

¹⁵ Aya Ben-Harush, Sharon Shiovitz-Ezra, Israel Doron, Sara Alon, Arthur Leibovitz, Hava Golander, Yafa Haron, and Liat Ayalon, "Ageism among physicians, nurses and social workers: findings from a qualitative study," *European Journal of Ageing*, 14(1), (March 2017): 39-48.

¹⁶ Debra Dobbs, J. Kevin Eckert, Bob Rubinstein, Lynn Keimig, Leanne Clark, Ann Christine Frankowski, and Sheryl Zimmerman, "An Ethnographic Study of Stigma and Ageism in Residential Care or Assisted Living," *Gerontologist* 48(4) (August 2008): 517-526.

discrimination that result in unequal outcomes.¹⁷ EveryAGE Counts argues that stigma in these forms can apply in some degree or another to people using aged care and that it can intensify within aged care settings for those who experience the greatest impairment or illness.

Here are some of the key ways that have regularly been reported by observers and residents/service users in aged care over a long period of time.

1. The depersonalisation built into the structure of institutionalised aged care, in which: privacy is lacking; life is conducted around the facility's own rules and schedules; personal authority in one's own life is replaced by bureaucratic and managerial structures; and people are excluded from decisions about their own care and daily living.
2. The diminishing of personal identity or reputation, where the culture and structures mean that most residents tends to be viewed narrowly and primarily through the lens of impairment and as care recipients, rather than as complex whole people with personal history, strengths, preferences and aspirations.
3. The use of condescending and infantilising language obvious in staff behaviour patterns on display from some staff members in many aged care facilities and often in home care situations.
4. The offering of a narrow range of stereotyped (sometimes even childlike) entertainments and activities, based on what older people are supposed to enjoy, rather than what individuals may wish to do.

EveryAGE Counts also recognises that stigmatisation can and does occur in aged care around other cross-cutting factors such as socio-economic status, race, ethnicity and sexual identity. The intersection of ageism with other forms of discrimination (usually cumulatively experienced over a lifetime) needs much greater examination and deeper understanding than we currently have.

As in all other aspects of this submission, EveryAGE Counts acknowledges those people working within the aged care system, family members, friends and older people themselves who stand up against stigmatisation or operate in more affirming and inclusive ways in care settings. We make the point however, that the main cultures and structures of the system are built around the fundamental stigmatisation of older age in general and impairment in older age in particular.

A key to challenging this would be the genuine integration of a strengths-based approach into aged care. The growing emphasis on philosophies and practices of reablement and person-centred care offer important opportunities in this regard. However, it is commonly pointed out¹⁸ that the emphasis now placed in aged care practice on reablement is contradicted by the funding structures underpinning the aged care system.

The Aged Care Funding Instrument (ACFI) is biased towards accepting and managing a decline in the cognitive and physical health of those accessing aged care. If an aged care

¹⁷ *ibid.*

¹⁸ Mamarelis, "How can we heal" *op. cit.*

resident's functional ability and health improves, the funding given to the provider for that person decreases. As an aged care provider CEO has said

This is fundamentally counterintuitive to our evolving view of the role of the aged care provider. While clinical services will always be a core component of the support we provide, more attention is needed on encouraging and enabling stronger social connections, meaningful activity and engagement in a full life – all of which contribute to a person's wellbeing.¹⁹

Related to this, we also recognise that individuals do not necessarily always enter or progress through aged care in a linear fashion. People can start, stop and start again in accessing home based care over time. Some older people will progress from home based care to a residential care facility, some will enter residential care never having accessed home based care and some will enter and exit residential care on a respite basis. Others still, will not use either form of aged care at any stage in their lives. However this complexity and variability of individual use of aged care services is often overlooked. The common narrative of a one-way street of increasing decline and dependency in older age frames popular perceptions of aged care as well as other aspects of later life.

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.

The absence of a vision of a 'good life' in older age with impairment

A recent report of an Aged Care CEO Roundtable event hosted by the National Ageing Research Institute (NARI) stressed the crucial need to define what makes a good old age and that any new aged care model has to be based on this.²⁰ This is the latest in a long line of discussions over the past couple of decades or more on trying to shift the focus of older age from loss and decline, to quality of life.

The eight quality principles contained in the recently passed Aged Care (Single Quality Framework) Reform Act²¹ are welcome moves in the right direction. These are structured around outcomes for people in aged care that take account of a number of important quality of life domains, including in Standard 1, "Ican maintain my identity."²²

¹⁹ Ibid.

²⁰ Briony Dow, *What makes a good old age? Aged Care Roundtable Discussion Paper*, (NARI, May 2018) 2

²¹ See <https://www.legislation.gov.au/Details/F2018L01412>

²² See <https://agedcare.health.gov.au/quality/aged-care-quality-standards>

Coming from the other direction, what do we know about what older people themselves want for a good life with impairment – information that is crucial to the relevance, quality and safety of aged care?

Australian longitudinal analysis on older people's life goals (and the significance that health had for them), reported in 2014,²³ that life and health ideals centred around keeping active, feeling well, a positive outlook and capacities to maintain their independence and make ongoing contributions. Importantly, visions around the type of care they would receive, if needed, did not rate a mention. Possibly they expected (not unreasonably) any care function to deliver service in keeping with, supporting and secondary to their life and health ideals and goals.

Further, research undertaken in the UK in 2009 found that older people with high support needs outlined a good life for themselves that placed personal identity and self-esteem at the centre, without which choice and control in aged care cannot be delivered. The research identified five additional 'keys to a good life for older people with high support needs' that sit around personal identity and self-esteem: personalised support and care; meaningful daily and community life; home and personal surroundings; personal authority and control; and meaningful relationships.²⁴

A crucial insight in the latter research which was undertaken with people already experiencing high support needs was that they wanted high value, meaningful aspects to their lives. They did not appear to see themselves "...already in the midst of death..."²⁵ as frailty and impairment can so often be depicted by our society and systems of care.

EveryAGE Counts believes that older people living with impairment are actively living and growing through a life stage, like many they have lived through before. One of ageism's and ableism's (discrimination in favour of able-bodied people) most pernicious joint impacts is to rob older people of any sense of value in an older life with impairment.

We contend that there is still a long way to go to embed practice and culture that support what older people themselves see as a good life with frailty or impairment into standard operating procedure in aged care. We also contend that the focus of quality discussions in aged care has largely to date operated from the perspective of quality of care and health

²³ Hal Kendig, Colette Browning, Shane Thomas, and Yvonne Wells, "Health, lifestyle and gender influences on aging well: An Australian longitudinal analysis to guide health promotion," *Frontiers in Public Health*, (2 July 2014) Doi: 10.3389/fpubh.2014.00070

²⁴ Helen Bowers et al, *Older people's vision for long-term care* (UK: Joseph Rountree Foundation, November 2009), 7 AND

See also Helen Bowers et al, *Widening Choices for Older People with High Support Needs* (UK: Joseph Rowntree Foundation Report, January 2013)

²⁵ Judith Butler, quoted in Gaynor MacDonald, "Why person-centred care is not enough," in *Dementia as Social Experience: Valuing Life and Care*, eds Gaynor MacDonald and Jane Mears (UK: Routledge, 2019), 203.

economics²⁶, rather than the broader umbrella of quality of life from the perspective of the user of home-based aged care and aged care resident – in which high standard care is just one component.

EveryAGE Counts argues that among the many and varied factors that are generally acknowledged as contributing to wellbeing and quality of life at all ages, it is the opportunity for individuals to maintain meaning and purpose in their lives that is most seriously under-supported in aged care.

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; and
- developing an outcomes framework that enables continuous improvement in service delivery and facilitates transparent reporting to those using or selecting aged care services.

The absence of a vision for a good end-of-life experience and death

With the Royal Commission into Aged Care Quality and Safety promoting discussion on how we approach quality-of-life in aged care perhaps how we approach and ensure quality of death requires greater consideration.²⁷

EveryAGE Counts includes a brief discussion of end-of-life and death in this submission because we consider that there is a strong, if complex, relationship between it and ageism in aged care. We also believe that it is urgent to improve end-of-life care options for older people in aged care and improve processes to identify when a person is transitioning towards end-of-life and death and can access palliative care.

Just as important as a vision for a good older life with impairment, is a vision for a good death in aged care and in the community. EveryAGE Counts agrees with Grattan Institute, among others, that a “good death meets the individual physical, psychological, social and spiritual needs of the dying person” and gives real choice to them about their circumstances.²⁸

²⁶ See OECD, *A Good Life in Old Age?* (Paris: OECD, 2018). Note that despite the title, it devotes only a tiny portion of the brief to quality of life issues, but rather focuses narrowly on delivery, measurement and funding of quality care.

²⁷ Liana Green, *Building a relationship with death: How do residential aged care workers find meaning when caring for people who are dying?* Meaningful Ageing website: <https://meaningfulageing.org.au/building-a-relationship-with-death-how-do-residential-aged-care-workers-find-meaning-when-caring-for-people-that-are-dying/> accessed 24 July 2019

²⁸ Hal Swerissen and Stephen Duckett, *Dying Well* (Australia: Grattan Institute, September 2014), 8.

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In 2017 66% of deaths registered in Australia were among people aged 75 or over. Around a third of all deaths in Australia take place in residential aged care²⁹ and a AIHW study of older people who died in Australia between July 2012 and June 2014 showed that 80% had used an aged care program at some time before death.³⁰ In addition, about half of those who die in Australia do so in a hospital. Research shows Australia to rank 19th out of 20 OECD nations when it comes to people over 65 dying in their own home.³¹

This brief sketch illustrates the deep importance of our cultures and practices around dying to all people facing death, but particularly older people. Demographic and healthcare shifts are making this even more pressing as

Increasingly people die when they are old. They are also more likely than their forebears to know that they are going to die in the relatively near future. But we are not taking the opportunity to help people plan to die well. In the last year of life, many experience a disconnected, confusing and distressing array of services, interventions and relationships with health professionals. Many do not get enough palliative care.³²

Experts in the field reinforce this, saying that “there is a lack of understanding and attention given to palliative care in the aged care system.”³³ Evidence given to the Royal Commission by Dr Jane Fischer from Palliative Care Australia outlines a significant array of barriers in aged care planning, policy and funding arrangements to the establishment of palliative care in the aged care system.³⁴

The question for EveryAGE Counts is why, when so many people die in aged care, there is so little public conversation about the lack of end of life services and options for older people. We acknowledge that there is a strong movement of people within the palliative care field working hard to improve the situation in aged care, but they are not yet supported by a groundswell of broad community support. We believe this situation is tied to ageism, in the following ways:

- a broad-based culture of discomfort and denial around death, and its negative association with older age, is widespread in our society, militating against looking directly at the process (in its broadest sense) of dying and death for the group of people most immediately affected – older people in general and those in aged care in particular

²⁹ Swerissen and Duckett *op. cit.*, 2

³⁰ Australian Institute of Health and Welfare (AIHW), *Cause of death patterns and people's use of aged care: a Pathway in Aged Care analysis of 2012-14 death statistics* (Australia: AIHW, 24 January 2018)

³¹ Swerissen and Duckett *op. cit.*, 4

³² Ibid.

³³ Dr Jane Fischer, Palliative Care Australia, *Witness Statement to the Royal Commission on Aged Care Quality and Safety* (Australia: Royal Commission on Aged Care Quality and Safety, 29 May 2019), 4

³⁴ Ibid., 7

It is important to recognise that Palliative Care Australia promoted the broad World Health Organisation (WHO) definition of palliative care, which extends to care provided by all health and aged care professionals involved supporting people living with a life-limiting illness, their families and carers; takes a broad approach including early intervention to prevent or relieve physical symptoms, psychological and spiritual support and social support; and begins much earlier than the very end-of-life, in the course of an illness.

- the separation of many older people from the mainstream community into residential aged care reduces the opportunity for many people to view dying and death among older people, and this invisibility of older death results in a lack of engagement and sense of urgency with improving services and support;
- the availability of broad-based palliative care (not just specialist medical care) is still a work in progress in Australia for everyone who needs it, and the urgent necessity for it is only just beginning to register properly in the aged care system as in the community more broadly
 - the Aged Care Roadmap, for example, makes no reference to improving the experiences of death and dying or a requirement for palliative care as an integral part of the system; and
- aged care staff (in facilities and home-based care) are not necessarily end-of-life or death care specialists in their various fields, jobs and roles, and reflect the broad sweep of community responses to death – yet they are often tasked with supporting older people through this experience.

EveryAGE Counts agrees strongly with the Principles for Palliative and End-of-Life Care in Residential Aged Care, prepared by a coalition of key stakeholders, which argues Ensuring the availability of high quality palliative care and end-of-life care services in aged care facilities and people’s own homes, will enable more older Australians to have a good death, better support their families and carers during the dying and bereavement processes and facilitate the better allocation of scarce health resources.³⁵

Unchallenged institutionalisation and segregation of people experiencing impairment in older age

Older people (currently generally identified as those 65 years of age in policy settings) in need of personal or clinical care outside of the hospital system, are segregated into a separate system of aged care with its own arcane operation, funding arrangements, models of care, narratives and philosophies. EveryAGE Counts argues that the collision of ageism underpinning the separate system and the architecture of institutionalisation (which is still a big part of the system), results in poor outcomes in the wellbeing of older people.

The continued segregation of older people in their own care system, however well-intentioned, draws on ageist assumptions about the ‘sameness’ of all older people in their preferences and needs. We also argue that the segregated, resource constrained, out-of-sight system reinforces within the broader community a sense of the low value of and stigma attached to older life with impairment or frailty.

³⁵ Palliative Care Australia, et al, “Principles for Palliative and End-of-Life Care in Residential Aged Care”, https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2017/05/PCA018_Guiding-Principles-for-PC-Aged-Care_W03-002.pdf

The *Drivers of Ageism* research found that the environments in which people connect with older people influenced some participants' perceptions of ageing; with exposure to people living in residential aged care specifically having a negative impact on attitudes towards ageing.³⁶

This finding indicates the essential role played by our residential aged care environment not only in the quality of life for residents but also in influencing the broader population's vision of what late life looks like. We question whether the negative reaction to ageing from respondents who had engaged with residential aged care is generated by seeing older age impairment per se, or by seeing it within the particular structures of contemporary residential aged care.

Another important feature of our current institutionalised residential aged care system is the dominance of a one-size-fits-all style approach, which, once again, draws on and in turn reinforces ageist views about the homogeneity of older people. This approach finds a ready home in institutionalised care, which given the imperatives of efficiency, may rely on one-size-fits-all approaches.

Ageism treats all older people as if they are the same, despite great diversity based on gender, cultural and linguistic backgrounds, economic backgrounds, locations, sexual identity, personal history, physical and cognitive health, quality of life preferences, and much more. Frailty and functional decline, if they do occur, also take multiple pathways and are as individual as each person themselves who is experiencing these changes.

EveryAGE Counts welcomes the important developments in government policy around diversity in aged care. These include:

- the 2017 Department of Health, Aged Care Sector Committee Diversity Sub-group *Aged Care Diversity Framework*; and
- subsequent Aged Care Diversity Framework Action Plans for older people from CALD backgrounds, and LGBTI and Aboriginal and Torres Strait Islander people.

These developments recognise that catering for diversity must be a fundamental design approach to and objective of aged care.

Clearly older people display the same diversity of characteristics and life experiences as the broader population, and yet the aged care system has struggled to date to reflect this. New diversity strategies and frameworks are a good step forward, but to succeed, there will need to be a significant shift away from dominant thinking about people in older age as an undifferentiated group, defined primarily by chronological age.

The emergence of a system of aged care under the 20th Century welfare state³⁷, was an essential social justice and human rights measure, ensuring care was delivered to an under-served and vulnerable part of the population. Indeed it could be viewed as 'positive

³⁶ The Benevolent Society, *The Drivers of Ageism*, op. cit., 24

³⁷ Cathy Gong and Hal Kendig, "Ageing and social change in Australia", in *Population Ageing and Australia's Future*, edited by Hal Kendig, Peter McDonald and John Piggott, (Canberra: ANU Press, 2017) 22

discrimination'. But it was achieved at the cost of entrenching a stigmatising approach to older age that involved removal from socially integrated mainstream life and placement in largely undifferentiated, institutionalised, often poor quality care in which individuality and personal biographies and agency largely are left at the door.

While institutionalised responses have also historically been common for people of all ages with disabilities, times have begun to change significantly for younger people with disabilities in Australia and internationally – but there is still a gulf though between young and old in this regard, as these observers in the US have noted.

....there is evidence to suggest that society's response to disability differs substantially by age. ...older adults are seen as frail and vulnerable people who need protection whereas young individuals with disability accept risk as the price of free social participation. As a result of these differing attitudes, public programs for younger disabled people in large part fund community care options and independent living, whereas programs for older disabled people fund nursing home (NH) care (Kane et al.). Thus, it is no surprise that one of the shortcomings reported of LTC [Long Term Care] personnel is that they do not take the time to watch, stand by, or assist residents, but instead themselves make the bed, prepare the meal, and perform all tasks. This behavior is in opposition to the promoted goals of LTC, which are to improve or maintain health and functional abilities. Such promotion requires an attitude that encourages residents to do things for and by themselves.³⁸

Nonetheless, EveryAGE Counts looks for inspiration to the success of the social and political movements of people with disabilities, who achieved a decisive response from governments to their needs and rights with the implementation of a new National Disability Insurance Scheme (NDIS). NDIS takes a more contemporary rights-based and social integration approach, and is underpinned by an uncapped, demand-driven funding model. We recognise that there are critics of NDIS, continuing debate around its scope and coverage and still very real challenges with its implementation. We are yet to confirm whether the principles will successfully translate into consistent practice. Nonetheless it offers a contemporary, highly relevant, Australian policy comparison from which aged care systems can learn, as entry to NDIS is limited to people under 65 years of age.

Those excluded from NDIS by age are directed to the aged care system which, despite reform, is still a long way from universally embracing values of inclusiveness, social integration, human rights and personal agency. Furthermore, the aged care system remains underpinned by a supply-based funding system that caps the number of packages/places available to older people, currently well below meeting the level of need, as demonstrated by the waiting list.

Despite the rise of expanded and improved home care for older people, promising more contemporary values and practices, institutionalised residential aged care remains a hallmark of our system for those with the greatest need, generally closest to death and, increasingly, experiencing dementia. This unquestioned continuation of large-scale separate residential aged care stands in stark contrast to the broad social rejection of

³⁸ Dobbs, et al, *op. cit.*

institutionalisation, not only in regard to younger people with disabilities, but in almost all other facets of our society.

EveryAGE Counts recognises that there is a place for congregate living and benefits for some older people for whom the potential for social engagement combats the isolation they may experience in the community setting. There is also an appetite in the aged care industry and growing pressure from older people and the broader community to investigate, explore and introduce better practice, new models of living and care within and as an extension of residential facilities. There are many hopeful emerging examples which push the boundaries of residential care, such as: cluster housing; micro-towns or suburbs; digital innovation and robotics in personalised treatment; consumer-friendly facility design; dementia villages; aged care precincts within educational campuses and alongside childcare facilities; and various methods for integrating intergenerational contact into residential aged care.

EveryAGE Counts acknowledges the potential for these innovations to lay some groundwork to shift power relations in aged care and give greater protection to the rights of older people. However, despite the significant amount of positive innovation going on, we should not view this as the full story of the current directions of residential aged care. Concurrent with and contrary to these micro innovations, there is also a macro trend towards an increase in the size of residential aged care facilities and their location on the edges and outskirts of cities, driven by planning, land costs and objections from residents in established communities.³⁹

Both these macro trends have the potential to work against the aims of integration of residential care within the communities in which people have been living; the creation of more home-like environments in residential aged care; and more personalised knowledge and understanding of individual residents.

Nonetheless, even though EveryAGE Counts is concerned about the current model of aged care in Australia, we are acutely aware of the dangers in a call for rapid, wholesale deinstitutionalisation of aged care or its full integration into mainstream health and social care systems.

Lessons learnt from the deinstitutionalisation of other care sectors are important⁴⁰, including the absolute requirement for assured levels of appropriate, accessible and quality

³⁹ Maree Petersen and Jeni Warburton, "Residential complexes in Queensland, Australia: a space of segregation and ageism," *Ageing and Society*, 32, (2012): 60, <https://doi.org/10.1017/S0144686X10001534>

⁴⁰ Alan Rosen, Roger Gurr, and Paul Fanning, "The future of community-centred health services in Australia: lessons from the mental health sector," *Australian Health Review* 34, (2010):106-115. AND Alan Rosen, "The Australian experience of deinstitutionalization: interaction of Australian culture with the development and reform of its mental health services," *Acta Psychiatrica Scandinavica* Vol 113, Issue s429 (23 January 2006): 81-89, <https://doi.org/10.1111/j.1600-0447.2005.00723.x> AND Miriam McNown Johnson and Rita Rhodes, "Institutionalization: A Theory of Human Behaviour and the Social Environment," *Advances in Social Work* Issue 8 No 1 (2007): 230-231.

care available to replace institutional care. This is crucial not only for older people in need of services, but for their families and communities as well; especially the women who continue to carry the main caring workload in those settings.

Therefore EveryAGE Counts recognises that reform towards new models of living and care in older age need to be created over time through innovation and ingenuity. However, without a strategic commitment and a plan from the community, governments, civil society and the aged care industry to move in that direction, older people will continue as the only part of our population for whom we now accept an old and discredited model of segregated and institutionalised care.

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.

Lack of awareness and understanding of ageism and its impacts in aged care

There is latent concern in the community about ageism in aged care. EveryAGE Counts' foundational research found that 33% of survey participants in the community identified aged care as an important area in which to address ageism (following behind only the workplace and healthcare in importance)⁴¹.

⁴¹ The Benevolent Society, *op. cit.*, 19

However, social norms and cultural assumptions can be hard to identify and name. They are simply part of the way we think or do things. Ageism is highly tolerated. It is built into our language and our expectations of growing older. We believe that the ageism is carried into aged care by the workforce in their engagement with older people, by those community and family members who implicitly sanction the current system and by older people themselves who have internalised negative social attitudes.

At the service level, The Benevolent Society (TBS), a leading EveryAGE Counts coalition member, is currently conducting a project among its home-based aged care staff members to assess awareness about ageism and views regarding its presence or otherwise in the aged care system.

Although the project is still in progress, early findings from workshop discussions indicate similar outcomes to those in the foundational *Drivers of Ageism* research regarding awareness of ageism⁴²; familiarity with the concept is low, but when prompted TBS staff can easily identify numerous forms and examples of ageism at work in their sphere. Largely, they view it coming from ‘benevolent’ drivers, and see it most clearly in the behaviours of service recipients’ families and carers and in interactions with the general public such as shop assistants and medicos.⁴³

A further, powerful example of the potential for ageism to undermine progressive reforms in aged care relates to the adoption of the Choice and Control approach (formerly referred to as Consumer Directed Care (CDC)). Choice and Control was fully introduced into Home Care Packages in 2015 in order give older people more say over what services they receive and where and when.

While Choice and Control offers the potential for an important power shift from care providers to older care recipients, research by National Seniors for the Department of Health in 2018 found that “many home care clients have not yet been empowered by the introduction of CDC”, due to confusion about the industry, the program and the fees, as well as issues with coordination.⁴⁴ Concern was also expressed about the difficulty of those with cognitive decline to operate as empowered consumers.⁴⁵

Clearly these findings can be explained by the introduction of a complex paradigm shift in a system of care requiring different competencies from service users than previous arrangements. However, EveryAGE Counts argues that a key barrier to Choice and Control is ageism – internalised by many care recipients; prevalent in the behaviours of many family members and carers; and apparent in the variability of assessor and provider interpretation of the concept and practices associated with it.

The way in which ageism manifests itself in Choice and Control includes:

⁴² The Benevolent Society, *op. cit.*, 18

⁴³ Internal TBS records

⁴⁴ J McCallum, K Rees and J Maccora, *Accentuating the positive: Consumer experiences of aged care at home* (Brisbane: National Seniors, 2018), 63.

⁴⁵ *Ibid.* 57-62

- lack of motivation and skill by some providers to support, encourage and educate older people in the new way of doing things;
- a lack of appropriate information on the system targeted specifically to the consumer (not intermediaries);
- ingrained paternalistic behaviours by some carers and family members;
- undue weight being given to the views of some family members and carers about the needs of the older person;
- poor skills in communicating directly with users about their needs and views; and
- lack of confidence and practice by older people in determining and expressing their own needs.⁴⁶

Ageism limits the dignity and autonomy of older Australians and impairs the effectiveness of service models designed to support wellbeing. The first step to its eradication in aged care, as in all other parts of society, is raising consciousness with policy makers, providers, practitioners and older people, their families and their representatives about its existence, sources and impacts. Activity to tackle ageism in aged care will have to be sustained and targeted, and will require clear leadership from older people themselves, the aged care sector, the bureaucracy and our elected representatives.

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.

⁴⁶ See discussion in Sarah Russell, "Older People Living Well with In-Home Support" *Research Matters*: (2019) AND Jenny Day et al, "Experiences of older people following the introduction of consumer-directed care to home care packages: A qualitative descriptive study", *Australasian Journal of Ageing* Vol 37 No4 (December 2018) 275-282.

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).

The lack of safeguards against neglect and elder abuse

EveryAGE Counts argues that abuse and neglect of older people, inside and outside of the aged care system, relies heavily on ageism. The ‘othering’ (treating a person as intrinsically alien to oneself) of older people which is central to ageism, creates an authorising environment for abuse and neglect to occur.

The contribution of ageism to elder abuse has been acknowledged by key public responses to the problem in recent years including:

- the ground breaking 2017 Australian Law Reform Commission (ALRC) Report into Elder Abuse that argued:
Vulnerability does not only stem from intrinsic factors such as health, but also from social or structural factors, like isolation and community attitudes such as ageism. All of these contribute to elder abuse⁴⁷; and
- the Council of Attorneys-General *National Plan to Respond to the Abuse of Older Australians (Elder Abuse) 2019-2023*, in which the impacts of ageism are highlighted prominently as
 - contributing to an environment in which individuals who abuse older people fail to recognise that their behaviour constitutes abuse
 - other members of society fail to notice these negative behaviours or take action to stop them, and
 - older people experiencing elder abuse blame themselves and are too ashamed to seek assistance.⁴⁸

There is an immense power imbalance between older people in aged care and the managers and staff of services, which, if it coincides with malevolent ageism, can be disastrous. Even though this imbalance may rarely be exploited to the point of neglect or abuse, it provides a structural risk that recent media exposés and other investigations have demonstrated can result in great harm to older people.

⁴⁷ Australian Law Reform Commission, *Elder Abuse – A National Legal Response* (Canberra: ALRC Report 131, tabled Canberra 14 June 2017), cl 1.6.

⁴⁸ Australian Council of Attorneys-General, *National Plan to Respond to the Abuse of Older Australians (Elder Abuse) 2019-2023* www.ag.gov.au/ElderAbuseNationalPlan

In a discussion of power differentials it is also important to recognise the way in which elder abuse is gendered. As with intimate partner violence where women are the main victims, available research also suggests that women are more likely than men to experience elder abuse.⁴⁹ It could be expected that this same situation would be the case in aged care, where in 2015 over two-thirds of people living in residential aged care were women, partly reflecting the fact that women, on average, live longer than men.⁵⁰

At its most basic in aged care, the power imbalance shows up in a lack of voice for residents and care recipients. Many aged care staff would argue that the families of residents and care recipients are often highly active and directive on behalf of their relative, but at best this is a mediated engagement and those who do not have family or friends advocating for them can be left voiceless. This barrier to being heard creates a highly vulnerable situation for residents and care recipients.

Within an environment of low empowerment and high vulnerability, aged care residents and service recipients are also vulnerable to abuse by other residents, family members, substitute decision-makers and visitors.

In addition, the 2017 Australian Law Reform Commission (ALRC) Report into Elder Abuse considered the concept of ‘institutional abuse’, described as occurring when the:
routines, systems and regimes of an institution result in poor or inadequate standards of care and poor practice which affects the whole setting and denies, restricts or curtails the dignity, privacy, choice, independence or fulfilment of individuals.⁵¹

EveryAGE Counts recognises that ‘institutional abuse’ related to residential aged care arises from a number of sources. To address just one of these, we note that aged care providers generally point to resource constraints preventing them from ensuring safeguards (including adequate staffing) are in place to protect vulnerable people. While clearly resources constraints do not tell the whole story, to the extent that they do play a part, we ask why, as a society, we allow inadequate targeting of resources to the protection a vulnerable group of citizens to continue when we know the likely outcome.

The neglect shown towards addressing institutional abuse in aged care extends beyond the boundaries of the care facilities themselves and into our broader legal and social systems. Bill Mitchell, in his recent powerful article on the adequacy of coronial and related systems in identifying institutional elder abuse, asks the question

Is ageism partly responsible for system failures such as the absence of coronial and other death processes for deaths in RACs [residential aged care facilities], the lack of prevalence and incidence data, the failure to align existing processes where opportunities exist, and the failure to improve obvious system failings or gaps?⁵²

⁴⁹ Australian Law Reform Commission, *op. cit.*, cl 2.40

⁵⁰ The Australian Bureau of Statistics, *ABS 4430.0 Disability, Ageing and Carers, Australia: Summary of Findings, 2015* <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features1022015?OpenDocument>

⁵¹ Australian Law Reform Commission, *op. cit.*, cl 4.39

⁵² Bill Mitchell, “Identifying Institutional Elder Abuse in Australia through Coronial and Other Death Review Processes,” *Macquarie Law Journal* 35 (2018): 18.

He highlights the work of others⁵³ who suggest that it is easier for the community to view most deaths of older people, and especially those in an aged care setting, as inevitable, rather than seeking to identify preventable factors.

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.

The absence of a human rights approach and framework in aged care

The aged care system in Australia is governed by a raft of primary and subordinate legislation (the leading piece of which is the Aged Care Act 1997), which has been undergoing significant change in recent years under the Aged Care Reform Agenda. This governance platform plays the key guiding role in the type of system we have delivering care to older people. EveryAGE Counts believes that it needs review, using a human rights lens to redirect it from speaking almost solely to providers, and shift the objects (purpose), principles and application of the system of care. We believe it is essential that the focus of the legislative framework be on the realisation of the rights of older people, including but not limited to the ‘right of everyone to the enjoyment of the highest attainable standard of physical and mental health’ (Article 12, International Convention on Economic, Social and Cultural Rights).

Key principles of a rights based approach include a person centred approach that:

- is transparent about the rights covered;
- gives priority to ensuring that people understand and are able to claim their rights; and
- requires the disaggregation of data to ensure that duty bearers are meeting the rights of priority groups equitably.

EveryAGE Counts acknowledges that the aged care system has moved closer towards elements of a human rights approach in its embrace of the model of Choice and Control in Home Care Packages which requires that duty bearers (governments) ensure that all citizens, including those with physical or cognitive impairment, are able to fulfil their rights. This principle underpins successful disability policies, has been enshrined within United

⁵³ Tatiana Hitchen, Joseph Ibrahim, Marta Woolford, Lyndal Bugeja, and David Ranson, “Premature and Preventable Deaths in Frail, Older People: A New Perspective” *Ageing & Society* 37(8) (2017): 1532.

Nations disability instruments⁵⁴ and is seen as an alternative to the medical, institutionalised model of care that predominated for many years in the disability sector.

In trying to understand how and why the difference exists between aged care and disability policy, Swedish academics have highlighted the tendency in residential aged care to use internal (other residents) rather than external (older people or all people outside of residential care) reference points for defining injustices and claiming rights:

Concepts like equality, justice, and human rights refer to comparisons with the ordinary citizen in media and policy documents on disability. In texts on care for older people, such concepts refer to comparisons within the category of care users...

.....whereas policy makers and care providers define goals for non-old people with impairments in terms of citizenship (a term frequently used in government investigations on disability policies) and access to society, goals for older persons relate to the quality of care itself. For non-old persons, the goal is to participate in society; for older persons, the goal is to participate in activities relating to home or care, such as social activities at the care facility or household tasks such as peeling potatoes when preparing a meal. This internalizing paradigm of eldercare becomes visible as the absence of goals and concepts like those used in disability policies.⁵⁵

By way of comparison, they give two examples where external reference groups are used to establish rights for people within Swedish aged care facilities:

- in a few municipal locations, to normalise living conditions, rooms were renamed 'apartments' and people in them were formally categorised as 'residents'; and
- the Swedish Social Service Act now entitles cohabiting couples to live together in residential care in cases where only one has the need – noting that advocates for this change argued it was indecent to force couples to live apart.⁵⁶

The key point EveryAGE Counts wishes to draw out of this discussion is that the task of clarifying, promoting and defending the rights of people in residential aged care in particular is made both urgent and harder (technically and culturally) by ageism. Ageism has led to a segregated, partly stigmatised care system in which residents are cast as 'other' – other than everybody else including people their own age not living in residential care. Their capacity to exercise their human rights has been significantly diminished. The undoing of ageist norms in aged care and the project of placing human rights at the centre of aged care, go hand in hand.

Lastly, an aged care human rights agenda must also extend to the pathways taken by older people into aged care. The common use of language that refers to families 'putting' older relatives into aged care should raise our collective antenna to the shift in power dynamics, choice and rights facing older people at this transition point. Equally, culture and practice around fraught and often chaotic transitions of people from hospitalisation to permanent entry into residential aged care needs continual vigilance to ensure the rights of older people are protected.

⁵⁴ Hakan Jonson and Tove Harnett, "Introducing an Equal Rights Framework for Older Persons in Residential Care," *The Gerontologist* 56(5) (October 2016): 800-806.

⁵⁵ *ibid.*

⁵⁶ *ibid.*

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)⁵⁷; and is reflected in aged care policy and program design, implementation and accountability measures.⁵⁸ 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.

⁵⁷ United Nations, *United Nations Principles for Older Persons*, (Adopted by UN General Assembly resolution 46/91 of 16 December 1991) <https://www.ohchr.org/EN/ProfessionalInterest/Pages/OlderPersons.aspx>

⁵⁸ World Health Organization, *Human Rights Fact Sheet* <https://www.who.int/en/news-room/fact-sheets/detail/human-rights-and-health>

Responses- what are the priorities for addressing ageism in the aged care system?

EveryAGE Counts recognises that there is no ‘quick fix’ or ‘silver bullet’ for tackling ageism within the aged care sector, nor society more broadly. However, the responses outlined by EveryAGE Counts throughout this submission and below identify a holistic suite of actions that if taken together, over time, will shift the ageist underpinnings of the system.

Important initiatives that could disrupt ageism are already at the heart of the existing aged care reform agenda. These include:

- embedding within aged care funding structures, training, service design, scope and nature of service delivery, physical environment and location, daily routines and interpersonal interactions, the principles and practices of:
 - person centred care
 - consumer choice and control
 - co-design
 - reablement;⁵⁹
- a focus on consumer outcomes in the broader quality domains now covered by standards under the *Aged Care (Single Quality Framework) Reform Act 2018*;⁶⁰
- a focus on consumer rights through the new, single *Charter of Aged Care Rights*, from 1 July 2019;⁶¹ and
- the overhaul of workforce strategy in aged care, which offers the opportunity to embed culture and competency changes in regard to fundamental issues such as ageism.

However, we argue that part of the resistance to and uneven implementation of these measures to date – and likely going forward – is the barrier created by widespread underlying ageism. To succeed, each of these approaches relies on an acceptance that older people (including many of those with high support needs) have the capacity (even if requiring assistance) and human rights to exercise agency over, and take risks within, their own lives and the circumstances of their daily living.

Further, these reforms alone are not enough to offer the comprehensiveness of quality of life sought by older people in residential aged care,

⁵⁹ See, David Tune, *Legislated Review of Aged Care 2017*, (Canberra: Australian Department of Health, 2017) AND
Kate Carnell and Ron Paterson, *Review of National Aged Care Quality and Regulatory Processes*, (Canberra: October 2017) AND
Aged Care Workforce Strategy Taskforce, *A Matter of Care Australia's Aged Care Workforce Strategy* (Australian Department of Health, June 2018) AND
Aged Care Sector Committee, *Aged Care Roadmap*, (March 2016)
https://agedcare.health.gov.au/sites/default/files/documents/04_2016/strategic_roadmap_for_aged_care_web.pdf

⁶⁰ See <https://www.agedcarequality.gov.au/resource-library?resources%5B0%5D=topics%3A211>

⁶¹ See <https://agedcare.health.gov.au/quality/single-charter-of-aged-care-rights>

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...even if there were no quality of care problems in nursing homes, conventional nursing homes arguably fail the quality test because of the severe strictures on life in these settings. Put simply, the total disenfranchisement associated with living in a nursing home is too high a price to pay for even high-quality technical care.⁶²

Success in current reform measures also requires a fundamental respectfulness and empathy towards people receiving care and support, no matter what their age or circumstances. While there are many individuals delivering the aged care system who embody respectfulness and empathy towards care recipients, this is not universal, and the system itself is not adequately structured, designed or funded around these values.

Hard wired negative and limiting assumptions about and stereotypes of older people permeate the system, going largely unrecognised and unchallenged, and will continue to undermine efforts to improve quality of care and the exercise of rights by older people.

Therefore we argue that in addition to the important existing aged care reform agenda, the following steps must be taken to disrupt counterproductive assumptions about older people and support improvements to systemic quality and safety in aged care. We offer recommendations including short and long-term actions, high level policy and political responses, specific changes to practice and local and national action.

EveryAGE Counts believes that the Royal Commission plays a unique and powerful role, able to analyse the issues before it within the broad scope of our political, economic and social systems and facilitate change at this level, as well as in more targeted ways. We offer the Royal Commission a holistic suite of recommendations below to reduce ageism in aged care, and its negative impacts on quality and safety.

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:

⁶² Rosalie A. Kane, "Long-Term Care and a Good Quality of Life: Bringing Them Closer Together" *The Gerontologist* Vol. 41 No. 3 (June 2001):293-304.

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)⁶³; and is reflected in aged care policy and program design, implementation and accountability measures.⁶⁴ 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

⁶³ United Nations, *United Nations Principles for Older Persons*, (Adopted by UN General Assembly resolution 46/91 of 16 December 1991) <https://www.ohchr.org/EN/ProfessionalInterest/Pages/OlderPersons.aspx>

⁶⁴ World Health Organization, *Human Rights Fact Sheet* <https://www.who.int/en/news-room/fact-sheets/detail/human-rights-and-health>

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- 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.

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APPENDIX 1



EveryAGE Counts Coalition Steering Group

Organisational members [A-Z] (Representative)

1. Aboriginal Community Services (Graham Aitken, CEO)
2. Aged & Community Services [ACSA] (Pat Sparrow, CEO; Elizabeth Teece, Policy and Member Advice)
3. Australian Association of Gerontology [AAG] (James Beckford-Saunders, CEO)
4. Australian Human Rights Commission (Dr Kay Patterson, AO, Age Discrimination Commissioner)
5. COTA Australia (Ian Yates AM, CEO)
6. ECH (Dr David Panter, CEO)
7. Federation of Ethnic Communities Council of Australia [FECCA] (Tina Karanastasis, Senior Deputy Chair)
8. National Seniors (Prof John McCallum, CEO)
9. Per Capita Australia (Emma Dawson, CEO)
10. Regional Australia Institute (Liz Ritchie, Joint CEO)
11. The Australian Centre for Social Innovation (Kerry Jones, Principal: Ageing, Disability and Partnerships)
12. The Benevolent Society (Dr Kirsty Nowlan, Executive Director, **CO-CHAIR**)
13. United Voice (Mel Gatfield, NSW Secretary)
14. Your Life Choices (Kaye Fallick, Publisher)

Individual members

1. Robert Tickner AO - humanitarian advocate, former CEO Red Cross Australia and former Minister for Aboriginal and Torres Strait Islander Affairs (**CO-CHAIR**)
2. Dr Mike Rungie - Global Centre for Modern Ageing
3. Jane Caro - Social commentator, author, facilitator, broadcaster and more
4. Sally Evans - Chair of LifeCircle, a Non-Exec Director of Rest Super, Primary Healthcare and Oceania Healthcare
5. A/Prof Kate O'Loughlin - Associate Professor Ageing, Work and Health Research Unit, The University of Sydney
6. Dr Helen Creasey AM - Professor of geriatrics, Director, Advisory Committee, Ageing and Alzheimer's Institute
7. Deborah Snow - Senior writer, Fairfax media