

Commissioners Tracey and Briggs
Royal Commission into Aged Care Quality and Safety
By email: agedcareconsultation@health.gov.au

15 April 2019

Dear Commissioners Tracey and Briggs

Submission to the Royal Commission into Aged Care Quality and Safety on Aged Care Quality & Safety in Rural, Regional & Remote Areas

The National Association of Community Legal Centres (NACLCLC) Older Persons Legal Services Network welcomes the opportunity to provide this submission on aged care quality and safety in rural, regional and remote areas to inform the Royal Commission into Aged Care Quality and Safety.

NACLCLC is the national peak body for the community legal sector. Our members are the eight State and Territory Community Legal Centre Associations of community legal centres that represent around 200 centres in various metropolitan, regional, rural and remote locations across Australia.

The Older Persons Legal Services Network is a Network of NACLCLC. Its members include representatives from a range of community legal centres across Australia. The Network plays a national role in sharing information and good practice and undertaking law reform and policy work.

The Network members that contributed to this submission have specialist expertise in seniors' rights issues and elder law. As a result, this submission draws on many years of practical experience assisting older people across Australia. Relevantly, our members have been engaged in a range of work around aged care quality and safety including:

- Provision of information, legal advice, advocacy and representation in aged care and related matters;
- Aged care law and policy reform;
- Expert commentary on contemporary aged care issues; and
- Engagement with governments and other key partners and stakeholders in relation to the rights of older people and aged care matters.

NACLCLC and the Network also have a long history of international engagement with the United Nations Open-ended Working Group on Ageing (OEWGGA) which is looking at the human of older persons, including most recently on older persons' rights in long term care in the context of the possible development of a new international instrument on the rights of older persons. Attached to this submission is a copy of our submissions to the 9th and 10th Sessions of the OEWGGA on autonomy and long-term care.

This Submission

We have previously provided submissions on the issue of aged care quality and safety to a range of Inquiries. These submissions are available to the Commission.

Our law and policy reform work in the area of aged care has focused on the importance and need for a shift from the current paradigm – a consumer rights/protection approach – to a contemporary human rights approach.

We have reinforced the view in its submissions that the rights of older Australians in aged care must be based in enforceable human rights, and those human rights should take account of existing and developing normative standards.

Notwithstanding the breadth of our expertise and interest, this submission focuses on the experience and challenges faced by older persons living in rural, regional and remote areas (RRR areas).

This submission broadly addresses specific terms of reference as follows:

c. the future challenges and opportunities for delivering accessible, affordable and high quality aged care services in Australia, including:

in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and in remote, rural and regional Australia;

We intend to make a further submission around other terms of reference at a later date.

CONTEXTUAL ISSUES

Key Policy Issues for RRR Communities

1. As far back as 2004, the Productivity Commission (the PC) was told:

The options for care in rural and remote areas are more limited and less specialised than in the capital cities. People living in more isolated areas - even a few kilometres from a small country town - have to travel to access even basic services. Many people in rural and remote areas are eligible for community care but there are often long waiting lists with no new clients being accepted because the available services have been allocated. For those lucky enough to receive assistance, there is difficulty moving through the various levels of care as their needs change. (ACSA/NCSA, 2004).

2. Fifteen years have passed, and this remains a lived experience for many older persons in RRR communities. Our older clients, their families, their supporters and their carers often raise these basic concerns. These issues are also regularly agitated by statutory entities such as Public Advocates and Guardians
3. In 2011, the Productivity Commission restated the fundamental problem that “[R]ural and remote areas generally do not have the population density or demand to sustain many

types of aged care services that are available in urban areas” (PC, 2011). The Commission listed the costs of service provision, staffing difficulties and access to health services as significant obstacles (PC, 2011). These principally service-based issues are also high on our client’s concerns.

4. Older persons are less likely to live in major cities (one-third lives outside major cities), and tend to have poorer health outcomes in RRR communities (AIHW, 2018). Thomas et al (2015) suggested, “outcomes reflect both the high proportion of socioeconomically disadvantaged and Indigenous residents with high disease burdens, and the inequitable access to primary health care (PHC) services for those living in rural and remote communities”.

5. Further, the Australian Association of Gerontology (AAG) reported:

People in rural and remote areas are more likely to use home care services than residential aged care. This may result from a lack of available places in residential aged care or to higher levels of social capital, volunteering and informal support from neighbours, friends and the community in rural areas. People living outside major cities often wait considerably longer to enter residential high care after being approved for a place, which results in higher hospital admissions for those waiting for residential aged care. (AAG, 2017)

6. The observations of the Australian Association of Gerontology reflect our own clients’ experiences.

7. In 2017, the AAG’s Regional, Rural and Remote Special Interest Group made 6 (six) recommendations, including:

- The need for a national Action Plan for aged care for people in Rural and Remote areas should be the next priority under the Diversity Framework;
- The need for a review of rural and remote aged care service access and quality;
- Development of minimum service access standards for rural and remote aged care;
- Government policy and funding in rural and remote aged care should be based on principles of co-operation and collaboration between service providers, rather than competition;
- Workforce-related initiatives should include regional rather than organizational approaches to workforce; and
- The need to improve the evidence base for aged care service delivery, a national research and data strategy for aged care.

8. We supports and reiterates those recommendations.

9. We also support the need to better understand the circumstances of older persons in RRR communities as they plan for, and transition into aged care and any specific vulnerabilities they have or risks they face. The Australian Law Reform Commission reported, “For people living in rural areas there may be distinct dynamics at play”, referring by way of example to family communities and families (ALRC, 2017). The ALRC also noted:

In the context of family violence, it has been suggested that in rural and regional areas, issues such as social and geographic isolation, limited access to support and legal services, as well as complex financial arrangements and pressures, including limited employment opportunities, may heighten vulnerability and shape the experience of violence. (ALRC, 2017)

10. Also, borne out by our client's experience, the ALRC noted that in respect of abuse:

An older person may be reluctant to repeat their concerns numerous times to different professionals. They may also be unable to seek legal assistance discreetly. These concerns may be magnified in smaller rural and regional communities, where an older person may face greater fears of discovery. (ALRC, 2017)

11. It seems uncontroversial that the provision of consumer directed care faces serious challenges in RRR communities:

Central to this reform is the introduction of a consumer directed care (CDC) model, with the goal of improving choice and flexibility to consumers. However, the implementation of a CDC model is likely to face obstacles which are particularly apparent in rural areas. Low population density across remote areas already causes aged care facilities to operate on the cusp of viability, organization of care services incurs additional costs (i.e. medical staff who need to travel from cities) and older people have limited access to these services. (Jukic, 2018)

12. In our view many of these policy challenges would be ameliorated by taking a deliberate human rights approach to aged care.

The Need for a Human Rights Focus

13. There are significant examples that reveal the difference between a consumer rights focus – where industry takes lead responsibility for meeting need, and a human rights focus where responsibility lies more broadly with Government. This guarantees essential services to all older Australians on an equal basis. The market approach leads to winners and losers in the area of aged care and allows cost-shifting from Government.
14. The Australian Human Rights Commission (2012) has stated the importance of a human rights approach to aged care and noted that “the provision of quality aged care and support in the appropriate environment is a fundamental human right.”
15. A human rights approach is the application of a set of essential principles to policies and programs that provides a baseline for human rights protection. The approach is a systematic way of integrating the norms, principles, standards and goals of national and international human rights law into all decision-making processes, law and policy development and project implementation (AHRC, 2012).
16. A human rights approach requires that the content and process of all our actions are informed by human rights principles including participation, accountability, equality and empowerment. Central to human rights is the protection of the most vulnerable and older

persons entering or in aged care are among our most vulnerable. Older clients are often those who have faced a lifetime of disadvantage, suffer social, financial and health inequity and their ability to claim their rights is severely compromised.

17. For example, one particularly vulnerable group are people ageing alone, a growing proportion of the population. There is a broad assumption that many older people will have a trusted next of kin to help them. As a result, many laws, systems and services are not adapted to their needs. Instead, they are left to navigate an already complex aged care sector on their own; or, at best, with the help of an already-stretched support professional; or, at worst, excluded from services and society altogether, with serious impacts on their rights, health and wellbeing.
18. A human rights approach would assist to enable these older persons to claim their rights. (AHRC, 2012)
19. The AHRC restated the outcome of such an approach:

The application of a human rights approach will assure a strengthened focus on a people-centred approach to aged care and the requirement for meaningful participation by older Australians. The approach will assist with ensuring that older recipients of home and residential care can help to set their own agenda and have their decisions respected. (AHRC, 2012)

20. Australia's aged care system has a history of haphazard rights protections and has been revamped on several occasions. The latest iteration places the protection of rights within the framework of a newly developed Charter of Aged Care Rights. The enforcement of those rights is through "Aged Care Quality Standards, amendments to the User Rights Principles 2014 (User Rights Principles), and other laws that inform the delivery and quality of aged care." (Department of Health)
21. Notwithstanding this framework, the aged care quality standards are effectively only enforceable as an accreditation measure by regulators. Similarly, the *User Rights Amendment (Charter of Aged Care Rights) Principles 2019* are framed as a responsibility of approved providers.
22. The Charter of Aged Care Rights includes fourteen (14) 'rights':

I have the right to:

1. *safe and high-quality care and services*
2. *be treated with dignity and respect*
3. *have my identity, culture and diversity valued and supported*
4. *live without abuse and neglect*
5. *be informed about my care and services in a way I understand*
6. *access all information about myself, including information about my rights, care and services*
7. *have control over, and make choices about, my care, personal and social life, including where choices involve personal risk*

8. *have control over, and to make decisions about, the personal aspects of my daily life, financial affairs and possessions*
 9. *my independence*
 10. *be listened to and understood*
 11. *have a person of my choice, including an aged care advocate, support me or speak on my behalf*
 12. *complain free from reprisal, and to have my complaints dealt with fairly and promptly*
 13. *personal privacy and to have my personal information protected*
 14. *exercise my rights without it adversely affecting the way I am treated*
23. These rights without exception articulate existing human rights under treaties or the expected outcomes of those rights including the interrelationship of rights. The Charter rights are drawn from various instruments including:
- the Universal Declaration of Human Rights (UN, 1948),
 - the Convention on the Elimination of All Forms of Racial Discrimination (ICERD, 21 December, 1965),
 - the International Covenant on Civil and Political Rights (ICCPR, 16 December, 1966),
 - the International Covenant on Economic, Social, and Cultural Rights (ICESCR, 16 December, 1966),
 - the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW, 18 December, 1979),
 - the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT, 10 December, 1984),
 - the Principles for Older Persons (1991),
 - the Convention on the Rights of Persons with Disabilities (CRPD, 13 December, 2006),
 - the Declaration on the Rights of Indigenous Peoples (UN, 2007).
24. The principal difference with the Charter and most articulations of human rights is that they are framed as the responsibilities of others. While Charter and user Rights might form the basis of a complaint to the Age Care Quality and Safety Commission, they do not provide human rights as we have come expect them.
25. The *User Rights Amendment (Charter of Aged Care Rights) Principles 2019* set out approved providers' responsibility for "not acting inconsistently with the legal and consumer rights of care recipients." (ss.5, 16, 23AA)
26. The use of the term 'charter' might be considered somewhat misleading given that Australia's other *Charter of Human Rights and Responsibilities Act 2006* is an enforceable legislative scheme.
27. The issues around how this might be resolved through legislative and policy measures will be a central focus of our subsequent submission.

Reporting of and Responding to Abuse of Older Australians

28. We are concerned that there are insufficient opportunities, processes and supports to identify, report and intervene in cases of abuse. We have made submissions on this issue to a number of inquiries and reviews over the last decade. As we know, abuse often isn't reported because of a range of factors and in fact may be less likely to be reported in RRR communities.
29. We note that alongside human rights approach, the issue of abuse will be a major component of our subsequent submission to the Commission.

The Needs of Aboriginal and Torres Strait Islander Communities

30. The AAG (2017) notes “[A]dding to the complexity of aged care in rural and remote areas is the higher proportion of Aboriginal and Torres Strait Islander people, who generally require aged care services at a younger age, consistent with their poorer health status and lower average life expectancy.” NACLC agrees with this damning statement of the impacts on older Aboriginal and Torres Strait Islander persons.
31. For Aboriginal and Torres Strait Islander people, poor design of aged care perpetuates “... the experience of government services as an inflexible imposition and extension of a colonial mindset that drives a cultural wedge between Aboriginal and non-Aboriginal Australia.” (Ottmann, 2018) Put more starkly, “a mainstream approach to the aged care of Indigenous Elder is likely to produce poor care outcomes.” (Ottmann, 2018)
32. We agree that the approach taken must have a human rights focus including the fundamental considerations in the United Nations Declaration on the Rights of Indigenous persons (UN DRIP) which emphasises rights to:
 - self-determination;
 - cultural identity
 - freedom from discrimination
 - freedom from assimilation or destruction of culture
 - belonging to an indigenous community
 - culture and spiritual and religious traditions and customs
33. The AHRC has noted that starting point ought to be that “Culturally appropriate care is essential for aged care services delivered to all older Aboriginal and Torres Strait Islander peoples and is particularly crucial for Aboriginal and Torres Strait Islander people with dementia.” (AHRC, 2012) We agree this should be a mandated.
34. OPLS members note that the situation for older Aboriginal and Torres Strait Islander people includes:
 - A lack of appropriate accommodation options;
 - Lack of cultural safety and trauma informed practices inside aged care services;
 - The complex interface with CDP where withdrawal has equated to reduction in informal carers;

- Re-institutionalisation for members of the stolen generation and other care leavers;
- Quality and safety issues linked to limited resourcing of residential facilities;
- Increased isolation and abuse where services are limited, especially advocacy and supports;
- Diversion of aged care or ageing resources to the NDIS;
- Limited recognition of informal and kinship carers;
- Limited access to respite and rehabilitation services; and
- Difficulty navigating the www.myagedcare.com system.

35. In addition, a particular issue for older Aboriginal and Torres Strait Islander clients is that where places are available, they are remote from community. There appears to be little or no support for older Aboriginal and Torres Strait Islander people who want to continue to live in their remote community. Coming in even to the 'nearest' town may mean these people are no longer living on their country, and will feel disconnected from country and family. Notably, the "nearest town" may be 500km away, for instance in the case of the remote community of Kalumburu, which is a 20-hour drive from Kununurra.
36. People in remote communities thus face an unenviable choice of staying on country with no formal aged care support and extremely limited medical and other support, or coming to town and being isolated from family and country.

The Impacts of Natural Disasters

37. Research shows that older persons are vulnerable during and after disasters including natural disasters. This includes vulnerability to safety and quality issues. Gutman et al (2014) explored older person's experience of elder abuse during heat waves, hurricanes, tsunami and earthquakes.
38. Based on the limited research, areas of risk include:
- General elder abuse
 - Post disaster contractor or consumer fraud
 - Financial abuse in emergency or temporary accommodation
 - Neglect
39. We consider that more needs to be done to identify how older persons living in RRR communities are impacted by natural disasters, both within the ordinary context of aged care and within the context of increased risk or vulnerability.

Obvious Diversity Deficits

40. The issues raised by the Law Council of Australia through its Justice Project Report on Older Persons (LCA, 2018) are relevant to the RRR experience. One case example given is the experience of a LGBTI older person who experiences homophobia as part of his aged care experience. This exemplifies the need to approach care from a human rights perspective.

41. Put simply RRR communities have fewer services for diversity communities and fewer agencies to respond to the specific needs of older persons from diversity communities. When abuses such as homophobia occur, older persons have less options for protection, remedy or redress.

SPECIFIC ISSUES

42. In addition to the contextual issues outlined above, there are also a number of specific issues affecting older persons in RRR communities.

Advanced Care Planning

43. We have concerns that older persons in RRR communities have relatively limited access to advance care planning and support and that there may also be limited specialisation among professionals and advisers within smaller communities. While RRR communities may have specialization in some areas of estate practice and planning, this may not extend to all RRR communities and may not extend into the area of aged care.

Transition into Care

44. A range of pressures impact on older persons while transitioning into aged care. These include relinquishing decision-making control: e.g.: pressure to have enduring documents in place, communications being directed towards family members [i.e. assumptions that decline is inevitable so get the decision-making issues all wrapped up early]
45. Older persons in RRR communities often find the fee assessment processes bewildering and lack access to assistance with most or all parts of the process.

Assessment

46. We are aware that older persons in RRR communities have more constrained access to specialist assessments and support through the assessment phases of aged care.
47. Conflict in assessing if residential aged care is congruent with the will and preferences of an older person (not responding when noticing that older person is being forced into aged care and there are other options) – wouldn't it be interesting if there was some kind of mandate to consider ageing in place (where desired) before accepting a placement into residential aged care i.e.: a residential aged care as a last resort framework

Places and Packages

48. RRR communities in some cases have zero available places with high levels of unmet demand including for specialist placement.
49. Other RRR communities have packages without any means of taking them up. For example, in the last round, the Northern Territory had one-third of places taken up and the remainder were reallocated to Eastern Seaboard states and South Australia. The failure of the market to pick up places when available is particularly problematic in communities with limited

services and high disadvantage. The reliance on profitability clearly impacts on where services establish (leaving gaps) and where existing services are available (leaving gaps).

50. Flexibility of packages needs to consider the actual needs of older persons in RRR communities. Items that assist with activities of daily living and improve functional capacity and address inequity can include items outside the scope of aged care. Yet these items would otherwise be available in a home care setting if the persons was eligible for services under the NDIS.

Respite

51. RRR communities may offer less options for respite to older persons and families than in other communities. Private arrangements are often prohibitive.
52. While the link between carer stress and elder abuse is diminished by later research (Joosten et al, 2017), very strong links remain between abuse and negative interactions or conflict within close and family networks (Liu et al, 2017).

Residential Care

53. Limited care plan review to ascertain changes in capacity, whether the services are appropriate, how isolation is being managed, etc. The visiting doctors prefer certain Medicare schedule items over others and this does not make for good health care in aged care settings

Staffing

54. Staff suitability assessments ought to be undertaken by an independent authority in a similar manner to working with children checks in Australia. In RRR communities, the effect of self-assessment of suitability may be even more constrained by staffing availability.
55. Staff training needs to address key areas of importance including:
 - Diversity training
 - Cultural safety
 - Rights of older persons
 - Identifying and acting in cases of elder abuse
 - Working with family members and informal carers
 - Respecting rights to independent advocacy, legal representation and
 - Understanding the critical importance of supports and safeguards

Quality and Safety

56. In RRR communities any older persons who travel away from their community to enter residential aged care lose existing close support networks and familial supports making them more vulnerable to isolation and abuse. Liu et al (2017) found the existence and positive nature of close social networks is a protective factor against exploitation.

57. We have concerns about the potential for greater social isolation and loneliness, and elder abuse in aged care within RRR communities as well as the potential for increased self-harm and suicidality.
58. Alongside these concerns for potential for greater harm is the possibility that RRR communities face lower levels of accountability, compliance monitoring and consequent reduction in quality and safety. There is a converse issue where the increased accountability on services is a barrier to entry in some RRR communities.

Conclusion

We trust this information is of use and the Network would welcome the opportunity to contribute further to the Royal Commission. The relevant contacts for the Network are:

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We attach a number of annexures including:

- *Substantive Inputs in the form of Normative Content for the Development of a Possible International Standard on the Focus Areas “Autonomy and Independence” and “Long-term and Palliative Care”* (2019)
- Joint submission by NACLC, AGE Platform Europe, HelpAge International, the Law in the Service of the Elderly to 10th Working Session of the Open-ended Working Group on Ageing (2019) on the normative elements of the right to care and support for independent living and to palliative care
- A joint Discussion Paper prepared by NACLC and others on autonomy, independence, long-term care and palliative care to inform the 9th Open-ended Working Group on Ageing (2019)

Kind regards

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