QACAG
Quality Aged Care Action Group Incorporated

QACAG SUBMISSION

Consultation on a new Aged Care Act

FEBRUARY 2024

qacag@nswnma.asn.au

www.qacag.org.au

About QACAG

Quality Aged Care Action Group Incorporated (QACAG) is a grassroots community activist group that aims to improve the quality of life for people in residential and community aged care settings. QACAG is made up of people from many interests and backgrounds brought together by common concerns about the quality of care for people receiving aged care services.

QACAG Inc. was established in 2005 and became incorporated in 2007.
Membership includes older people, some of whom are receiving aged care in nursing homes or the community; relatives and friends of care recipients; carers; people with aged care experience including current and retired nurses; aged care workers and community members concerned with improving aged care.

Membership also includes representatives from: Older Women's Network; Combined Pensioners & Superannuants Association of NSW Inc.; Kings Cross Community Centre; Senior Rights Service; Multicultural Communities Council of the Illawarra; Public Services Association; Carers Circle; Aged Care Reform Now; NSW Nurses and Midwives' Association and the Retired Teachers' Association.

QACAG members welcome the opportunity, through this submission, to provide input to *the new Aged Care Act*.

Margaret Zanghi
President
QACAG Inc.

QACAG members are pleased the focus of the draft new Aged Care Act (Act) places older people who need aged care at the centre of the aged care system. It will be vital to ensure these principles are not only embedded in the Act, but in any subordinate legislation and the system for regulating aged care. The new Act will set the scene for years to come, we therefore urge this work is not rushed to ensure we get it right, by allowing sufficient time for feedback to be considered.

To ensure the consumer voice is carried in this submission we held a hybrid caucus for members, held individual conversations, invited handwritten and electronically submitted feedback and sought feedback from our organisational membership which includes consumer and workforce representatives. The feedback received is incorporated throughout.

Recommendations

1. The Act should be re-drafted incorporating changes and consulted upon again prior to finalising.

2. The Act should be widened to incorporate privately funded aged care services.

3. The United Nations Principles for Older Persons should be referenced in the Objects, and relevant principles incorporated throughout the Act.

4. Object (g) should be amended to state: *provide for sustainable funding arrangements for the delivery of funded aged care services by sufficient numbers of ~~a~~ diverse, trained, ~~and~~ appropriately skilled ~~workforce~~, well-resourced and empowered workers.*

5. The definition of high-quality care must be reviewed so it can be measured and enforced.

6. High-quality care must also prioritise the right to be respected and support lifestyle choices, including dignity of risk.

7. The priority which refers to interpreters should be amended to ensure these services are not only provided on request, but proactively offered.

8. High-quality care must also prioritise professionally delivered care by sufficient numbers of skilled, and well-supported workers, including nurses.

9. The Act must make provision for the setting of numbers and skills mix of workers.

10. Under Definitions and Key Concepts - list 14(2)(a) – (h) should contain the following addition:
    'The staffing arrangements in which funded aged care services are required to be delivered'.
    In support of this, an additional point should be added to the list of reportable incidents, which reads '*Failures in provision of staffing leading to an episode of missed care of an individual'.* Missed care being separately defined within the Act as 'Missed care, defined as any aspect of a person's care that is omitted or delayed'

11. p25-26 17(1) of the draft Act dealing with restrictive practices should this be amended as follows:

    *(b) require that, to the extent possible, alternative strategies**, including consideration of additional staffing resources** are used before a restrictive practice in relation to the individual is used; and*
    Or
    (*c) require that alternative strategies that have been considered or used**, including consideration of additional staffing resources** in relation to the individual are documented; and provision of additional staffing, specifically registered nurses*.

12. Additionally, p28 point 19(c)(xi) should be amended to read:

    *(xi) worker retention**, sufficient number and skills mix** and training to facilitate the delivery of the service by well-skilled and empowered aged care workers who are able to develop and maintain a relationship with the individual.*

13. Clinical care must be articulated throughout the Act to acknowledge the high level of heath care delivered through aged care services.

14. The definition of a responsible person must be reviewed to ensure it does not capture workers without organisational authority to make autonomous decisions on operational, purchasing, and staffing matters.

15. A person who has previously and continues to be the main care giver is the best person to fulfill the role of supporter or representative. This should be reflected.

16. For providers to interact effectively with representatives and supporters from CALD backgrounds they will need training, education, and resources to communicate effectively in the style and language which is culturally appropriate.

17. The eligibility for entry to aged care should include refugees at least 50 years and above.

18. Any system to determine classification prior to entry should include co-design with the person and/or the person who has previously and continues to be the main care giver if the person lacks capacity to participate in the process.

19. Emergency entry into long term care should only be undertaken if it meets the objectives of the Act, in that it upholds the rights of the individual.

20. The Act must be more prescriptive relative to digital platforms and make provision for matters such as misleading information about workers, elder abuse, and worker protections.

21. The complaints commissioner should have a deep understanding and sensitivity to the needs and challenges faced by people from diverse backgrounds.

22. The complaints mechanism should be equally accessible and transparent, and Advisory Council represent diversity in its composition.

23. Worker voice principles must be embedded in the Act, with workers empowered to act as advocates.

24. A review of the Act should occur every three years.

25. The aged care worker screening database should be extended to include mandatory registration of care workers with a body external to the Aged Care Quality and Safety Commission, such as Ahpra.

26. Screening or registration of workers should be retrospective, so it applies to all aged care workers currently in the system and not just those seeking entry.

27. There should be a working with older people check, like the working with children check with key differences as detailed in this submission.

28. Screening and registration must apply to all aged care workers, not just those delivering government funded aged care services.

As general observations, our members consider the Act lacks clarity and appears to have been written in haste. Important sections are missing and some of the sentences are grammatically poor. Whilst some of these observations are of lesser importance than others, they are indicative of a process which appears to lack the ability to be circumspect in its approach. Our first recommendation would be to **re-draft and consult again** ahead of the July deadline to allow for meaningful engagement, changes to be considered, rules drafted and the final version to be articulately and clearly drafted.

The draft legislation has been promoted as a rights-based Act, that no longer has funding at its core. However, we believe there are glaring omissions which still make this a funding-based, rather than human rights-based Act.

The fact that the Act only applies to funded aged care services is contrary to having older people at the centre of the legislation. Rather it focuses on the source of funding which can leave older people funding their own care without the protections of this law and all it brings. Given that the messages we continue to hear from the Department of Health and Aged Care and others about the system moving to a more user-pays system, we are concerned the Act will only apply to a smaller number of older people in the future and will have limited longevity.

In framing the Act this way, it also serves to exclude those people who have the financial means to pay for their own care, or those who do not have access to funded aged care services because they aren't Australian citizens (having a disproportionate impact on people who are Culturally and Linguistically Diverse (CALD)). Having the Act only apply to funded aged care services also means that providers could look to avoid the compliance of the system and move to a shadow unregulated private market, causing a free-market system collapse in the regulated market.

Additionally, this directly contradicts any attempt to bring platform agencies operating through a gig-economy into regulation. We know this is already a high-risk area, particularly for those living alone receiving home care. **We recommend the breadth of the Act is widened to incorporate privately funded aged care services**.

Objects

The objects give effect to the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of Persons with Disabilities but fail to mention the United Nations Principles for Older Persons[1]. We question this omission, given the Act is specifically designed for older people.

There are several principles worth noting in the United Nations Principles that should be referenced in the new Act:

- **Independence**

5. Older persons should be able to live in environments that are safe and adaptable to personal preferences and changing capacities.
6. Older persons should be able to reside at home for as long as possible.

- **Participation**

7. Older persons should remain integrated in society, participate actively in the formulation and implementation of policies that directly affect their well-being and share their knowledge and skills with younger generations.

- **Care**

10. Older persons should benefit from family and community care and protection in accordance with each society's system of cultural values.
11. Older persons should have access to health care to help them to maintain or regain the optimum level of physical, mental and emotional well-being and to prevent or delay the onset of illness.
12. Older persons should have access to social and legal services to enhance their autonomy, protection and care.
13. Older persons should be able to utilize appropriate levels of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment. (*however we believe that we should look to deinstitutionalise aged care*)
14. Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity,

[1] United Nations (1991) *United Nations Principles for Older Persons*. Available at: https://www.ohchr.org/en/instruments-mechanisms/instruments/united-nations-principles-older-persons.

beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.

- **Dignity**

17. Older persons should be able to live in dignity and security and be free of exploitation and physical or mental abuse.

18. Older persons should be treated fairly, regardless of age, gender, racial or ethnic background, disability, or other status, and be valued independently of their economic contribution.

Additionally, many older people accessing aged services do so because of age-related frailty not disability. Whilst the characteristics of both may appear similar, frailty is potentially reversible whereas disability is more permanent[2,3].

We believe a fundamental principle of aged care must be restoration of function. Indeed, separating the terms frailty and disability assists in addressing their impact on the older person and enhancing care outcomes[4]. **The United Nations Principles for Older Persons would be a useful addition to the Objects**.

Although implied in the previous objects we have concerns object (g) does not go far enough as it only provides assurance of *funding for*, and not *delivery by* a diverse, trained and appropriately skilled workforce. Nor does it assure the supply relative to numbers of workers and offer protections for workers.

Workers who are disempowered, unsafe and lack proper resources will not deliver safe care. Without these assurances, none of the other objects can be met. Indeed, the Royal Commission into Aged Care Quality and Safety final report recommendations included minimum staff time standards for residential aged care[5].

Object (g) should be amended to state: *provide for sustainable funding arrangements for the delivery of funded aged care services by sufficient numbers of ~~a~~ diverse, trained, ~~and~~ appropriately skilled ~~workforce~~, well-resourced and empowered workers.*

[2] Zhang, Q. et al. (2020) Frailty as a predictor of future falls and disability: a four-year follow-up study of Chinese older adults. *BMC Geriatrics* 20, p 388.
[3] Zamudio-Rodríguez, A. et al. (2020) The disability process: is there a place for frailty? *Age and ageing*, *49*(5), pp.764–770.
[4] Fried, L. P. et al. (2004) Untangling the Concepts of Disability, Frailty, and Comorbidity: Implications for Improved Targeting and Care, *The Journals of Gerontology: Series A*, Volume 59, Issue 3, March 2004, pp. M255–M263. Available at: https://doi.org/10.1093/gerona/59.3.M255
[5] https://www.royalcommission.gov.au/aged-care

Definitions and Key Concepts

The definition of high-quality care is aspirational but lacking in ability to enforce. It uses broad terminology that cannot be measured. For example, the inclusion of 'kindness' as a key indicator. In 2021-22 over half of all people living in permanent residential aged care had dementia[6]. A person who lacks ability to articulate themselves clearly would be unable to express if they were being treated with kindness. Indeed, the word kindness within a medical context has been found problematic since its interpretation differs from culture to culture[7].

'Keeping staff' is another ambiguous example. It provides no direction as to what it means to keep staff, nor how this relates to high-quality care. If existing staff are poor, it would not serve the interests of high-quality care to keep them. Furthermore, we would question how a quality assessor would measure this, for example, would the parameters for 'keeping' be a week, month, year or longer. **The definition of high-quality care is highly problematic and must be reviewed so it can be measured and enforced.**

Our members consider the definition of high-quality care is not only poorly articulated but lacks key considerations. It mentions respect, but not the right to be respected, nor does it include the need to support people's lifestyle choices, including dignity of risk. Whilst we support inclusion of bilingual aged care workers and interpreters, we believe this should not only be on request, but more purposefully, be offered. Many people from culturally and linguistically diverse (CALD) backgrounds can be disempowered or lack knowledge of available services.

High-quality care must also prioritise the right to be respected and support lifestyle choices, including dignity of risk.

The priority which refers to interpreters should be amended to ensure these services are not only provided on request, but proactively offered.

Whilst we support the need for a workforce who are trained and skilled to develop and maintain a relationship with the person they are caring for, this would seem lower on the priority list for achievement of high-quality care than having enough staff to deliver care. Also

[6] AIHW (2023*) Dementia in Australia web report*. Available at: https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/aged-care-and-support-services-used-by-people-with/residential-aged-care.
[7] Sokol, D. (2023) Do doctors need to be told to be kind? *BMJ*, 382, p 1976 (published 25 August 2023). Available at: https://www.bmj.com/content/bmj/382/bmj.p1976.full.pdf.

having clinical care professionally delivered should be a benchmark from which high-quality care is determined. This is particularly important given many people, particularly in residential aged care require high levels of nursing care.

High-quality care must also prioritise professionally delivered care by sufficient numbers of skilled, and well-supported workers, including nurses.

We understand the requirement for the Act to provide an overarching structure and that detail will be provided in subordinate legislation. However, we note a separate staffing standard is excluded from the list of prescribed standards. **The Act must make provision for the setting of numbers and skills mix of workers**.

The inclusion of the following addition to list 14(2)(a) – (h) is requested:
The staffing arrangements in which funded aged care services are required to be delivered.

In support of this, **an additional point should be added to the list of reportable incidents, which reads '*Failures in provision of staffing leading to an episode of missed care of an individual'.* Missed care being separately defined within the Act as 'Missed care, defined as any aspect of a person's care that is omitted or delayed'**[8].

We believe missed care episodes provide a measurable outcome relative to the meaning of high-quality care as detailed on p27 point 19(c)(ii) of the draft Act '*the timely and responsive delivery of the service to the individual'.*
In further support of this important area, p25-26 17(1) of the draft Act dealing with restrictive practices should this be amended as follows:

> *(b) require that, to the extent possible, alternative strategies**, including consideration of additional staffing resources** are used before a restrictive practice in relation to the individual is used; and*
> Or
> (*c) require that alternative strategies that have been considered or used**, including consideration of additional staffing resources** in relation to the individual are documented; and provision of additional staffing, specifically registered nurses*.

[8] Gustafsson N. et Al (2020) Missed Care from the Patient's Perspective - A Scoping Review. *Patient Prefer Adherence*. Feb 25,14. Pp. 83-400.

Additionally, p28 point 19(c)(xi) should be amended to read:

> *(xi) worker retention**, sufficient number and skills mix** and training to facilitate the delivery of the service by well-skilled and empowered aged care workers who are able to develop and maintain a relationship with the individual.*

The Act must provide for the creation of environments where restrictive practices are a last resort. Availability of staff who are well trained, in sufficient number and skill mix and who themselves are kept safe are essential prerequisites to reduce measures such as antipsychotics as a means of controlling challenging behaviours.

In addition, we note the absence of clinical care in any of the descriptive language. Clinical care is a cornerstone of the services required and delivered, particularly in residential settings. If this important area is omitted, it will leave a huge gap in the ability of subordinate legislation to articulate the arrangements required to safely deliver clinical care. **Clinical care must be articulated in the Act.**

Responsible person

The definition of a responsible person is too broad and potentially captures those who lack organisational authority to influence the services delivered. It could be interpreted to include registered nurses in charge of a span of duty. However, even a Director of Nursing in an operational role may lack the authority to override registered provider decisions relative to purchasing and staffing numbers and skills mix, so crucial to achieving the objects of the Act. **The definition of a responsible person must be reviewed to ensure it does not capture workers without organisational authority to make autonomous decisions on operational, purchasing, and staffing matters**.

Supporters and representatives

Being unable to have a supporter and a representative might provide some challenges in circumstances where a person chooses to have both. In addition, consideration should be given to decisions regarding who can be appointed, particularly where a person lacks capacity. Drawing on the experience of our membership, **a person who has previously and continues to be the main care giver is the best person to fulfill the role of supporter or**

representative. The ability for this to be a primary consideration should be embedded in the Act.

For providers to interact effectively with representatives and supporters from CALD backgrounds they will need **training, education, and resources to communicate effectively in the style and language which is culturally appropriate**. This is particularly important when managing complex care and interpersonal needs.

Entry to the Commonwealth aged care system

The eligibility for entry to aged care should include refugees at least 50 and above. People from refugee backgrounds can age prematurely due to number of factors, including trauma and grief related symptoms. We also believe subordinate legislation should consider the principles contained within the *UN Refugee Agency Integration Handbook*[9] as good practice in the care of older refugees as it is developed.

Any system to determine classification prior to entry **should include co-design with the person and/or the person who has previously and continues to be the main care giver** if the person lacks capacity to participate in the process.

Emergency entry into long term care should only be undertaken if it meets the objectives of the Act, in that it upholds the rights of the individual. We have concerns that the emergency entry powers may be used as a means of moving older people out of public hospitals. However, our experience is that once a person leaves hospital and enters aged care their recovery process is dismantled. In part, this is due to the stark differences in staffing profiles between the two.

Digital Platforms

Whilst it is pleasing to see the Act recognise the current and future significance of digital platforms in the delivery of aged care services, this section is unclear in its intent and does not correlate well to both the objects of the Act and definition of high-quality care. Gig economy workers predominantly provide services in people's own homes and the potential for abuse and exploitation is high.

[9] UNHCR Integration Handbook. Available at: https://www.unhcr.org/handbooks/ih/age-gender-diversity/older-refugees

In addition, gig-economy workers themselves are also at risk of exploitation and lack the work health and safety protections found in other environments where care is overseen by a registered provider and therefore subject to the requirements of the existing Aged Care Act. **The Act must be more prescriptive relative to digital platforms** and make provision for matters such as misleading information about workers, elder abuse, and worker protections.

Complaints and Whistleblowing

Relative to whether the complaints commissioner will ensure appropriate outcomes are achieved for those who raise complaints. **The complaints commissioner should have a deep understanding and sensitivity to the needs and challenges faced by people from diverse backgrounds, such as CALD**. This is not only through the provision of translated resources but also demonstrated through use of multiple forms of engagement that are appropriate for people from CALD backgrounds.

The complaints mechanism should be equally accessible and transparent, and Advisory Council represent diversity in its composition.

Other barriers that may deter people disclosing information are fear of retribution, even with whistleblowing protections and experience such as racism in the workplace. As stated in our previous submission to the *foundations of a new Aged Care Act consultation paper No. 1*, worker voice is essential in any risk-based systems for regulation.

Worker voice principles must be embedded in the Act, with workers empowered to act as advocates. There's a real power imbalance that needs to be considered in the arrangements for whistleblowing. Our members would feel much more empowered speaking to a care worker, or nurse than a manager in an office.

A system such as work health and safety representatives, union representatives formalised in the workplace as a point of contact for whistleblowing would ensure workers have protections. Workers making disclosures in good faith often see the regulator as remote and bureaucratic lacking in their ability to pivot quickly and offer both immediate and lasting protections.

Review period

Currently the Act has provisions for review every five years. We believe that due to the complexity of this Act and unintended consequences resulting from its implementation, **this review period be reduced to three years**.

Worker registration and screening

Division 7 of the draft legislation related to an aged care worker screening database, however we would like this **extended to include mandatory registration of care workers with a body external to the Aged Care Quality and Safety Commission, such as the Australian Health Practitioner Regulation Agency (Ahpra)**. The level of registration and information contained within the database should be different for the different types of workers (i.e., the information on the lawnmower man, will be different to that of a personal care worker).

We agree with the idea of the screening database but would extend it so that it becomes a mechanism providing transparency into the aged care workforce that will hopefully lead to building trust back into the sector. **The "screening" or "registration" should also be retrospective so that it applies to all aged care workers currently in the system** – not just those seeking entry. **There should be a "working with older people" check, like the "working with children" check**, however with some key differences:

- Under purposes of the database, we would like it to act as a public record, accessible not only by employers but also the general public so that those receiving care and their loved ones can see whether there are any workers providing care to their loved ones who may be in breach of regulations or have any complaints against them. This could be linked to the star ratings system to make it easier for people seeking care services to find out all the information in the one place. Currently it's very difficult to get a complete picture of the quality of services provided with information about compliance still separate from the star ratings system.
- Under information in the database section e – information relating to each screening applicant in respect of whom a decision (an exclusion decision) should also include the reason for the exclusion. This should also apply to suspending a clearance decision.
- The database should also include the training and certification that the aged care worker has undertaken (like Ahpra registration for health professionals). Again,

transparency around training and staff will help to restore trust in the system. It will also help professionalise the system and create better career pathways.

It is also important that this **screening and registration applies to all aged care workers, not just those delivering government funded aged care services**. This will provide protection to all older people living in Australia receiving care.