



The Royal Commission
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Dear Commissioners

Inquiry into Aged Care Quality and Safety

The Health Care Consumers' Association (HCCA) is very pleased that the Royal Commission into Aged Care Quality and Safety was established. The Commission will undoubtedly uncover cases where older Australian's have not been treated with the dignity and respect they deserve. In doing so, you will give them a voice with which to be heard.

When consulting with consumers about aged care the following four issues emerge repeatedly:

- The need for consumer-centred care
- High quality services
- The importance of good communication
- The affordability of services

These issues are of importance to people living in residential aged care facilities as well as those people receiving care in their own home. These issues are magnified for people from culturally and linguistically diverse backgrounds and people who identify as lesbian, gay, bisexual, transsexual, intersex and queer.

About HCCA

The Health Care Consumers' Association (HCCA) is a health promotion charity and the peak consumer advocacy organisation in the Canberra region. Last year we celebrated forty years of incorporation. HCCA provides a voice for consumers on health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through

- consumer representation, and consumer and community consultations,
- training in health rights and navigating the health system,
- community forums and information sessions about health services, and
- research into consumer experience of human services.

HCCA is a member-based organisation and for this submission we consulted with HCCA's Health of Older People Consumer Reference Group and our Health Policy Advisory Committee.

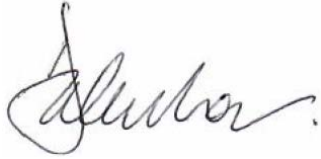
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We hope that the Commission's report will provide a plan for action that any government cannot ignore.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Darlene Cox', with a stylized flourish at the end.

Darlene Cox
Executive Director

18 June 2019



**Royal Commission into Aged Care
Quality and Safety:
Health Care Consumers' Association (HCCA)**

Submitted 18 June 2019

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Executive Summary and Recommendations

In consulting with its members, Health Care Consumers' Association (HCCA) found that four themes emerged repeatedly:

- Quality services
- Affordability
- Good communication
- Consumer-centred care

In addition, HCCA believes that the needs of older Australians from culturally and linguistically diverse communities are not being met. We discuss each in turn and we make the following seven recommendations:

- Recommendation 1. That the new Aged Care Quality Standards are applied compulsorily to both profit and not-for-profit aged care providers
- Recommendation 2. That providers who do not meet the standards are required to address them within a specified timeline
- Recommendation 3. That sanctions are imposed on providers who do not address identified shortcomings or consistently fail to meet the standards.
- Recommendation 4. That the financial affairs of aged care providers, particularly for-profit providers, are legally subject to scrutiny.
- Recommendation 5. That aged care services prioritise all elements of communication.
- Recommendation 6. That all aged care services take a consumer-centred approach to aged care.
- Recommendation 7. That all aged care services provide culturally inclusive training, as determined by the local demographics, for all levels of aged care staff

Introduction

The Health Care Consumers' Association (HCCA) is a member-based organisation. We have been giving voice to consumer concerns and promoting their suggestions for health policy and service improvement since 1978. For this submission we drew upon 40 years' experience and consulted with our Health of Older People Consumer Reference Group and our Health Policy Advisory Committee. In addition, we revisited consumer contributions to the following recent aged care related inquiries or public consultations:

- Parliamentary Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia (Feb 2018) (available [here](#))
- Inquiry on the Financial and Tax Practices of For-Profit Aged Care Providers (June 2018) (available [here](#))
- Draft Charter of Aged Care Rights (Oct 2018) (Available [here](#))
- Streamlined Consumer Assessment for Aged Care (Available [here](#))

We consulted with our members for each submission. On each occasion the same broad themes emerged. Consumers want high quality services, affordability, good communication, and consumer-centred care. These themes map well onto four of the Commission's terms of reference. The extent to which aged care services meet the

needs of culturally and linguistically diverse communities is also a concern for HCCA and we address this under Term of Reference G.

Theme	Terms of reference
Quality services	A
Affordability	C
Good communication	D
Consumer-centred care	E
Culturally and linguistically diverse services	G

HCCA believes that the forthcoming *Charter of Aged Care Rights*¹ (the Charter) and implementation of the *Aged Care Quality Standards*² (the Quality Standards) will help address the deficits in aged care services. However, we note that the final version of the Charter does not explicitly mention “access”, the first right under the *Australian Charter of Healthcare Rights*.³ It also does not explicitly address the needs of vulnerable consumers. Our regular conversations with the ACT AIDS Action Council highlight the particular challenges faced by people who identify as LGBTIQ. The Appendix contains the case study we provided the Department of Health as part of our submission on the Draft Charter of Aged Care Rights. We believe this summarises the issues well.

Term of Reference A – Quality services

- a. the quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response;

The right to safe and high-quality care and services is the first right mentioned in the *Charter of Aged Care*. Furthermore, Standard 3 of the *Aged Care Quality Standards* clearly state what is expected of services in terms of personal and clinical care. In addition, Standard 7 requires a service to have skilled and qualified workforce that provide safe and respectful and quality care.

However, all the standards need to be rigorously monitored. Any failure to meet the standards must require the service provider to meaningfully address the identified inadequacies in a given timeframe. Ultimately, serious consequences must be applied to any service provider who does not address recognised deficiencies. Therefore, HCCA supports the introduction of aged care standards by the Aged Care Quality Standards and Safety Commission and awaits their meaningful application.

Recommendation 1. That the new Aged Care Quality Standards are applied compulsorily to both profit and not-for-profit aged care providers

Recommendation 2. That providers who do not meet the standards are required to address them within a specified timeline

Recommendation 3. That sanctions are imposed on providers who do not address identified shortcomings or consistently fail to meet the standards.

Term of Reference C – Affordability

- a. the future challenges and opportunities for delivering accessible, affordable and high quality aged care services in Australia, including:
 - i. in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and
 - ii. in remote, rural and regional Australia;

Choice is desirable but is often limited by an individual's financial resources. Considerable public money is directed towards aged care and consumers are adamant that they expect to receive the benefit of that funding. Our members are concerned that in some cases the funds are not used for the benefit of older people, particularly by for-profit providers. Through involvement in a Clinical Governance Committee, one member has become aware that some for-profit services are referring their care packages client to free public community services, rather than providing those services themselves. Effectively, some for-profit services are receiving public money but not providing the service. Therefore, the government are paying twice for a single instance of service. HCCA is aware of the economic analysis undertaken by Richard Cumpston and Kasia Bail which analyses data on residential aged quality. Naturally these findings are disturbing.

For-profit providers had had [sic] non-compliance risks about 1.70 times those of not-for-profit providers, sanction risks about 2.78 times, satisfaction scores about 0.98 times, and complaint numbers about 1.77 times.⁴

The Charter refers to having control over one's financial affairs (Right 8), but neither the Charter nor the Quality Standards address a situation where public money is being incorrectly used. Another of our members suspects that the government's push for "sustainability" in aged care funding signals a shift towards consumers bearing the primary responsibility for funding their care.^a

Recommendation 4. That the financial affairs of aged care providers, particularly for-profit providers, are legally subject to scrutiny.

Term of Reference D – Good communication

- a. what the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe;

The *Charter of Aged Care Rights* reflects the importance of good communication between consumers and service providers, particularly

- Right 5. To be informed about my care and services in a way I understand, and
- Right 6. To access all information about myself, including information about my rights, care and services.

^a The member plans to make a private submission.

Communication is not limited to the provision of information about a service in an appropriate format. It requires consumers and service providers to engage as partners in discussions about individual care (Standard 2). Ideally this consumer-provider engagement extends to service planning, implementation and evaluation. To some extent this is reflected in Standard 8 Organisational governance. Additionally, consumers must feel free, and be adequately supported, to comment and provide constructive feedback to service providers (Standard 6).

Recommendation 5. That aged care services prioritise all elements of communication.

Term of Reference E – Consumer-centred care

- a. how to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters;

HCCA supports a consumer-centred approach to aged care. In summary,

*consumer-centred care meets the physical, emotional and psychological needs of consumers, and is responsive to someone's unique circumstances and goals.*⁵

You can read a more detailed description of the consumer-centred care [here](#).

HCCA is pleased to see that a consumer-centred approach is inherent in *Australian Charter of Aged Care Rights*. And that other elements of a consumer-centred approach are found in the *Aged Care Quality Standards*, particularly

- Standard 1. Dignity and choice,
- Standard 2. Ongoing assessment and planning with consumers, and
- Standard 4. Services and supports for daily living.

Unfortunately, the need for this royal commission indicates that consumers are not always at the centre of care.

Recommendation 6. That all aged care services take a consumer-centred approach to aged care.

Term of Reference E – people from multicultural communities

The challenges for older people accessing safe and good quality aged care services are amplified by linguistic and cultural barriers. Older people from culturally and linguistically diverse backgrounds are underrepresented in aged care facilities. In part, this is due to expectations that children will care for their parents at home. However, language barriers and lack of culturally appropriate care make for an unwelcoming environment, and may negatively affect their health and well-being.

In contrast to low numbers of multicultural people in residential facilities, almost a third of total home care recipients in Australia are from culturally and linguistically diverse backgrounds. Elderly migrants in particular, struggle to adapt to a foreign environment outside their home. In both aged care facilities and home care services the high staff turnover makes it difficult for people to develop trust or build rapport with their carers.

As a priority, providers need to address:

- The lack of culturally inclusive training for all levels of aged care staff
- Ways to reduce the high workforce turnover
- Social isolation caused by lack of social activities for older multicultural people
- Home Care Package waiting lists (the preferred type of care for older people from multicultural populations)

Recommendation 7. That all aged care services provide culturally inclusive training, as determined by the local demographics, for all levels of aged care staff.

Conclusion

When consulting with consumers about aged care the following four issues emerge repeatedly:

- Consumer-centred care
- Quality services
- Good communication
- Affordability

These issues are magnified for people from culturally and linguistically diverse backgrounds who are in aged care facilities and are also faced by those receiving care in their home.

¹ Charter of Aged Care Rights. 1 July 2019. Commonwealth Department of Health. Available at <https://agedcare.health.gov.au/quality/single-charter-of-aged-care-rights>

² Aged Care Quality Standards. 1 July 2019. Aged Care Quality and Safety Commission. Available at <https://www.agedcarequality.gov.au/providers/standards>

³ Australian Charter of Healthcare Rights. 2008. Australian Council for Safety and Quality in Healthcare. Available at <https://www.safetyandquality.gov.au/wp-content/uploads/2012/01/Charter-PDF.pdf> (Accessed 6 June)

⁴ Cumpston R and K Bail. 2019. "Data on residential aged care quality." Submission to the Royal Commission into Aged Care Quality and Safety. Available at http://drnurse.com.au/wp-content/uploads/2019/04/Cumpston2019_Data-on-residential-aged-care-quality.pdf

⁵ Consumer-Centred Care Position Statement. Health Care Consumers' Association. June 2018. Available at <https://www.hcca.org.au/wp-content/uploads/2018/09/Consumer-Centred-Care-Position-Statement-FINAL-.pdf> (Accessed 3 May 2019)

Excerpt from HCCA's submission on the Draft Charter of Aged Care Rights (October 2018)

Case study: ACT LGBTIQ community considerations in aged care

The five proposed principles and the 12 proposed rights in the draft Charter are broadly consistent with many of the key areas of concern for members of the ACT's LGBTIQ communities. The quotes below speak to LGBTIQ consumer and community priorities in relation to:

- Safe, high quality care (proposed right A),
- Dignity and respect (proposed right B),
- Valuing individuality (proposed right B),
- Culture, diversity and identify (proposed right C),
- Living free of abuse and neglect (proposed right D),
- Control over decisions (proposed right G), and
- The right to complain (proposed right J), and to nominate an advocate or representative (proposed right I).

These comments were shared with the AIDS Action Council of the ACT and are reproduced here with permission of the Council:

"I can see myself reflected around the aged care service or in their documentation, this includes pictures, rainbow and other LGBTI flags, posters and flyers about LGBTI services etc."

"I want the right to be supported to access LGBTI specific activities and events."

"It's important to me to be able to access LGBTI social groups in the local community and to maintain my connections to my community."

"I want to right to access an effective complaints process that is timely and inclusive and provides support when I feel afraid or uncertain about making complaints. And I can use external or internal advocates."

"It is important to me that policies are enacted to support older LGBTI people and people with HIV."

"I do not want to be made to feel different. I want to be respected and my partner and family feel safe to visit and spend time with me."

However, feedback from ACT LGBTIQ communities provided by the ACT AIDS Action Council also highlights that while the proposed rights are broadly in line with consumer priorities, they are expressed in such general terms that it is difficult for consumers to see how their concerns and preferences are reflected in the standards.

The priority concerns of LGBTIQ communities in the ACT in relation to aged care include:

- Fear of discrimination, stigma and judgement by aged care staff,
- Fear of disclosure and privacy not being respected,
- Fear that a person's wishes for their chosen family to be involved in decision-making may not be respected by health professionals or family of origin,
- Heteronormative assumptions, attitudes and behaviours expressed through general policy, language and visual resources,
- Unhelpful assumptions that LGBTIQ people share homogenous spiritual, cultural, religious or personal beliefs,
- Lack of awareness of the issues affecting trans and gender diverse people, and
- Health professionals often lack experience in communicating about specific health issues and concerns affecting intersex, transgender and gender diverse people.ⁱ

Best practice approaches to LGBTIQ inclusive health and aged care service delivery are well understood in Australia, though they are not consistently implemented. Best practice includes:

- Actively support the recognition of partners and families of choice of LGBTIQ people,
- Ensuring staff have received LGBTIQ inclusivity training,
- A code of conduct for staff and other service users that states that discrimination and harassment of LGBTIQ people, family and friends will not be tolerated,
- LGBTIQ people are made aware of the complaints process and their complaints are respected,
- Visible signs of respect for LGBTIQ people to continue to enjoy their spiritual and cultural life,
- Providing a safe environment within services to promote and respect disclosure or non-disclosure,
- Policy to support the client to maintain their affirmed gender or identity, and
- Knowledge of other culturally competent services and organisations within the community that could be recommended for referral or to promote access for LGBTIQ people.ⁱⁱ

In recent years LGBTIQ organisations have led significant work to support aged care services to deliver better LGBTIQ inclusive aged care, in partnership with Australian and State and Territory Governments. This includes work undertaken by the National LGBTI Health Alliance including through its Australian Government-supported Silver Rainbow education program (see <https://lgbtihealth.org.au/ageing/>). HCCA suggests that the Charter's roll-out should be supported by specific information and education material for LGBTIQ consumers, and for service providers and personnel, with the aim of ensuring that all of these groups understand how the Charter relates to and supports LGBTIQ inclusive care in practice.

There is potentially some overlap in consumer understandings of some of the rights. For example, the rights to (A) "safe, high quality care" and (E) "to live free from abuse and neglect" each speak to aspects of the consumer experience of *safety*. For aged care consumers, "safety" often relates to the experience of holistic emotional, psychological and/or cultural safety as much or more than to an understanding of safe medical or personal care (where the focus is on physical safety and/or an

acceptable risk of adverse outcomes or complications). The discussion above of the concerns and priorities for members of the ACT's LGBTIQ communities underscores the reality that many consumers hold significant concerns about the safety of the care they will receive because of valid fears of discriminatory and non-inclusive practices. This highlights the need for further explanation in the Charter of what is meant in practice by each of the rights, in particular what is meant by "safe" and "high quality care". HCCA recommends that DoH work with providers, consumers and consumer organisations to develop additional education material that explains what the rights "look like" in practice, including for consumer groups at risk of non-inclusive service delivery – at a minimum, LGBTIQ communities, Aboriginal and Torres Strait Islander people, and people of diverse cultural and linguistic backgrounds including refugee communities.

Another example of potential overlap in the Charter relates to those rights dealing with information and communication. Both (F) ("be informed about my care in a way that meets my needs, have access to information about my rights, care and accommodation and anything else that relates to me personally, and get the information I need in a timely way") and (I) relate to information and communication and could perhaps be grouped together. (F) is also rather long and could perhaps be condensed for easier readability. (F) could also usefully include specific mention of the consumer's right not only to be "be informed" but also to "be involved" in decision-making about care.

HCCA suggests that the Charter should include specific mention of the right of consumers to be involved in decisions about service planning, evaluation and governance including in aged care facilities. This right is consistent with key principles of health literacy and consumer partnership in health and aged care service delivery. The Australian Charter of Health Care Rights recognises this right to participation. Additionally, HCCA suggests that the Charter should recognise the right of consumers to involve (or not involve) their family of choice in decision-making about their care. The involvement of family and loved ones in decision-making is a well-recognised principle of person-centred/ consumer-centred careⁱⁱⁱ that could usefully be recognised in the Charter. The perspectives of LGBTIQ consumers shared above indicates the importance of the right to choose not only a representative (I) but also to have family of choice involved in decision-making about care, to the extent that the consumer would like this to occur.

ⁱ AIDS Action Council of the ACT. 2018. Input into HCCA Submission: Draft Charter of Aged Care Rights. AIDS Action Council of the ACT.

ⁱⁱ AIDS Action Council of the ACT. 2018. Input into HCCA Submission: Draft Charter of Aged Care Rights. AIDS Action Council of the ACT.

ⁱⁱⁱ Health Care Consumers Association. 2018. See Note 1.