Civil Liberties Australia Inc., Box 7438 *Fisher 2611*
Australia

Mr Trent Zimmerman MP
Chair
Standing Committee on Health, Aged Care and Sport
Parliament House
CANBERRA ACT 2600

Dear Mr Zimmerman

Civil Liberties Australia (CLA) thanks the committee for the opportunity to make a submission on this important issue. We have two primary concerns for the committee's consideration at the outset:

1. The language of the reference:

We note that the Terms of Reference refer to "residents" and "consumer protection", rather than referring to "people", "older Australians" or "citizens". In this language lies the danger of treating older Australians merely as "profit units" for an industry portrayed in the public perception as "caring", because of its links to churches and the like, but which is in truth as hard-nosed and bottom line-driven as any other.

Criticising the language of the inquiry is not a precious point, because the language bounding the inquiry is fundamentally crucial in evaluating the baseline treatment of special Australians. The focus of the committee should be safeguarding the rights and liberties of older citizens, not evaluating commercial considerations as the ToR indicates.

Australians don't lose rights and liberties when they pass an age milestone, say 70 years. If anything, they should gain greater rights, more respect, increased consideration and extra care. That is not how the system works now. We urge the committee to recommend solutions that take the basic rights and liberties enjoyed by middle-aged working Australians, and expand on them.

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Civil Liberties Australia is a not-for-profit association which reviews proposed legislation to help make it better, as well as monitoring the activities of parliaments, departments, agencies and forces to ensure they match the high standards that Australia has traditionally enjoyed and continues to aspire to.

We work to keep Australia the free and open society it has traditionally been, where you can be yourself without undue interference from 'authority'. Our civil liberties are all about balancing rights and responsibilities, and ensuring a 'fair go' for all Australians.

2. The need to "consider' individual cases:

While the committee has said it will not "investigate" individual cases, the committee needs to consider some individual cases in depth to learn generic lessons. There is no other practical way to approach this inquiry, in our opinion.

The inquiry's outcome should ensure that no older Australian is disadvantaged by the recommendations, when implemented. To achieve that, the inquiry needs to consider – in detail – as broad a range of individual circumstances as people and organisations are willing to bring to the committee's attention.

The committee should at least consider instances where an individual's issue represents and reflects a general problem.

3. The core issues are mental health and physical well-being:

The mental and physical health of older Australians is what should drive this inquiry's considerations, not financial considerations.

The real problem in aged care is the demoralisation of aged people in nursing homes, which has been highlighted recently.

> "A mental state of lowered morale and poor coping, characterised by feelings of hopelessness, helplessness, loss of meaning and loss of purpose in life." This is how Professor David Kissane (Monash University, Melbourne, Vic, Australia) introduced attendees of the *Cicely Saunders International Annual Lecture 2017* to the concept of demoralisation.
>
> – Katherine Townsend – The Lancet Oncology, Vol 19 No 2 p168, February 2018

Turning to the individual reference points:

Point 1: Mistreatment of people, whistle blowers:

Under point 1, we pose the question: how can an individual making a submission to this inquiry address the "incidence of mistreatment of residents…" <u>without</u> referring to individual cases? How will the committee know the complaints are valid without chapter and verse of the name(s) and details, and without investigating them?

Further, the individual treatment of whistleblowers is a crucial question. Staff have the customary freedoms and liberties of all Australians. CLA believes one of those most fundamental rights is to speak out for a "fair go", either for yourself or for someone else – like a person in an aged care facility – when you know she or he is not receiving a fair go.

Staff of residential facilities need greater whistleblower protection than do average Australians: they are usually poorly paid, very job dependent, and relatively powerless in society. They fear sacking, which would in practice lead to virtually no chance to get a job in a similar facility. Similarly, the relatives fear repercussions on the personal welfare of their dear ones by an establishment if they complain.

Because these groups are de-powered by their positions, CLA looks to the inquiry to devise a method of giving them greater encouragement to speak out, and the assurance that neither the resident nor the staff member will suffer in any way if a whistleblower makes a reasonable complaint that she or he believes at the time to be legitimate (whether the claim is proven or not subsequently).

An innovative approach to greater public scrutiny of aged care facilities might be annual national awards for courage for staff members who speak out, and whose claims are proven. Rewards might include a national medal and/or financial assistance to undertake further study in the aged care sector. Any such scheme(s) could be paid for by a small levy on those running aged care businesses.

Point 2: The effectiveness of monitoring bodies:

Obviously, such bodies are not effective. If they were, this inquiry would not be occurring.

On top of 'formal' bodies like the current ones, CLA believes there should be a super-monitoring panel for each state. This could be a group of four-to-six people drawn from those prepared to nominate themselves, selected by a representative body and/or the federal minister. They would hold "office" for 18 months.

They would meet four times a year. On the day of their meeting, they would select an aged care facility to examine. They would meet at that facility and be legally entitled to view any document and have the right to interview any resident or staff member on any matter.

They would report within two weeks of their meeting on how the rights and liberties of the people in the facility were being ensured, on whether or not an adequate quality of care was being provided to the people living in the facility, and on whether the staff and management arrangements were appropriate.

While a possible outcome from such a system could be punitive, it would also be open to the panel to report in favorable terms in such a way as to enhance the reputation of the facility to its commercial benefit.

One aspect of inspection by such panels could be how well the residents know and understand their own rights. A small generic example provides an abiding illustration of how easy it is to demoralise people living in "institutions".

CLA argues that the right to the companionship of a cat or dog (of appropriate size and temperament) is of fundamental importance to older people. This particularly applies when the aged person already owns a companion animal on admission to the residential facility. In many cases, distressed older people – forced by circumstances to give up their homes of many decades in some cases – must also arrange for their companion animal to go to a neighbour or relative, or be put down, because the facility has a "rule" saying: 'NO ANIMALS'.

But that is not the real rule. That is only a "rule" of the establishment made by the operator when the facility is established.

Residents are not – or at best minimally – informed of individual rights to propose rule changes(s) and their collective right to enforce change(s) in many if not most facilities. No mechanism to achieve rule change is provided by the operator; residents are not made aware of such rights if they do exist; and there is no way for a person-soon-to-be-a-resident to achieve a rule change in anticipation of the day they enter the facility.

CLA urges the committee to recommend that there be a mandatory requirement on all aged care facilities that they fully, openly and repeatedly alert residents to their rights to change rules by resolution. Even where such rights are contained in legislation, they are in practice all but ignored by operators of facilities.

Point 3: 'Guardian angel' care for those without relatives or friends:

Without the support of family or friends to act on their behalf, aged care facility residents are almost completely powerless.

Life is like a roller coaster: in the beginning, you start mewing and gurgling and murmuring, full of growing pains and potential, and usually you have a parent or two to help at all significant points. At the other end, the faculties you've nurtured and educated and trained over many decades start to fail, and you end up dribbling and aching and failing, at a time when you need the equivalent of a "parent" to look after you.

At that time, an aged care resident without anyone to turn to for help needs a "guardian angel" to look out for her or his rights and liberties, as well as assisting with personal and financial affairs. Such a role can only be adequately met by having independent evaluation of the situation by "auditors" whose responsibility is to the government, not to the aged care facility operator.

If this means the government must provide more funds, CLA strongly suggests that the committee recommend this measure be actioned. Funding for "guardian angels" might come from a combination of the aged person, facility providers and interest on moneys they hold, public trustee mechanisms and, ultimately, from government(s).

We draw the Committee's attention to the Australian Law Reform Commission's 2017 report: *Elder Abuse - A National Legal Response*. It contains a set of 43 recommendations aimed at achieving a nationally consistent response to elder abuse. The ALRC also looked to the horizon and developed a conceptual template to guide future reform through a National Plan to combat elder abuse.

The recommendations in the Report seek to balance two framing principles: dignity and autonomy, on the one hand; and protection and safeguarding, on the other. Autonomy and safeguarding, however, are not mutually inconsistent, as safeguarding responses also act to support and promote the autonomy of older people.

Recommendations embody the 'three Rs': reducing risk; ensuring an appropriate response; and providing avenues for redress. The report presents two long horizon ideas: one, the National Plan to combat elder abuse; and the second, the introduction of state and territory legislation for safeguarding adults 'at risk'.

https://www.alrc.gov.au/news-media/speech-presentation-article/elder-abuse-world-elder-abuse

In conclusion, CLA respectfully asks the Committee to address specifically:

- rights and liberties in aged care facilities: are these being met?
- what power (and what awareness of any power) do older Australians have to create change and improvement in their situations in aged care facilities, eg votes on 'house' rules, etc?
- what external body monitors – or will in future monitor – the liberties and rights of people in aged care facilities?
- how can the government ensure that the liberties and rights of people in aged care are annually promulgated, regularly reviewed, and honoured?
- is the pay/conditions of employees in aged residential care facilities appropriate to best or even reasonable care?
- are the staff fully informed about both their own rights and the rights of residents? If not, we ask the committee to propose altered legislation to remedy the situation.

While the above are the major points we wish to stress in our submission, we asked our members if they would like to put forwards ideas and issues. These are responses we received:

Sedatives, painkillers and falls:

An important issue is that it is apparent that all too often sedatives or painkillers, including SSRIs (common anti-depressants*), are administered without due regard to the risks of dysphagia and falls. Opiates, for example, can adversely affect motor function of the oesaphagus.

(R.E. Kraichely, A.S. Arora, J.A. Murray, 'Opiate-induced Oesophageal Dysmotility', Alimentary Physiology and Therapeutics, 31, No. 5, (Mar 2010), 601-606.) and antipsychotic medications are known to cause dysphagia (J. Regan, R. Sowman and I. Walsh, Prevalence of Dysphagia in Acute and Community Mental Health Settings', Dysphagia, 21, No. 2, (Apr 2006), 95-101.)

Falls are a well known cause of morbidity, mortality and premature admissions in older people, and psychoactive drugs increase those risks.

There has been a 400% increase in preventable deaths in nursing homes over the past decade. http://www.smh.com.au/national/aged-care-preventable-nursing-home-deaths-surge-20170526-gwdx2q.html

Falls, choking and suicide were the leading causes and certainly medications contributed to the former two.

–DR, CLA member, PhD Candidate, History of Mental Health Care,
Research School of Social Sciences, Australian National University

* Selective Serotonin Reuptake Inhibitors

Navigating the system, caution re medication:

Re the Aged Care submission, from my experience caring for my mother and now my wife, I agree that a single person would find it extremely difficult to navigate the system to find a place in residential care. Being alone and in poor health, lacking computer skills and access to transport would be virtually insurmountable obstacles. Financial problems including the sale of a house to fund the accommodation deposit could expose older people to unscrupulous 'service' providers. Accreditation for advisors would be a useful first step to protect vulnerable people from financial exploitation.

Another issue that arises for people in care is the delivery of medication. Residential care facilities aren't hospitals and staff training is sometimes inadequate. I would go so far as to say that the quality of life for some residents would be diminished by medications not being given correctly. It is not unreasonable to suggest that there is a risk of illness and even premature deaths occurring for want of rigorous control of medication.

– MT, Yarragon Victoria

'Light years ahead', blind spot:

The main problem I see is that in Australia aged care is big business, ie largely privately owned or run by churches, and as such directed towards profit and authoritarian rule without any independent external control.

But there is an added problem: aged care in Australia is primarily regarded as in need of better management… but not needing an entirely different value given to old age. Nowhere is it seen as a priority to listen to and speak with elderly people themselves, as the main people that Aged Care should be for.

For that it would perhaps be useful for people interested in changing Aged Care from the ground up to visit Scandinavia or The Netherlands, where they are light years away from what is done in Australia.

As an elderly woman (85) with a considerable first-degree experience (as a retired NSW Health Dept. interpreter) of how nursing homes and hospices look from the inside, I have

long decided that nothing will get me in any of those institutions. It is therefore essential that any debate about voluntary euthanasia no longer ignores this aspect of death and dying, if the people involved in such campaigns do not want to be accused of deliberate silence about the plight of the elderly in this matter.

This is a serious blind spot in the community, which will not be erased with endless articles about how better to monitor aged care operators, because there is no way that subjective and totally useless assessments will reach the day-to-day abuse and mismanagement of the elderly who have no voice.

– MC, Annandale NSW

Freedom <u>from</u> religion:

Freedom **<u>from</u>** religion is another important issue. People are very vulnerable if carers want to push their religious views: with June (my wife) in Bendigo, the nurses at night used to change her radio station to a religious radio station. She was a life-long atheist. The carers would put her in the front row of the preacher's visits: June didn't want to go to those visits. A young male nurse was opposed to this practice but couldn't make his views heard.

– KMcE, 93 year old Bonython ACT

Finally, Civil Liberties Australia makes the same plea to the Australian Parliament that we make whenever a social issue, or one of rights, liberties and freedoms, arises:

Australia needs a Bill of Rights:

All this demonstrates once again why it is important that Australia should have a Bill of Rights. As set out above, Australians lack any firm basis for even agreeing what rights exist for older Australians in aged care facilities, or how their rights and liberties interact with other freedoms and legal protections.

Australia is one of the few democratic countries not to have a Bill of Rights setting out basic minimum freedoms and protections for all people. If Australia intends to instruct and advise other countries about their laws and practices, for example during its terms on the United Nations' Human Rights Commission, this needs to be put right.

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