



# Response to “A new Aged Care Act”

8 September 2023

Joint response by: AGED CARE REFORM NOW (ACRN) and Carers' Circle

Aged Care Reform Now (**ACRN**) is a non-partisan grassroots organisation, consisting of aged care services recipients, families and friends, and current and retired aged-care workers – all who have personal experiences with aged care and want to make a change. ACRN advocates for aged care reform that delivers improved benefits to all Australians receiving residential and in-home aged care services.

**ACRN's vision is a transparent and effectively regulated aged care system that is focused on the human rights and quality of life of older people.**

For more information, please visit our website [www.agedcarereformnow.com.au](http://www.agedcarereformnow.com.au) or contact [info@agedcarereformnow.com.au](mailto:info@agedcarereformnow.com.au)

**Carers' Circle** is Australia's only general website dedicated to helping the children (or nieces or nephews) of ageing parents, who are often the ones supporting people as they age. The site's purpose is to help people age and die well, covering a wide range of issues aimed to help both the children and their older loved ones – written from the perspective of a carer. The team also advocates on aged care issues as it believes that Carers' Circle should provide both practical support and promote systemic change so older Australians can live their best lives.

Founded by Michelle Chaperon while navigating her own father's care needs, and now supporting her mother, the website draws on contributions from experts as well as everyday people navigating their own care journeys.

More information can be found at [www.carerscircle.com.au](http://www.carerscircle.com.au) or contact [info@carerscircle.com.au](mailto:info@carerscircle.com.au)

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## Overview

Aged Care Reform Now (ACRN) and Carers' Circle welcome the opportunity to provide input into the new Aged Care Act as it is the foundation of a collaborative, transparent and effectively regulated aged care system that is focused on the human rights and quality of life of older people as their needs change.

Overall, we're pleased to see that the focus of the Act has shifted from funding and providers, to the individual – however we don't believe this has carried through to all areas of the Act under consideration. We will point these out throughout this submission, starting with the key issue of the application of the Act being limited to Commonwealth funded aged care services.

## Executive summary – 10 key points

1. 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. It also means that providers could look to avoid the compliance of the system and move to a shadow unregulated private market.
2. Enforcement is critical. Rights are only as good as the enforcement of those rights. Currently there are perceived little to no consequences for the provider and the sense of injustice causes ongoing trauma for families.
3. All workers providing services to older people must be registered, with registration requirements to be written into the New Aged Care Act. We also support the Royal Commissions recommendation of mandatory minimum qualifications for all personal care workers. This also protects the rights of workers and supports duty of care.
4. The [World Health Organisation definition of elder abuse](#) needs to be used in all settings (including residential aged care) and be included in the New Aged Care Act.
5. Complaints management needs to be overhauled with all complaints registered with an independent party so that issues can be monitored over time. (see our suggestion for a triage system on page 8). Complaints should be dealt with in a reasonable timeframe proportionate to the risk to help prevent further harm, and the complaints handling process should not be closed if the person dies.
6. The Aged Care Act should have regular revision provisions built in so that it's able to be reviewed and assessed if it's fit for purpose at set intervals (every five years).
7. We should be working to a model of deinstitutionalisation of aged care and this should be incorporated into the Act
8. We believe the statement that providers or workers who "consistently do the wrong thing will be targeted" when discussing duty of care does not protect an individuals' right at all. It is a subjective term, leaves too much to interpretation and suggests harm can occur to a number of individuals before action is taken.
9. There is little reference to the importance and rights for involvement of family and chosen family as support persons/carers in the Act. Their rights should be recognised and supported given the important role they play in enabling older people to live their best lives. However, it's important that they should be subordinate to the rights of the older person themselves.
10. Developing community support network hubs and local reporting and investigation of complaints is crucial. We recommend the use of Primary Health Networks to support these hubs.

## Structure, purpose and constitutional foundation for the new Act

### Key issue with Act only applying to funded services

All legislation can have unintended consequences and one of the key issues we see with the Act is how it **only applies** to people seeking and accessing “**funded**” aged care services as per the Proposed Object of the new Act:

*“ensure people accessing funded aged care services are free from mistreatment and neglect, and harm from poor quality or unsafe care”.*

If human rights are truly at the centre of the aged care system, shouldn't the protection and upholding of human rights be carried across to all older people living in Australia who seek and receive aged care services? This should be regardless of funding sources.

The exclusion of self-funded and non-subsidised services shows that it's still funding at the centre of the legislation and not human rights as is the objective of the new Act. The focus on funded services also leaves those not eligible for Government funded services such as older people from overseas, without the consumer protections they deserve. It's hardly an equitable system if those who have been able to fund their own care do not have the same rights and protections as those requiring Government assistance.

We believe an unintended consequence of this inequity, is that it may see providers leaving the funded space and moving to a private market model only, where they aren't subjected to the same compliance obligations as those who need to comply with the Act. This could be a shadow unregulated private market. In turn, those receiving aged care services from the private market operators will not be protected under the same laws. There is already an issue with keeping the “market” going in some areas of Australia, particularly regional and rural. What's to stop a provider being a private aged care services provider only, charging full fees and not being subject to these laws and regulatory framework?

We appreciate that this might require harmonization of consumer protection laws across States and Territories, but it's an effort worth making to truly ensure that all older people living in Australia can equally access aged care services free from mistreatment and neglect, and harm from poor quality or unsafe care – regardless of funding sources.

### Australia's obligations under the Convention on the Rights of Persons with Disabilities, the International Covenant on Economic, Social and Cultural Rights, and other relevant instruments

- We believe that the Act should also consider and reference [the United Nations Principles for Older Persons](#), particularly:
  - **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 ACRN and Carers' Circle believe that we should look to deinstitutionalise aged care – more on this below)*

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, 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.

ACRN and Carers' Circle are concerned that human rights conventions in relation to torture are not being observed in regards to residential care. ACRN and Carers' Circle see locked dementia units as being a restrictive practice that does not consider the social, emotional and general wellbeing of people living with dementia in these units.

It would be beneficial for the following from The Statement for Carers in the *Carers Recognition Act* to be referenced in the Aged Care Act at least in relation to the provision of services to carers.

- Statement 1: All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
- Statement 6: The relationship between carers and the persons for whom they care should be recognised and respected.
- Statement 7: Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers

### **Deinstitutionalisation of aged care**

There needs to be a broader vision for aged care than the current model. We need to look outside the current two-tier system of home or residential care funded separately. We need to consider small housing models of care and de-

institutionalisation of aged care. Currently we are tinkering at the edges, but there needs to be a complete overhaul. Could we see a reference to deinstitutionalisation included specifically in the Act?

### **Harmonisation of purpose right and principles**

We need to make sure that the purpose, rights and principles all work together – i.e. rights rarely appears in the statement of principles.

### **Mandatory registration for all workers**

All aged care workers should be registered through a central body such as AHPRA with any serious incidents reported and made publicly available. It is not acceptable that workers convicted of abusive behaviour be able to seek similar work elsewhere.

### **Other points to consider on structure, purpose and constitutional foundations of the Act**

The rights expressed in the Aged Care Act should be reflected in the contract signed between a provider and an aged care recipient. This is especially true in residential care.

## **Feedback on the Statement of Rights**

We believe the Statement of Rights should also be applicable to the family and chosen family/ carers, with their rights subordinate to those of the older person themselves.

In addition to the feedback above on the integration of the United Nations Principles of Older persons, we feel strongly that the following should change (our edits in green)

We believe that a right to quality care should be included in the Statement of Rights.

**1. exercise choice and make decisions that affect their lives and the manner of their death, including where personal risks are involved, and that are in pursuit of their quality of life, their social participation, and intimate relationships, and be supported, if necessary, to make those decisions, and have those decisions respected**

after lives should include manner of their death

**3: exercise choice between available aged care services they have been assessed as needing, and how these services are delivered**

This should include access to gender specific services including in residential care.

**4. communicate in their preferred language or method of communication, with access to interpreters, or preferred support person/advocate and communication aids as required**

Insert preferred support person/advocate to acknowledge the important role family or chosen family play in the care of older people.

**6. freedom from all forms of degrading or inhumane treatment, violence, exploitation, neglect and abuse**

Here we believe that the [World Health Organisation definition of elder abuse](#) needs to be used in all settings (including residential aged care) [with sexual abuse included](#). Currently elder abuse is only a term used in the community, with the same level of treatment in residential care being called “substandard care”. Abuse is abuse regardless of the setting and should be treated as such.

**7. freedom from ~~inappropriate~~ use of restrictive practices**

Remove the word inappropriate. Restrictive practices should not be part of a base expectation. Rather it should require special circumstances.

**9. equitable access to palliative and end-of-life care in their residence if they choose when required. Access to voluntary assisted dying should also be included.****10. be supported to exercise their rights, voice opinions ~~and~~, make complaints and have access to legal support/guidance without fear of reprisal, and have their complaints dealt with fairly and promptly**

add access to legal support/guidance

**11. have their identity, culture, spirituality and diversity valued and supported, including in accessing funded aged care services that are culturally appropriate, trauma aware and healing informed**

add spirituality

**12. opportunities and assistance to stay connected (if the individual chooses) with family members and other significant persons in their life, including safe visitation by family members and friends ~~at reasonable times~~ in residential care homes.**

- Could this also include animals/pets? Some of our membership have support animals or pets as close companions. One consideration for them when moving into residential aged care is whether they will see their pets again.
- We question the use of the word “reasonable” and who decides what this is. Safe visitation should cover if it’s too late at night for example. An example of this is Western Australia was Covid free for 11 months with the general community living and moving freely. Yet during that time, residential facilities were still restricting visiting hours especially on weekends and restricting visits out of the nursing home by residents.
- In residential care providers should show cause to ACQSC or the department if they wanted to ban a friend/family from visiting. We believe the right to stay within their local community is vitally important. This is where deinstitutionalisation and supporting small group models of residential care are crucial. Staying connected in community should also extend to people having their complaints dealt with at a local level.

**13. ~~the right to seek, and~~ be provided with, personal information about them held by Commonwealth agencies and registered providers, as well as information about their rights and the funded aged care services they are accessing or have accessed**

This should be the right to be provided with, not simply “seeking”, this extends to medical

records.

## Feedback on the Statement of Principles

2. The delivery of funded aged care services by registered providers and aged care workers should comprise the provision of person-centred care that:

- takes into account dignity of risk, and the preferences, individual needs, goals and aspirations of older people
- is free from any form of discrimination, abuse and neglect
- treats older people as unique individuals, and with kindness, dignity and respect, and
- supports all older people's connection to their community This includes the rights and encouragement to utilise resources that are available to other members of the community eg free continence advisors
- in the case of First nations people, supports their personal connection to community and Country.

Recognise community connection is important to all older people while acknowledging the special connection to community and Country for First Nations people

9. The aged care system should fund aged care services, ~~which are not unlimited~~, which are limited for older people most in need - taking into account the individual needs of older people, and with individuals expected to meet some of the costs of services they use where they have the financial means to do so.

Remove the double negative - not unlimited. Let's just be honest and admit that support to older people unlike the NDIS will be limited.

13. The regulation of the aged care sector should:

- promote innovation, continuous improvement and contemporary evidence-based best practice within the aged care system,
- include a robust, responsive complaints system that ensures that the individuals human rights are the first priority
- identify and address failures and risks of failures within the aged care sector,
- be responsive, risk proportionate, and principles based,
- focussed on the health and safety of older people, and prioritised to areas of highest risk to older people,
- promote the delivery of high quality, person-centred and culturally appropriate care to people accessing aged care services, and
- ⊖ strive for regulatory alignment with other care and support sectors where it is appropriate to do so and will benefit older people ~~and the aged care sector.~~

Add address failures as we believe there's no point in identifying failures without addressing them.

We question whether regulatory alignment should only occur if it benefits the aged care sector. If the Act is to move away from being provider centric, then it should remain consistent. The focus should be if it benefits the individual.



We believe in having a robust complaints system that ensures that the individuals human rights are the first priority. ACRN and Carers' Circle, advocate for an improved complaints system that focuses on timely responses. We have proposed a centralised triage solution in a number of submissions including our [response to the new regulatory model for aged care](#) and [this one on the Serious Incident Response Scheme](#)<sup>i</sup>.

We propose an independent central triage point, with a single 1300 phone number and/or online submission point to manage all incoming complaints. A single triage point would allow for the independent evaluation of all incidents, whereby serious incidents are referred to SIRS for investigation and complaints are referred to ACQSC.

A single triage point independent of ACQSC would go some way towards garnering trust of consumers and their families / representatives that a serious incident will be fairly and promptly investigated.

A single triage point would also make it simple to communicate to all stakeholders in the aged care system — this includes providers and their staff, individual private service providers, consumers, families and their support networks. It is critical that any genuine mechanism for reporting an incident is streamlined, easy to understand, simple to access, and contains no reporting blockages. It's important to respect that the consumers who may need to report a serious incident may comprise some of Australia's most vulnerable people.

Complainants should be supported by a pastoral care/counselling/advocacy service which is triggered when a complaint is made and have the option to have an independent advocate.

It is important that the role of the Inspector General in overseeing and reviewing the complaints process is robust. In our [submission on the role of the Inspector General](#) we called for provision for the Inspector-General to consistently review the regulator's performance to have a proactive process to report issues in need of review. We note there will be a new review of the changes made to the ACQSC in two years and hope the Act will be flexible to allow any additional changes this review may involve. Again we stress the need to have a decentralised complaints system.

## What high quality aged care means

We asked our membership what high-quality aged care means to them. Recurrent themes included:

- Upholding the human rights of older people by demonstrating respect and enabling them to **live with dignity** by having their **clinical, safety, physical, emotional, social and spiritual needs met**.
- **Holistic person-centered care at all times** that sees, **acknowledges and respects the person as an individual** with a life story, as part of a community/family and with individual needs and preferences.
- Care based on the **individual** needs of the older person delivered at the **right time and in a timely manner** (i.e showering when suits the older person, not waking them up at 5am to have a shower. Or help them with using the toilet as soon as required, rather than every four hours).
- **Trained staff** with the **skills, education and time** to support the older person **live their best life** (it's not just about clinical care, but also emotional and social support).
- **Going above the minimum standard**. We see the minimum standard as having adequate staffing levels, the right medication delivered at the right time, decent food, access to physio, dental and other allied health services.

- **Consequences for breaches of care.**
- Must include **good palliative care**, some members would like to include access to **voluntary assisted dying, mental health, allied health and dental care**
- **High quality care must be related to evidence based practice and we believe the right to quality care should be specifically listed in the statement of rights.**

## Duty of care and compensation pathways

The duty of care states-The intention of this approach is to target the behaviour of substandard registered providers, responsible persons, governing persons and aged care workers who consistently do the wrong thing with no, or little regard, for the safety and well-being of older people. As stated in our executive summary we have concerns with the use of the word consistently and believe this should be removed. This mirrors the language in the current Act where breaches have to be “ongoing” before penalties apply. We believe this does not protect the individuals Human Rights.

We also have some questions on what is defined as serious and who will be monitoring any breaches of duty of care by boards and responsible persons.

While we agree with the duty of care extending to responsible persons and members of boards, we have some concerns in regards to the extension to aged care workers. This is especially true where breaches may occur because of inadequate staffing or decisions or practices enforced by management.

This is why we believe it is vitally important that Recommendation 77 of the Royal Commission- National Registration Scheme under AHPRA and Recommendation 78 Mandatory minimum qualification for personal care workers should be included in the Act.

## Protection for whistleblowers

We need to be aware of subtle retribution to individuals/families in residential care when they report complaints. There should be a pathway for families/individuals to quickly access support/advocacy if they believe this is happening. As stated previously we also believe that in residential care providers should need to apply to the Department or to ACQSC if they are wishing to bar a family member/friend from a facility. Obviously this is not applicable if the individual or their nominee wishes to bar an individual.

There is a requirement for providers to have complaints policies/pathways as well as policies to protect whistleblowers but we question the need for providers to do this independently. We suggest that there be standardised processes that providers must follow. This will increase ease of use for advocates, families and workers across providers

We support consistency of these provisions with the whistleblower protections contained in the *Corporations Act 2001*, the NDIS Act and the new *Inspector-General of Aged Care Act 2023*. We strongly support inclusion of qualifying disclosures by independent advocates. We believe it is crucial that a whistleblowers identity is not disclosed to a provider. This is true regardless of whether the whistleblower is staff, family, volunteer or advocate. We recommend that any disclosure must only be made with the informed consent of the whistleblower.

## Supported decision making

The proposed system of having a supporter and nominee seems overly complicated. If the supporter role is to allow access to information to family members who may not be the nominee (or power of attorney or guardian) there may be other ways to do this. What if an individual desires more than 1 supporter or for all family members to have access.

We believe that the current system is not compatible with state rules on power of attorney and guardianship and will be confusing to both individuals and providers.

Work is currently being undertaken in the Disability sector around supported decision makers. It would make sense to have the same rules in all areas. The federal government should step in and provide a national system that is consistent across all sectors.

## Eligibility for Commonwealth funded Aged care services

In our submission on the proposed principles of funding for the Aged Care system, ACRN advocated for a whole of life funding model. We believe it is inherently unfair and ageist to have an age cut off for funding of services.

We do however take a pragmatic approach and realise that we must work within the current system. We do not believe that if someone is receiving NDIS support prior to turning 65 that they should lose that support on attaining the age of 65.

There have been some suggestions made that eligibility of funding should align with the age for receiving the Aged Care pension- currently 67 with suggestions it will eventually reach 70. If this were to occur the cut off level for the NDIS should rise in conjunction with this. It would not be tenable for there to be a gap where people are unable to access any services.

## Conclusion

ACRN and Carers' Circle vision is a collaborative, transparent and effectively regulated aged care system that is focused on the human rights and quality of life of older people as their needs change wherever they may live. To do this we need a strong, registered, appropriately skilled workforce supported by a transparent, effective regulation system.

While the proposed Act has made a much-needed shift in its focus to the individual, there is still work to do in the drafting of the Act. We would hope that our 10 key points and other comments are incorporated into the revisions to ensure that it improves quality of life and outcomes for older people living in Australia.