



The lost face of care

Voices from the Royal Commission into Aged
Care and Safety

Perspectives of the existing aged care system
Aged care in the home
Dementia care in a residential setting
Care in remote areas
Person-centred care
Access to flexible aged care programs
Unpaid carers for older Australians
Regulation of aged care
Young people in residential aged care
Diversity in aged care
Aged care workforce
Aged care in regional areas
Approved providers, an insight
Interface between aged care and health care

Interim report extract – *Neglect*

As was observed in our first hearing in Adelaide, this Royal Commission is a once-in-a-generation opportunity to make substantial reforms for this vital sector. Nowhere is the need for reform more pressing than in relation to the aged care workforce.

- Rozen, October 2019

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This paper covers the Australian Royal Commission into Aged Care and Safety up to and including Melbourne 3 hearing. Further hearings commenced in Mudgee in November then proceeded to Hobart and Canberra in December.

Prepared by Sue Glaisher

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Introduction

This paper outlines the key issues raised in the Royal Commission into Aged Care and Safety up to and including the Melbourne 3 hearing – 14 to 18 October, 2019. Clear messages arising from the Commission hold no surprises to people accessing services or working in the aged care sector. These messages will be identified throughout the paper. What is less clear, is the depth of complexity that resides both in the provision of aged care services and the workforce that supports these services. Coupled with these complexities is the opaque relationships between public service entities and their provision of timely information.

Perhaps the most damaging side effect of this Royal Commission into Aged Care and Safety is that instead of dealing with the problems of the aged care system, we have a de facto policy of 'wait and see'. Actions and policy initiatives we know are urgent are simply not happening (Fine, 2019).

The structure of this paper reflects the roll out of the Commission's hearings beginning in Adelaide on the 11 February, 2019. The paper's purpose is not to be another report, rather it is a guide or a sign post to the issues raised in the ACRC, an echoing trace to orient the reader to the voices and stories that contribute to the ACRC findings. The key philosophy identified from the evidence provided thus far, is that as soon as you take humanity out of care whether it is as a public servant, CEO, nurse or personal care worker, one thing is lost – the face of care.

We have a responsibility as individuals, community and country to not allow inertia to lull us into complacency, a scan through the artefacts, exhibits and transcripts brings home the level of abandonment of our older Australians in their later years.

The quotes are included not only to echo but to emphasis the gravity of each hearing and play an integral part in engaging the reader with the poignancy and authenticity of the case studies.

The aged care sector – a fractured space

The background to the Aged Care Royal Commission

The aged care sector in Australia is a fractured space. There are spots of light on the landscape, but they are few and far between. From the systemic level through to the organisational level and down to individual care, direct evidence and witness statements have highlighted a sector that is riven with systems failures, inadequate communications between agencies, self-serving owner/operators and poorly trained and overworked staff.

Over the decade that Mum has spent in aged care, I have experienced the good, the bad and the downright unacceptable. I have tried to work in partnership with facility managers, have been through periods where we have fought openly over my mother's care and have been reduced to tears by the compassion and benevolence shown by countless carers, nurses and nurse managers.

Older Australians like Mum have given of their bodies, minds and spirits to grow a future for their families and communities and have laid the foundations of a society we enjoy today. Growing old should be a dignified experience where self-respect can be maintained. The next generation must have confidence that their basic physical, psychological and human needs will be met and hopefully exceeded when they are at their most vulnerable.

The current situation is heartbreaking at best, criminal at worst. When we look back in years to come, much like the orphanages of yesteryear, this will be our country's greatest shame (Backhouse, 2019).

The Aged Care Royal Commission (ACRC) was announced by Prime Minister Scott Morrison on the 16 September, 2018 after a number of care failures were identified across Australia and established on the 8 October, 2018 by the Governor-General, His Excellency General the Honourable Sir Peter Cosgrove AK MC (Retd). The Honourable Richard Tracey AM RFD QC, the Honourable Tony Pagone QC and Ms Lynelle Briggs AO opened with preliminary remarks on the 18 January, 2019.

We will look to the future, canvassing demographic pressures, community expectations, technology, risks and opportunities. We will consider aged people's position in society, what they want and how they are perceived. We will give voice to them. We will look at experiences here and overseas and draw on lessons and ideas that may improve our aged care system. The Letters Patent direct us to make recommendations about any policy, legislative, administrative or structural reforms that we consider necessary. A policy and research program has been developed to assist us to make recommendations that would provide a sustainable aged care system of high quality that is safe and meets the expectations of the Australian community (Commissioner Briggs, 2019).

The responsibility is broad, particularly, because of the changing demographic of the Australian population and includes the following areas (ACRC website 2019):

- The interface between health, aged care and disability services in metropolitan, regional and rural areas.
- The issues surrounding young people with disabilities living in aged care facilities.
- The ageing population and the increased number of residents with dementia.
- The diverse needs of community groups such as:
 - Aboriginal and Torres Strait Islander people
 - People from Cultural and Linguistically Diverse (CALD) backgrounds
 - Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) people
 - Rural and remote areas
 - People with disabilities
 - People with mental health issues
 - People who are homeless or at risk
 - Veterans
 - People who have been in long-term institutional care (Forgotten Australians)
 - People experiencing socio or economic disadvantage.
- The quality and safety of aged care services both in residential aged care facilities and home community services.

The hearings are held in different states and territories beginning in Adelaide. The ACRC is open to the public in various courtrooms and convention centres, recorded, transcribed and available for viewing on the ACRC website via the Webcast.

The courtroom – a difficult space

The courtroom is a difficult space, the Commissioners are seated on judicial benches. The witnesses sit in small booths with a microphone, water and a box of tissues. For direct evidence witnesses, they are there to tell their story, to engage, plead and highlight their experiences of the aged care sector. Often experiences are deeply personal embracing themselves, spouses, partners, parents and in some cases, parents with children in aged care.

I know only too well that speaking out is not an easy thing to do. I'm not usually the sort of person who complains. I would rather compliment than criticise. I am an ordinary person without any formal education or qualifications. But when I knew things had been wrong with Bob's treatment, I had to keep pushing. I couldn't stay quiet

knowing that others might face similar experiences to what he had been through (Spriggs, 2019).

Owners and operators of aged care facilities are there to defend and justify their organisational position, others highlight good practice. Clinical and care staff are there to provide personal accounts of working within aged care and, as with the owners/operators, reveal the noble, the mediocre and the unscrupulous.

Advocacy groups are there to lobby for all users of the aged care sector. Industry bodies provide overviews of the sector, whilst public servants from both Federal and State jostle issues back and forth, exposing decisions made without appropriate data and little consultation between agencies.

Some testimonies are skyped in, often with technical issues. Witnesses swear either on the Bible or from an affirmation card. The strain, nerves and tension are fixed in most faces. Faces that have a story to tell preoccupied with emotion, they are solitary figures sitting in the witness box.

The number of counsel supporting the ACRC comprises three Queen's counsellors, one senior counsellor and five supporting counsellors. The legal team, over the period of the ACRC, become familiar with their individual style, moving between conciliatory demeanour and hard-nosed questioning and their faces thinly disguising their feelings.

Below are four data breakdowns highlighting the breadth and time span of the ACRC. They have not been included as appendices as the author wanted to highlight the breadth of the ACRC.

Table 1 - Royal Commission 18 January, 2019 – 18 October, 2019

Month	State	Transcripts	Witnesses
January	Adelaide	1	0
February	Adelaide 1 Hearing	8	27
March	Adelaide 2 Hearing	5	25
May	Sydney Hearing	8	46
June	Broome & Perth Hearing	8	16 & 30 respectively
July	Darwin, Cairns & Mildura Hearing	11	32, 20 & 23 respectively
August	Brisbane Hearing	5	33
September	Melbourne 1 Hearing	4	26
October	Melbourne 2 & 3 Hearing	10	27 & 41 respectively
November	Mudgee & Hobart Hearing		
Total as of 18 October, 2019		60	346
As of January 2020			
7,747 submissions received by the Royal Commission			
5368 telephone calls to the Royal Commission information line			
Most common term of reference – substandard or unsafe aged care services/neglect, dignity and governance (Aged Care Royal Commission website January 2020)			

Table 2 - Witnesses

Type of witness
Direct evidence – recipients of aged care including young people under the age of 65 (aged care residences and home care), spouses, children and parents with children in aged care.
Care workers – Personal Care Workers, Personal Care Assistants, Health Care Workers (titles vary between facilities) and Carers (unpaid).
Clinical care workers – RN Nurses, EN Nurses, Nurse Managers
Allied health – dentists, physiotherapists, occupational therapists, wellness and lifestyle
Medical – general practitioners, geriatricians, The Geriatric Flying Squad
Management – facility managers
Operators of aged care facilities
Owners of aged care facilities
Researchers into aged care – dementia, dignity of risk, person-centred care, societal beliefs around aged care
Advocacy groups and peak bodies (for all residents in aged care, including young and over 65) – examples include COTA Australia, National Seniors Australia, Summer Foundation, Young People in Nursing Homes National Alliance, Youngcare Connect
Industry bodies – Australian and New Zealand Society for Geriatric Medicine, Australian College of Nursing, The Royal Australian College of General Practitioners
Public Service (State)
Public Service (Federal) – NDIA, NDIS, (quality and safety commission), Australian Bureau of Statistics, Commonwealth Department of Health, Commonwealth Department of Social Services, Aged Care Quality and Safety Commission

Table 3 - Roundtables by state (Interim Report Volume 1)

Location	Date	Theme
Melbourne	22 November, 2018	Preliminary: young people in residential aged care
Adelaide	27 November, 2018	Commonwealth agencies Aged care data holdings Advocacy groups
Sydney	27 February, 2019	Experts: home care
Melbourne	4 March, 2019	Experts: dementia
Canberra	29 April, 2019	Commonwealth agencies: the aged care system
Sydney	30 April, 2019	Experts: culturally and linguistically diverse community
Sydney	30 April, 2019	Experts: lesbian, gay, bisexual, transgender and intersex community
Sydney	2 May, 2019	Experts: workforce issues
Adelaide	28 May, 2019	Experts: Aboriginal and Torres Strait Islander service delivery
Canberra	1 July, 2019	Younger people in residential aged care Informal carers

Table 4 - Community forums

Location	Date
Launceston	3 October, 2019
Rockhampton	20 August, 2019
Brisbane	19 August, 2019
Adelaide	12 August, 2019
Townsville	18 July, 2019
Broome	19 June, 2019
West Melbourne	3 May, 2019

Location	Date
Wollongong	13 March, 2019
Bendigo	5 March, 2019
Bankstown	1 March, 2019

Interim report - *Neglect*

The interim report – *Neglect* was handed to the Governor-General David Hurley on the 31 October, 2019. It would be the final contribution to the ACRC from Commissioner Richard Tracey AM, RFD, QC who passed away on the 11 October, 2019. It comprises three volumes:

Volume 1: Written in three parts:

- The Road to Reform
- ‘An overwhelming sense of loss’
- Inconvenient Truths.

Volume 2: Describes the hearings from the first hearing in Adelaide (February) to Darwin and Cairns (July) hearings, but is influenced by hearings up to September 2019.

Volume 3: Details the community forums and roundtable discussions including participants.
Witness lists and exhibits.
Post-hearing submissions and service provider visit.

Volume 1 written with a subheading - *A shocking tale of neglect*, is the mirror being held up to the reader, there is nowhere to hide from the facts that are laid to bare concerning the failures of the aged care system and the response to the investigation into the aged care sector. Their response as cited in the report follows:

Some providers of aged care have appeared before the Royal Commission to be defensive and occasionally belligerent in their ignorance of what is happening in the facilities for which they are responsible. On many occasions when case studies were presented in hearings, providers were reluctant to take responsibility for poor care on their watch (Tracey, 2019).

Under the title of ‘The Road to Reform’, the reader is provided with a brief introduction to:

- The current system and its complexities and diversity.
- The number of reviews that have been conducted and not acted upon.
- Challenges for a ‘system in crisis’ – where do we start?
- Piecemeal reform at systemic, organisation and individual level.
- Reflections on ‘consumer-driven care’, what issues arise?
- Changing demographics and economic pressures within the system.

‘An overwhelming sense of loss leads the reader along the path of:

- Home care provision, highlighting quality issues.
- Residential age care, highlighting quality issues and care deficiencies.
- Re-evaluating the complex issue of dementia care – how can we do better?
- Palliative care, understanding cultural and diverse needs.

The compelling titled ‘Inconvenient Truths’ tells a critical and complex story about:

- The long waiting lists for home care packages.
- Diversity within the aged care sector, how do we meet the needs of CALD residents?
- Accessing aged care from the systemic, organisational and individual level.
- Place-based models for the provision of care for local Aboriginal and Torres Strait islanders.
- Challenges for regional and remote provision, attracting appropriate staff.
- Removing restrictive practices, particularly, for dementia patients.

- Workforce issues including heavy workloads, poor remuneration, undervalued work and inconsistent education and training.
- Young people in aged care – why are they there?
- What are we going to do and how are we going to do it?

Adelaide Hearing 1 – perspectives on the present aged care system – February

This hearing in February is different. Its focus is not limited to any particular aspect of the terms of reference. It has a special purpose which is to provide background information for what is to come and to identify in advance the issues that are going to require attention as widely and as generally as possible. I will briefly mention the reasons for that. First, it is necessary to describe and understand the aged care system as it currently exists. This includes the services that are meant to be included, the ways access is supposed to be given to them and the framework for regulating them. All of this is supposed to safeguard quality and safety.

The dominant narrative in current Australian culture seems to be that older Australians are a burden. We reject that narrative. A culture of appreciation and respect for older people is needed. This is not a matter of bearing a burden, but of becoming the nation we know we should be. And for the thousands upon thousands of informal and unpaid carers of elderly parents, partners, relatives and friends, they must be given the supports they need. The work of this Royal Commission will challenge all Australians to reflect on our attitudes to caring for loved ones as they age. It will challenge us more generally to reflect on our responsibilities to older Australians whom we've never met but whose contribution has given us so much. (Gray, 2019)

Focus for the hearing (ACRC website 2019)

- Advocacy bodies concerns relating to the current state of the aged care system.
- The clinical issues affecting elderly people and general challenges that arise in meeting clinical needs.
- The concerns and view of medical and nursing professional bodies relating to the current state of the aged care system.
- Demographic information relating to the provision of aged care services.
- The perspectives of government and regulators as to the state of the aged care system.
- The perspectives of workforce representative bodies as to the state of the aged care system.
- Experiences of people receiving services in the aged care system or their family members.
- Key features of the aged care quality, safety and complaints system at Federal level prior to 1 Jan 2019 and then by the establishment of Aged Care Quality and Safety Commission.
- Change in demographics of the population and what that implies for the future of aged care.
- What is the nature and meaning of 'quality' and 'safety' within the system viewed from different national perspectives?
- Key issues affecting the aged care system from the perspective of representative bodies and from personal experience receiving or seeking aged care services.

Key findings

- Regulatory failures highlighted in the Oakden case study. The regulatory framework was 'overly process-driven and flawed' and the training of the accreditors was insufficient.
- The Carnell and Paterson review found 10 recommendations as follows:
 - Establish an independent Aged Care Quality and Safety Commission to centralise accreditation compliance and complaints handling.
 - The Aged Care Commission will develop and manage a centralised database for real-time information sharing.
 - All residential aged care services in receipt of Commonwealth funding must participate in the National Quality Indicators Program.
 - The Aged Care Commission will implement a star-rated system for public reporting of provider performance.
 - The Aged Care Commission will support consumers and their representatives to exercise their rights.
 - Enact a serious incident response scheme (SIRS) for aged care.
 - Aged care standards will limit the use of restrictive practices in residential aged care.
 - Ongoing accreditation, with unannounced visits, to assure safety and quality of residential aged care.
 - Ensure that assessment against Standards is consistent, objective and reflective of current expectations of care.
 - Enhance complaints handling (Carnell & Paterson Report, 2017 p. xii).

Adelaide Hearing 2 – Aged care in the home – March

In any consideration of aged care services provided in a person's home, it is necessary to acknowledge the significant contribution made by informal carers. These are partners, children, very often daughters, grandchildren, nieces, nephews, neighbours and friends, all caring and supporting older Australians. In 2015 you will recall that Deloitte estimated that 1.9 billion hours were provided by informal carers. The replacement value for these services, as estimated by Deloitte, would be \$60.3 billion. That is to say approximately 3.8 per cent of Australian GDP.

In terms of workforce issues, you have heard evidence about the high turnover of staff in home care, the lack of a mandated training regime for personal care workers with no clear career pathways, and how personal care workers' wages do not amount very often to a living wage, and that registered nurses are paid less in aged care than their colleagues in the acute sector. In the week ahead you will hear directly from personal care workers. They will tell the Royal Commission of the issues that concern them, including the continuity and stability of work, working in isolation, including training and support, concerns about work, health and safety, and other such matters (McEvoy, 2019).

Focus for the hearing (ACRC website 2019)

- Perspectives of people seeking or receiving aged care services in their home.
- Quality and safety in aged care in the home, accessibility to aged care in the home, the interface between aged care in the home and other care and the sustainability.
- Other key issues affecting the function of the above.
- The regulatory framework as it applies to aged care in the home.

Key findings

- The aged care sector is too complex.
- Changes are made in an ad hoc way, with problem solving done in isolation rather than as a system.
- A number of reviews of aged care have been conducted with little fundamental change.
- We as a country, fail in our care for older Australians – a poor culture towards ageing.
- Inadequate support for older people to stay in their homes, significant delays in receiving home care packages.
- Insufficient or ineffectively trained staff to look after complex needs.
- Older people are not receiving access to doctors and allied health services in residential care.
- Increase in the number of Australians suffering from dementia with staff not adequately trained to deal with complex issues.
- Retention of staff, lack of remuneration and low staff morale.

Sydney Hearing – Dementia care and residential care - May

And as Professor Brodaty said, we can't just lock people with mental illness away in secure units or institutions now without going through a whole range of legal sanctions and, yet, for the last 30 or 40 years, we've been locking people who need assisted living support, either with or without dementia in actual fact because, in the first facility that my father-in-law lived in, even though it was a low care, he couldn't get out the front door. So we've taken to thinking it's okay to incarcerate people for getting old or for having dementia (Swaffer, 2019).

Well, I haven't got my own things around me. I have got a lot of things around me but I can no longer reach out and grab an atlas if I hear something on the news. I can no longer reach out and get my favourite book because there's a limit in how much you can actually bring with you. And there's just that feeling that this isn't a proper life, and so there is that feeling that the quicker it's all over, the better it is for everybody – yes (Mitchell, 2019).

Focus for the hearing (ACRC website 2019)

- The perspective and experience of people in residential care and people living with the dementia and their family and carers.
- Quality and safety in residential aged care, particularly people living with dementia.
- The use of restrictive practices in residential aged care.
- Does the current aged care system meet the needs of residents?
- Good practice care for people with dementia in the context of residential aged care.

The concept of the 'dignity of risk' principle

So dignity of risk is a concept from the 70s, came from the disability sector, which said that one of the fundamental ideas of being a person is you have autonomy: "I get to choose what I want to do with my life." And that's fine as long as I don't hurt anyone else.

And when people look at autonomy, autonomy is being able to choose and being able to choose not what the outcome of your choice is, but purely the act of choosing. And so dignity of risk is really about, "I get to do – or I get to at least try something that I want to do." Whether I succeed or fail is not the issue. Whether it's safe or unsafe is not the issue. Whether you think it's okay or not is not the issue. It has nothing to do with you. It's all to do with the person who is making their choice. So dignity of risk is, "I get to take risks with my life, because, by taking risks with my life I feel alive, I have my autonomy, and I learn. And sometimes things go brilliantly and I'm very pleased with my choice and sometimes they go horribly wrong and I'm not so happy with my choice, but I'm left always knowing I chose that and I screwed that up, and so I can live with it (Ibrahim, 2019).

Professor Ibrahim (2013), in his journal article titled *Impediments to applying the 'dignity of risk' principle in residential aged care services*, highlights the four core factors that impedes the principle in residential aged care. They are as follows:

- Residents' fluctuating decision-making abilities.
- The multiple parties involved in the decision-making process.
- Lack of consistency between values and actions.
- Confusion and fear around legal responsibilities among care providers.

The article provides the following recommendations around these impediments which should be **critical** to any discussion around aged care services:

- Recognise and respect the decision-making ability of residents with impaired cognition.
- A shared vision between the multiple participants in decision-making.
- Seek consistency between values and actions.
- Clarity and confidence around legal responsibilities among care providers (Ibrahim & Davis, 2013).

Key findings

- Inadequate dementia training for support staff.
- Looking at different models of dementia care, particularly around understanding the person, building appropriate environments, a carer-led mode.
- The concept of 'dignity of risk' as a human rights issue, not respected in aged care provision.
- The widespread practice of physical and chemical restraint.
- Workload pressures leave little time for managing dementia patients, leading to restrictive practices.
- Laws around consent are different in each State and Territory and are often complex.

Broome Hearing – Access and inclusion – June

I turn now to the question of culturally safe care. There are also particular important considerations that arise in relation to the provision of aged care for Aboriginal and Torres Strait Islander people which will be explored at this hearing. It's important to note the diversity of Aboriginal and Torres Strait Islander cultures and language. There are over 500 indigenous nations and over 250 different language groups across Australia. An approach that works for one particular cultural group may not be appropriate in another setting. At the forefront of these challenges, whether care is delivered in the city, rural or remote Australia, it needs to be culturally safe and culturally appropriate. Whilst this encompasses many things and will hold different meanings for different cultural groups, for Aboriginal and Torres Strait Islander people we will hear that at its centre is the acknowledgement of the identity of the person and their connection to community and country, their community and their country.

The barriers that prevent access to the aged care system or getting the types of level of assistance they need come in many forms. The aged care assessment process requires a person to talk about their intimate and personal health, their domestic situation; all of this with a complete stranger. That stranger may be of the opposite sex and may not have had any cultural awareness training. You will hear that this framework leads to Aboriginal and Torres Strait Islander people avoiding the aged care system, withdrawing from the ACAT discussion (Bolster, 2019).

Focus for the hearing (ACRC website 2019)

- Needs of Aboriginal and Torres Strait Islander of people in relation to aged care, both from a cultural and safety lens.
- Caring for people in remote areas.
- The challenges of maintaining an adequately skilled and culturally appropriate workforce.
- Good practice models for people living in remote areas.

Key findings

- Connection to community underpins identity of Aboriginal and Torres Strait Islander people.
- Lack of funding in residential aged care to support cultural activities to maintain the connection to Country.
- The importance of culturally safe care for the Stolen Generation.
- Regional and remote care is impounded by small numbers needing care which limits access to supports and resources.

Perth Hearing – Person-centred care - June

*Person-centred care. Person-centred care is an approach to care that is derived from the work of the American psychotherapist Carl Rogers and the English social psychologist and dementia expert Tom Kitwood. In his important 1997 book *Dementia Reconsidered: The Person Comes First* and his work at the Bradford Dementia Group in the United Kingdom, Kitwood advocated a new culture of dementia care based around the idea of personhood which he defined as a standing or status that is bestowed upon one human being by others in the context of relationship and social being.*

Central to Kitwood's work is the idea that having dementia in itself does not entail a loss of personhood, and although Kitwood's work focused on dementia, the evidence this week will demonstrate that person-centred care is a philosophy that applies to all forms of care. More recently, others have built on Tom Kitwood's work by focusing on the importance of relationship centred care. The importance of relationships in the provision of aged care is expected to be a recurring theme in this week's evidence. I want to say a little bit about what has been said in the hearing so far about person-centred care. The Commission has already heard from witnesses who say that person-centred care should be the foundation of all aged care (Rozen, 2019).

Focus for the hearing (ACRC website 2019)

- How aged care services can be person-centred, valuing identity, life experiences and autonomy and promote choice and control?
- What are the factors influencing person-centred delivery.
- Relationships between person receiving care, people supporting and the service provider.
- Broader societal attitudes towards older people.
- Perspective and experience of people receiving care, whether it is person-centred or not.
- Good practice models.
- Role of advance care planning.
- How accessible is palliative care.
- Quality of palliative care.

Key findings

- Person-centred care is a philosophy that applies to all areas of aged care, not just in relation to residents suffering from dementia.
- Relationships are an integral part of care for older Australians.
- There is no consensus on the meaning of person-centred care but some themes have arisen:
 - Recognition of a person as an individual, has a unique life story, culture, interests and beliefs and that care must reflect this individualisation.
 - Emphasis on 'doing things with people, not to them'.
 - Partnerships between the person receiving care, their carers, families that is underpinned by 'respect, emotional support and physical comfort.
 - The aged care systems should be built around people, not the other way around.
 - Aged care services are 'highly institutional' and not responsive to needs.
 - Personal-centred care is about the 'whole experience not just the clinical indicator experience'.
 - Staff need to build high quality interpersonal communication with respect and trust.
- The critical role that families play, both in advocacy and in their knowledge of the person's personality, likes/dislikes, interests and occupations.

Darwin and Cairns Hearing – Access to aged care and clinical care – July

Other key messages have emerged from the hearing over the last eight days in Darwin and Cairns, including that it is clear that quality care has multiple dimensions, namely, safety, various domains of clinical and personal, care and quality of life, including cultural, socioeconomic and geographical factors. Secondly, quality care is not being delivered at a systemic level in Australia's aged care system.

This is despite the undoubted commitment and care offered by the overwhelming majority of those work is in the sector. Thirdly, aged care providers in rural and regional locations face particular challenges in providing quality care, including funding issues and access to skilled workers and specialist care (Rozen, 2019).

Focus for the hearing (ACRC website 2019)

Aspects of care in residential, home and flexible care programs.

- Accessibility and availability,
- Wound medication and pain management,
- Nutrition and hydration,
- Continence care,
- Mobility,
- Social supports,
- Rural and regional issues in service delivery,
- Quality of life.

Key findings

- Issues with the provision of aged care services in the Northern Territory.
- Failure of appropriate continence care which impacts on 'other care domains, creating more complex care needs, disability and pain'.
- The Maggie Beer Foundation – An appetite for life highlighted the correlation between good food and better clinical outcomes, particularly around the quality of life and wellbeing.
- The need to identify dental issues in older residents which can result in malnutrition causing physical decline, muscle wastage and the increased risk of falls.
- Different models of care which carry on the person-centred care such as:
 - Eden Alternative
 - NewDirection, Bellmere
 - HammondCare
- The tension around clinical/care interface – is a residential aged care facility like a hospital, a home or a hotel? (Trigg, 2019).

Mildura Hearing – Carers for older Australians - July

Providing care for an ageing family member or friend can bring personal rewards and satisfaction. It is a choice that many people willingly make but it comes at a cost.

It can have detrimental effects on the health and wellbeing of the carer; the physical, psychological and financial impacts can be significant. Over time, not only might the carer be affected but so might the quality of care that their loved one receives. If informal care becomes unsustainable permanent entry into a residential aged care facility will probably result at significant public cost. Family and friends of older people have already appeared throughout the Royal Commission hearings to tell us of the experiences of their loved ones. Many have incidentally also explained the challenges of accessing and managing formal services as well as the financial, social and emotional toll that a caring role can have. In this hearing those matters will be central (Gray, 2019).

Focus for the hearing (ACRC website 2019)

- How good are the current arrangements?
- How can things be improved?
- Respite care and its role.

Key findings

- Definition of carer – ‘informal carer’ such as family and friends who care for older people as compared to formally employed or volunteers within the aged care.
- The role of respite in caring for a family member at home. Difficulties have been encountered when the older person does not recognise their new surrounds. Ambiguity around respite – is it for the carer or the recipient of care?
- Types of respite:
 - Residential respite.
 - Commonwealth Home Support Program (CHSP) entry level assistance.
 - Respite services through the Home Care Package Program (HCPs).
 - Short-term and emergency respite through the Commonwealth Respite and Carelink Centres.
- Challenges when accessing formal services coupled with the financial, emotional and social toll on carers.

Brisbane Hearing – Regulation of aged care - August

There are fundamentally inadequate consequences for providers who fail to meet proper standards in their care of residents. Stronger powers should be bestowed on the regulator to allow for a broader range of punitive measures such as financial ramifications including fines and penalties for providers who fail to deliver adequate care, especially where it results in harm. We need a policeman on the beat, not a social worker (Backhouse, 2019).

Involve those people, involve residents, involve relatives in designing new models of care and delivering new models of care, in overseeing quality, in supporting, you know, the various things that need to be done to ensure people have their rights protected (Trigg, 2019).

Focus for the hearing (ACRC website 2019)

- Regulations around quality and safety in aged care and how the regulatory system operates.
- Different approaches to regulation, including other sectors.
- How to improve the above.

Key findings

- Failures to provide appropriate care at a systemic level – focused on two providers.
- Inadequate sanctions for residential care providers – should they be fined or face bans if they fail in their provision of aged care services?
- Do sanctions work in the regulatory framework?
- The role of advisors and administrators assisting operators of residential aged care – should it be as an advisor to improve services or as an agency to resolve sanctions.
- Lack of ‘candour, transparency and accountability’ on behalf of aged care providers and the regulators.

The lack of robust clinical processes and reporting provides an ongoing risk for the home, including the risk of a possible catastrophic clinical event (Ansell employee [anon], 2019).

Melbourne Hearing 1 – Younger people in residential aged care – September

We'll explore the interfaces between the health, disability and aged care sectors, identifying the barriers and levers that contribute to younger people being placed in aged care. Commissioner, you'll hear of the tension that exists between these systems and the inter and intra-jurisdictional issues that drive this tension. It's a tension that is no more evident than when hospitals aim to shift patients they refer disparagingly to as bed-blockers into alternative care arrangements. We will explore how the pressure on hospitals, aged care assessment teams and aged care homes influences the placement of younger people into aged care (Rozen, 2019).

Okay. My number 1 goal is to get the fuck out of the nursing home. My number 2 goal is to hug my children (Chard for Corcoran, 2019)

Focus for the hearing (ACRC website 2019)

- Impact on younger people living in aged care.
- Why younger people in aged care?
- Responsibilities – health system, social services system and aged care.

Key findings

- Almost 6000 people under the age of 65 live in residential aged care in Australia (ACRC Interim Report p. 233).
- There is no clarification around why young people are in aged care, the population is diverse and includes:
 - People living with a disability (approximately 3700 people under the age of 65).
 - People with palliative and end of life needs.
 - People suffering with early onset dementia.
 - People who are assessed as having an early need for aged care services, such as those who have experienced homelessness and Aboriginal and Torres Strait Islander people (ACRC Interim Report p. 235).
- Residential aged care facilities are not in the position to provide multifaceted care for young people with complex disabilities.
- Lack of alternative services and settings to support young people's needs, highlighting the lack of case management.
- Multiple systems involved with young people with disability, each difficult to navigate and disparate in outcomes.
- A 'pipeline' effect has developed between the acute care setting and aged care facilities, where young people ultimately reside in aged care facilities because there is no other alternative available – this is a state and national issue.
- The situation of young people in aged care can 'offend fundamental human rights principles as set out in article 19 of the Convention of the Rights of Persons with Disabilities, which is concerned with the right to live independently in the community (Rozen, 2019).
- Young people in aged care experience social isolation, neglect loss function, sense of hopelessness and grief (ACRC Interim Report p. 239).

Being in a place where people are constantly dying isn't the right place for young people. I feel isolated and alone. I don't have the freedom to get out. I feel like a prisoner. The outside doors are locked. When my bedroom door is shut I can't open it on my own, I have to ask someone to let me out, and then let me back in (Radley, Exhibit 9-8, Melbourne Hearing 1).

Melbourne Hearing 2 – Diversity in aged care – October

Diversity is a hallmark of humanity, yet aged care providers and the aged care system as a whole have not always responded to needs that are out of the so-called ordinary. Some needs remain invisible. Barriers of a cultural, linguistic and experiential nature can always too easily intrude between those providing and those receiving care. Unless careful attention is given to these aspects of care, there is a real risk that the system will leave older people isolated and neglected. This hearing will focus on the diverse experiences and needs of people from culturally and linguistically diverse backgrounds, of lesbian, gay, bisexual, transgender and intersex people, people who are separated from their parents, country and culture, including Forgotten Australians, former child migrants and the Stolen Generations, Aboriginal and Torres Strait Islander people, people who are homeless or at risk of becoming homeless, and our Defence Force veterans.

It's too simplistic to think about individuals as members of these groups. Collective descriptions of peoples' backgrounds and experiences are simply inadequate to convey the rich diversity of individual identity and need. That said, for some people, belonging to these groups and thereby acknowledging their fellowship with others of shared background and experience is a very important element of their own identities. And, of course, an individual may belong to more than one of these so-called groups. And the groups themselves are far from exhaustive.

There are many, many other circumstances that can give rise to needs that require special attention in aged care. To name a few, disability, mental illness, cognitive impairment, including dementia, and a history of trauma from mistreatment of various kinds, including family violence, or severe hardship from social and financial disadvantage, HIV positive status, a history of incarceration, and the list goes on (Gray, 2019).

Focus for the hearing (ACRC website 2019)

- People with culturally and linguistically diverse (CALD) backgrounds.
- People who identify as being lesbian, gay, bisexual, transgender, intersex (LGBTI).
- Care leavers, being people who spent time in care as a child, including institutional and out of home care arrangements.
- Aboriginal and/or Torres Strait Islander people (with a particular focus on people living in urban areas).
- People who are homeless or at risk of homelessness.
- Veterans.

Key findings

- The critical link between relationship-based care and social connection.
- Cultural connection and the ability to be able to share life experiences to reduce social isolation.
- Identified need for trauma-informed care.
- Appropriate responses to discrimination.
- Collection of reliable data for analysis.
- Person-centred care, inclusion and dignity are key underpinning values often missed in aged care.

Diversity and person-centred care

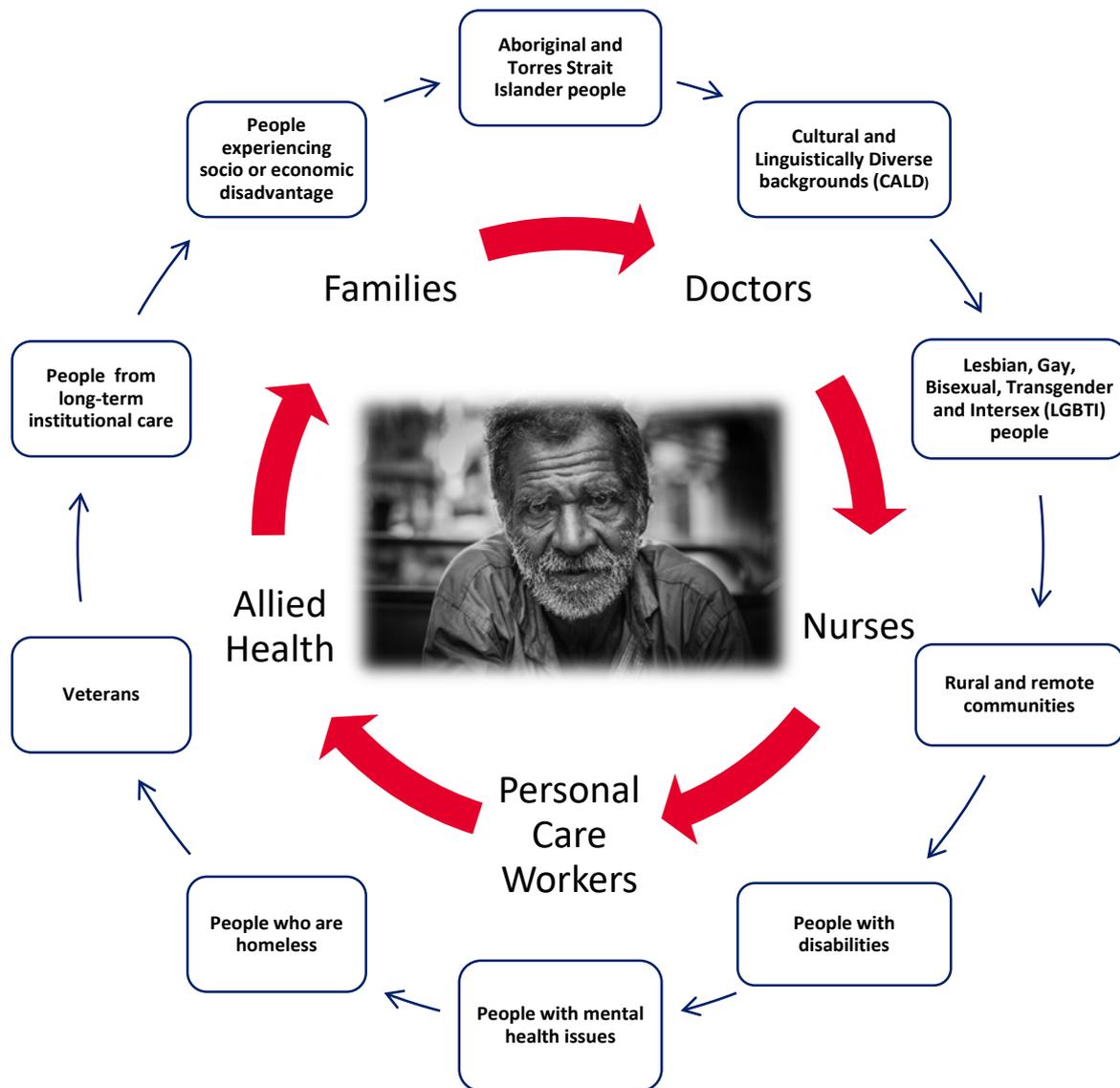


Image adapted from the Aged Care Diversity Framework – *Aged Care Sector Committee Diversity Sub-group, December, 2017*, p. 1

Image sourced: Photo by Aamir Mohd Khad www.pixabay.com. Downloaded on 28 January 2020

Melbourne Hearing 3 – Aged care workforce – October

The older Australians and their family members who have given evidence to this Royal Commission have told you about their lack of confidence in the aged care workforce to deliver the safe and high-quality care that older people need and deserve. The Commission has heard evidence from people who work in aged care, personal care workers, assistants in nursing, enrolled and registered nurses, nurse practitioners, directors of nursing, allied health workers, general practitioners, clinical consultants, geriatricians, team leaders, residential managers and chief executive officers. To date, 113 witnesses, whose images are now displayed on the screen, have provided the Royal Commission with their perspective of working day-to-day in aged care.

Some of the key workforce challenges identified in their evidence includes inadequate numbers and continuity of staff, the adequacy and relevance of training and education and low pay and limited career paths. You have also heard evidence about difficulties attracting and retaining high quality people to work in aged care and the importance of selecting the right people to work in aged care (Rozen, 2019).

Focus for the hearing (ACRC website 2019)

- Enhance the aged care workforce's capacity and capability to provide high quality care and support quality of life.
- Make the aged care sector more attractive and rewarding to work in.

Key findings

- Decrease in the numbers of registered nurses on shift, particularly at night.
- Increase in the number of personal care workers who are often doing duties above their skill level.
- Tension between the interface between clinical and personal care.

Mudgee Hearing – Provision of aged care in regional areas - November (not covered in this paper)

Focus for the hearing (ACRC website 2019)

- The perspective and experience of people who access or are involved in aged care in regional and remote areas.
- Challenges associated with delivering aged care in regional and remote areas.
- Models for and approaches to delivering aged care in regional and remote areas, including Multi-Purpose Services.

Hobart Hearing – Aged care operations of selected Approved Providers – November (not covered in this paper)

Focus for the hearing (ACRC website 2019)

- The hearing focused on the governance of particular approved providers of aged care services and the impact of that governance on the quality and safety of care.

Canberra Hearing – Interfaces between the aged care and the health care system – December (not covered in this paper)

Focus for the hearing (ACRC website 2019)

- The challenges faced by people living in residential aged care services attempting to access health services funded under Medicare or by the states and territories.
- Whether there is a need to improved access to primary health care services (particularly general practitioners, nurse practitioners and primary care nurses) for older people in residential aged care, and if so, how this could be achieved.
- Whether there is a need to improve access to high quality secondary and tertiary (sub-acute and acute) health care services for older people in residential aged care, and if so, how this could be achieved.
- The challenges faced by people living in aged care in accessing medical specialists, and the harms arising from inadequate access.
- Whether it is necessary or desirable to improve how older people are transferred to and from aged care and hospitals, including the appropriateness of rehabilitation and transition care services post hospital attendance.
- Where there is a need for improved data collection, communication and planning in relation to the health needs of older people accessing aged care services, including the interoperability of care management systems.
- The sufficiency of access to state and territory funded palliative care services for people living in residential aged care.

Models of care identified in the ACRC

NewDirection Care in Bellmere Queensland – This community, known as a microtown™ provides residents with a non-clinical environment respecting residents' interests, needs, values, aspirations and preferences. The community comprises 17 homes, each providing accommodation for 7 residents and supported by House Companions.™ Daily routines are determined by the resident and focuses on mental and physical wellbeing. House Companions are medication certified (only packaged drugs) and induction includes first aid, dementia care, food preparation, and food safety. A registered nurse administers unpacked medication and schedule 8 drugs. www.newdirectioncare.com.au

Montessori Ageing Support Services (MASS) focuses on the individual and their history, experience and relationships. Underpinning the service are the three values of person centred care, quality and altruism equity, which embraces all diversity. It develops techniques that assist people learn routines for independence and increased self-esteem through exercising individual choice. www.massa.org.au

The Eden alternative is a philosophical approach to older people referred to as elders. Underpinning the philosophy are the three plagues of residential aged care – loneliness, helplessness and boredom. Guiding principles include emphasis on creating human habitats, interaction with animals, children, keeping active and involved. www.edenalt.org

The Humanitas Foundation, a Dutch NGO, runs the *Levensloopbestendige movement* or *Apartments for Life (A4L)*. It provides accommodation for residents from three mixed aged groups:

- Residents who are 55 years and over, but independent.
- Seniors who require some assistance.
- Residents who need care including medical care.

It is underpinned by four values:

- Autonomy – allowing residents to remain in control of their lives.
- Use it or lose it – not allowing over provision to cause loss of independence.
- Yes culture – taking residents' wishes seriously.
- Family-centred approach – residents develop relationships and achieve an enhanced independence and mental wellbeing. www.centreforpublicimpact.org

Dr David Sheard from Dementia Care Matters (UK) established the Butterfly Household Model of Care to support dementia patients. The values that underpin this model are that 'people living with a dementia can thrive well in a nurturing environment where those living and working together know how to be person centred together (Dr David Sheard, 1995). It encourages leadership with staff, families and carers and promotes person-centred relationships.

RedUse (**Reducing Use of Sedatives**– medication management pilot involved general practitioners, aged care staff and pharmacists in a multidisciplinary approach/partnership focused on the inappropriate use of sedatives. The project developed training program for nurses, doctors and pharmacists on the risks and benefits of the use of sedatives in aged care. www.utas.edu.au/wicking/research/services/RedUSe

Teaching Nursing Homes (pilot 2010) – encourage GPs into nursing homes, residential aged care facilities become multidisciplinary training sites which includes research, clinical care and training.

<https://agedcare.health.gov.au/ageing-and-aged-care-publications-and-articles-ageing-and-aged-care-reports/implementing-the-teaching-nursing-homes-initiative>

EveryAGE Counts – is a strategy to combat ageism in Australia;
www.everyagecounts.org.au/

The Janus Dignity Approach is a model of person-centred care specific to RSL Care SA:

The Janus Approach is a philosophy of care, specific to RSL Care SA, that acknowledges residents are unique individuals, who have a variety of personal needs and preferences. In order to deliver the Janus Approach at RSL Care SA, we have identified speciality areas of care provision which are addressed through the 'Janus Keys'. The leader for each respective 'key' is accountable for maintaining current evidenced based practice and applying this in the performance monitoring of care delivery to the residents of RSL Care SA. We currently have six Janus Keys and have intentionally designed this model so that as the approach matures and the needs of residents' change, additional 'keys' can be added (RSL Care SA website, accessed September 2019).

The six keys are as follows:

- Dignity and person centred care.
- Meaningful and engaging programs.
- Spiritual care and connectedness.
- Mental Health.
- Sexuality and intimacy.
- Palliative approach.

<http://rslcaresa.com.au/the-janus-approach-keys/>

The Whiddon Group – large, not for profit organisation covering residential aged care, community care and retirement living.

So it's really about that level of work, introducing new programs to Whiddon and to the care delivery and enhancing our model of care – again, with research and evidence-based programs and work. It is important to Whiddon because we are continually trying to innovate as an organisation and we are continually trying to innovate our approach to care. It's a tone that's set at the top, from the board down, that we – we want to deliver and enhance care outcomes, and we've realised that in order to do that – we've made a decision that we needed research and an evidence-based approach. So we had to dedicate an executive and resources in order to do that (Mamarelis, 2019).

Examples of previous reports on the aged care sector

Pollaers J (2018) A Matter of Care Australia's Aged Care Workforce Strategy, Aged Care Workforce Strategy Taskforce.

Carnell K & Paterson R (2017) Review of national aged care quality regulatory processes, Office of the Minister of Aged Care.

Groves A, Thomson D, McKellar D and Procter N. (2017) The Oakden Report. Adelaide, South Australia: SA Health, Department for Health and Ageing.

National aged care alliance, position paper (2017) Aged Care Workforce.

Commonwealth of Australia (2015) Report into young people in aged care.

Blueprint for Aged Care (2012) National aged care alliance

Nay R, Fetherstonhaugh D & Garratt S. (2010) Innovative workforce responses to a changing aged care environment.

A salutary reminder...

And as I always say, that if we do nothing, then the people that will pay the penalty is everyone in this room. And so if no one wants to do anything, then the system that we accept now is what awaits us, and if I'm around long enough I will come around and say "I told you so" (Ibrahim, 2019).



Societal - view of older Australians is one of 'burden, encumbrance and obligation (Interim Report)

Systemic - poor interface between state and federal agencies, older people have difficulty negotiating services, sanctions are ineffectual and CEO's lack of insight into daily issues

Organisational - lack of care oversight, need improved policies and procedures and investment in staff skills and increase staff/resident ratios

Individual - needs are personal, complex and diverse. Staff at all levels need appropriate skills to meet their needs

Image sourced: Photo by Glen Hodson www.unsplash.com Downloaded 28 January 2020

Education and training – a call to action!

We can simply ask ourselves (as an education institution) what can we do? We are the driver in skill building and the flow on effect is social change – we need to put aside the 'but' and ask how? (Glaiser, 2019)

- Education and training in:
 - dementia,
 - wound care,
 - cultural diversity,
 - mental health,
 - continence,
 - palliative care.
- Emphasis on enterprise which provide the 'human skills' – see Skills Solution program.
- Preparation of PCWs in the event of mandatory registration – look at enrolled nursing as a guide.
- Increased skills in the use of technology through professional development.
- Identification of clear pathways in personal care, nursing and allied roles to attract people into the sector.
- Develop a traineeship model for PCWs.
- Develop a scholarship model for upgrading skills for PCWs.
- Postgraduate qualifications for nurses and allied workers focused on aged care.
- Professional development plans are part of a continuous cycle of improvement.
- PCWs train to be part of the development of support plans for older residents.
- Training in relationship building as relationships are critical between residents and PCWs, as well as relationships with other staff.
- Importance of leadership at all levels from the systemic through to operational areas.
- Develop recruitment skills in the organisation to identify appropriate staff at all levels.
- PCWs need to be medication certified using medical packs (Webster packs).
- Mentoring programs for staff in residential and home care settings.
- Staff training in the areas of person-centred care and the concept of 'dignity of risk'.
- Dementia training at Certificate III Individual Support should be core, not elective.

New skills solution program for professional develop or induction

Recognise grief:

- Understanding grief and depression.
- Recognising grief and depression in older people.
- Supporting the mental health of older people.
- Looking after your mental health at work.



Engage empathetically:

- Relate to older people with compassion, sensitivity, professionalism and with care.
- Ensure older people's privacy is respected.
- Identify and respect social, cultural, ethnic and spiritual differences.
- Reflect on and use verbal and non-verbal communication approaches that recognise older people's emotional needs.

Image sourced: Photo by Eberhard Grossgasteiger
www.unsplash.com
 Downloaded 28 January 2020

Food handling:

- Understand and use food safety program.
- Store food correctly with regard to storage area and temperatures.

- Prepare or pre-heat meals and snacks according to serving instructions.
- Prepare and plate food in an attractive and delicious manner.
- Ensure residents have the correct utensils for eating and drinking.

But if I can simply say that he had an agonising death, which, on the information available to me and subsequently checked, was avoidable, inexcusable and unforgivable. Brian, a very tactile, caring, loving individual, who was a big huggy kind of person, and he couldn't bear to be touched. So I couldn't hold him in my arms. I couldn't – I couldn't comfort him. I just had to watch him – sorry. In agony.

- Valier, November 2019

Appendix 1 – The New Aged Care Quality Standards

- Consumer dignity and choice.
- Ongoing assessment and planning with consumers.
- Personal and clinical care.
- Services and supports for daily living.
- Organisation's service environment.
- Feedback and complaints.
- Human resources.
- Organisational governance.

Appendix 2 - A matter of care - aged care taskforce

Chair: Professor John Pollaers AO

This report published in 2018 provides a clear framework for the aged care sector and the outcomes are being endorsed through the ACRC

Contents

Framing the case for change.

The taskforce's approach to building the workforce strategy.

Why aged care matters.

An aged care strategy.

Strategic action 1: Creation of a social change campaign to reframe caring and promote the aged care workforce.

Strategic action 2: Voluntary industry code of practice.

Strategic action 3: Reframing the qualification and skills framework – addressing current and future competencies.

Strategic action 4: Defining new career pathways, including how the workforce is accredited.

Strategic action 5: Developing cultures of feedback and continuous improvement.

Strategic action 6: Establishing a new industry approach to workforce planning, including skills mix modelling.

Strategic action 7: Implementing new attraction and retention strategies for the workforce.

Strategic action 8: Developing a revised workforce relations framework to better reflect the changing nature of work.

Strategic action 9: Strengthening the interface between aged care and primary/acute care.

Strategic action 10: Improve training and recruitment practices for the Australian Government aged care workforce.

Strategic action 11: Establishing a remote accord.

Strategic action 12: Establishing an aged care centre for growth and translational research.

Strategic action 13: Current and future funding, including staff remuneration.

Strategic action 14: Transitioning the industry and workforce to new standards.

Appendix 3 - Resources & references for aged care sector

Agency	Description	Website
Beyond Blue	<i>Depression and mental health agency</i>	www.beyondblue.org.au
The Communiques	<i>Aged care publication</i>	www.thecommuniques.com
Australian Ageing Agenda	<i>Bi-monthly newsletter</i>	www.australianageingagenda.com.au
Meaningful Ageing Australia	<i>Pastoral and spiritual agency for older people</i>	www.meaningfulageing.org.au
Aged Care Insite	<i>Aged care publication</i>	www.agedcareinsite.com.au
National LGBTI Health Alliance	<i>Peak health organisation providing health programs for the LGBTI communities</i>	www.lgbtihealth.org.au
Silver Rainbow	<i>LGBTI ageing and aged care</i>	www.lgbtihealth.org.au
Alice's Garage	<i>Promoting health LGBTI ageing</i>	www.alicesgarage.net
Val's Café	<i>Supporting older LGBTI community</i>	www.lgbtihealth.org.au/vals-cafe
Victorian Pride Centre	<i>Supporting older LGBTQI community</i>	www.pridecentre.org.au
Transgender Victoria	<i>Education and support for transgender community</i>	www.transgendervictoria.com
Opal Institute	<i>Part of the Celebrate Ageing Program promoting older people's sexual rights</i>	www.opalinstitute.org
The Dementia Society	<i>Blog focused on dementia and Kitwood's work (dementia equation)</i>	www.dementia-wellbeing.org
Dementia Australia	<i>Peak body representing Australians living with dementia</i>	www.dementia.org.au
Young People in Nursing Homes National Alliance	<i>Advocacy group for younger people (under the age of 65) in residential care</i>	www.ypinh.org.au
Summer Foundation	<i>Advocacy group for younger people (under the age of 65) in residential care</i>	www.summerfoundation.org.au
Global Centre for Modern Ageing	<i>Advocacy and research group</i>	www.gcma.net.au

Agency	Description	Website
National Ageing Research Institute Ltd (NARI)	<i>Research group involved with improving health outcomes and aged care practice</i>	www.nari.net.au
Australian Health Services Research Institute, University of Wollongong	<i>Research group involved with management and provision of health and community services</i>	www.uow.edu.au
Phoenix Australia	<i>Centre for post-traumatic mental health</i>	www.phoenixaustralia.org
Blue Knot Foundation	<i>Trauma-informed care</i>	www.blueknot.org.au
Healing Foundation	<i>Intergenerational trauma, Stolen Generation</i>	www.healingfoundation.org.au/intergenerational-trauma
Social Compass	<i>Research around Aboriginal communities and inclusive societies</i>	www.socialcompass.com
Australian Centre for grief and bereavement	<i>Resource for education and training in the areas of grief and bereavement</i>	www.grief.org.au
CareSearch	<i>Palliative care knowledge network</i>	www.caresearch.com.au
Palliative Care Australia	<i>Palliative care resources</i>	www.palliativecare.org.au
palliAGED	<i>Palliative care aged centre</i>	www.palliaged.com.au
ELDAC	<i>End of life directions for aged care</i>	https://www.eldac.com.au/tabid/5031/Default.aspx
RACGP	<i>Royal Australian College of General Practitioners (Silver Book on aged care)</i>	https://www.racgp.org.au/clinical-resources/clinical-guidelines/key-racgp-guidelines/view-all-racgp-guidelines/silver-book/part-a
Maggie Beer Foundation, Creating an Appetite for Life	<i>Advocacy and training provider for food experiences for older Australians</i>	www.maggibeerfoundation.org.au