

3 September 2019

Submission to the Inquiry into Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019 by the Parliamentary Joint Committee on Human Rights¹

Aged Care Crisis (ACC) welcomes the opportunity to make a submission to this inquiry. ACC is an independent group of Australian citizens. Members of our group are engaged with the aged-care sector in a variety of ways – as advocates, health professionals, legal experts, users of services and as volunteers. The tenor of much of our feedback indicates a high level of community concern relating to the mistreatment of aged care residents and the ineffectiveness of the current regulatory framework.

ACC have been monitoring and analysing failures in aged care since the late 1990's. The origins of the many current failures can be traced back to the introduction of the 1997 *Aged Care Act*.

We have made submissions to the many reviews, consultations and inquiries into the problems in the aged care system and in its regulation.

This inquiry shines a light specifically on minimising the use of restraints to which we respond.

“... Aged Care Crisis draws attention to the loss of human rights that so often occurs at the end of life – when it is far too easy for individuals to lose their social identity and the rights of citizenship once they enter the pressured world of the aged-care home. None of us should become merely a ‘feed’ or a ‘toilet change’ and all of us must work to ensure that the human rights of frail, aged people are upheld in every respect ...”

Source: *Aged Care Crisis submission to Productivity Commission ‘Caring for Older Australians’ 20 Aug 2010* <https://www.pc.gov.au/inquiries/completed/aged-care/submissions/sub433.pdf>

¹ https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Human_Rights/QualityCareAmendment

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1 Introduction

This inquiry was set up when many took issue with the proposed legislation. The inquiry and the committee received correspondence on this legislative instrument from [Human Rights Watch](#), the [Office of the Public Advocate \(Victoria\)](#) and a letter from Public Guardians and Public Advocates across the country², asking it to consider a number of human rights concerns in relation to the instrument.

We wish to support the evidence given to the Committee in Sydney on 20th August 2019 for all of those advocating for a different sort of system and for effective ongoing oversight

Since 1997 we have had a system that has been predicated on the assumption that aged care is primarily a market with providers and customers euphemistically called 'consumers'. They were expected to make market choices that profoundly affected their lives in a system, where even those with the capacity were not given the information needed to make choices effectively. This had nothing to do with care and has failed.

2 Care is a human right

Several presenters elegantly made the arguments that the concept of 'consumers' of aged care services provided in a marketplace that was expressed in the legislation being examined was bizarre. They argued that human rights and their protection were the concepts that should form the framework for aged care policy. The majority of those giving evidence called for the new legislation to be discarded.

We agree, but the issue goes even deeper than that. In our many submissions we have argued that this is a humanitarian service that we as caring individuals, caring communities and a civil society, provide to our fellows as they pass through the lows of life and are no longer able to fend for themselves. As fellow citizens we grant them the right to be cared for, protected and not be misused or exploited by the self-interest of others. We protect them from being harmed.

This right is based on our nature as social beings. We form relationships in which we imagine the lives of others and empathise with their plight when they are unable to care for themselves. Our responsibilities are underpinned by empathy, altruism and responsible citizenship. We do this together so it is a community activity and a community responsibility.

Prior to 1997, this approach was supported by a culture that embraced altruistic values and norms and exerted social pressures on those who were tempted to abandon them. This was given legislative support in probity regulations. These restricted those involved in the provision of aged care services to those of good character who could be trusted to care for our parents.

² Submission: Public Advocates and Public Guardians - ACT, Qld, NSW, NT, SA, Tas, Vic (PDF 50 KB)
<https://www.aph.gov.au/DocumentStore.ashx?id=631b4deb-8d01-4eb6-b8b1-54d2ec85d6c8&subId=668460>

2.1 An ‘Alice through the looking glass’ policy

The policies introduced in 1997 and supported since then by both major parties, were based on a philosophy of extreme individualism (described as neoliberalism) that had spread into Australia. This saw civil society (described as ‘the collective’) and the government it elected, not as the protectors of our democracy, our freedom and our rights, but as restricting the freedom of individuals.

It saw mankind as primarily self-interested. The values of society and its expectations, it asserted, restricted the ability of individuals to express themselves and realise their potential. This freedom was expressed through markets whose rights were supported instead. Free markets were seen as universally applicable and beneficial. The probity regulations which restricted the freedom of the market, were repealed and it welcomed anyone who saw care as an opportunity to make money. This was an ‘*Alice through the looking glass*’³ policy, where everything we knew about the provision of care was reversed.

Responsibility for aged care was taken away from society and handed to this market. It was driven by competing self-interests. The social benefits for the aged would come from competitive commercial self-interest. Government saw and still sees their role as supporting and assisting the market rather than regulating it. These are citizens who are profoundly vulnerable and depend on our altruism. Strangely, that was expected to work.

It is not surprising that this system has not worked in multiple vulnerable sectors including aged care. Not surprisingly, the distant arm of government and its occasional visits have been unable to control the perverse incentives that were introduced at this time. They have not prevented the steady reduction of staffing that the nurses giving evidence to the hearings described, nor the erosion of care and the use of restraints.

These changes were introduced in the face of extensive information showing that similar policies had failed elsewhere. This aged care system has only lasted so long because of the failure to collect information, a lack of transparency, commercial in confidence restrictions and a regulatory process that has been captured by industry.

We find it very disturbing that none of the multiple enquiries have confronted and examined these failed policies. What happened here illustrates this.

2.2 Natural justice for those who are harmed

Regulatory effort, particularly when there are complaints is focussed on resolution of the complaint rather than investigating the reasons for it. There is scant attention to the common law right of those who have been harmed to receive compensation. Those responsible are seldom penalised. We work closely with Rodney Lewis from Elderlaw. He has made a comprehensive submission addressing these issues.

³ Alice through the looking glass: - a classic children’s book by Lewis Carol https://en.wikipedia.org/wiki/Through_the_Looking-Glass

2.3 Cultural conflict

In his evidence, Geoff Rowe⁴ (*Aged and Disability Advocacy Australia*) spoke of the “*divided loyalty that exists for medical and nurse practitioners working in residential aged-care facilities*”. This reflects a deep conflict between the altruistic values that underpin their traditional professional responsibilities and the reality of the aged care marketplace. This leads to unhappiness and toxic cultures. These inhibit the development of the caring relationships that are needed for the development of empathy and altruism.

2.4 Policy made by a select few

The arrogant confidence of those involved in making policy is illustrated by the lack of consultation with those actually involved in implementing this legislation. Most of the witnesses complained about this. This is strikingly exposed in departmental emails released to the Royal Commission under Freedom of information⁵. These reveal how the entire process was managed by the current ‘family’ of policy makers, mostly industry groups and without wider consultation.

The minister was responding to a public outcry about chemical restraint and had promised to do something. In the correspondence the Aged Care Minister’s secretary indicated that “*the minister wants to have a ‘critical friends’ meeting on restraints at 5pm on Tuesday, in our Sydney Office*” because “*most of the proposed ‘critical friends’ will be on-situ, having attended a roundtable*”.

Someone later suggested that this matter was of considerable community interest and should be the subject of a wider consultation process. The email indicated that the community has strong views about restraints.

The deputy director of the Department of Health blocked that responding⁶:

“... If the Minister agrees with our latest approach, ie to amend the URP, I think we need to go back to the provider peaks and consumer peaks we have consulted with on the amendments. We have come a long way and arrived at an agreed position with this group. Consulting with a whole new group may open up more debate on the amendments and **the consequent risk that our agreed position is compromised.**

If we are going to handle the issue in supporting material, then I think we could use the consumer and provider forum for this. The Commission is part of this group...”

⁴ CEO of Aged and Disability Advocacy Australia, part of the OPAN advocacy network <https://opan.com.au/>

⁵ Chemical and physical restraint: What happened to Terry could happen again under new rules ABC Investigation 27 June 2019 <https://www.abc.net.au/news/2019-06-27/what-happened-to-terry-reeves-could-happen-again/11235804>
Email K.N. 13 Feb 2019 Royal Commission exhibit CTH.1007.1002.0939 <http://bit.ly/2kr6UCy>

⁶ Email K.N. 13 Feb 2019 Royal Commission exhibit CTH.1007.1002.0939 <http://bit.ly/2kr6UCy>

2.5 A different approach is needed

Aged Care Crisis are pressing for structural changes that return the responsibility for the wellbeing of ageing citizens to the community where it rightfully belongs. Government policy and regulation should be directed to working with, enabling and supporting community in overseeing the care of the aged and protecting their rights. Aged Care Crisis has been making submissions to inquiries with objectives similar to this for over 10 years

2.6 Closer oversight

Several of those giving evidence at the hearing spoke out about a regulatory system that set out expectations but had no way of enforcing them. The community that is in a position to insist that these expectations are met has been pushed aside since 1997.

An editorial from the UK⁷ in 2010 described the way human rights were being ignored in health and aged care. The British Geriatrics Society listed the many failures in doing so. They were clearly unable to adequately oversee what was happening and confront the culture by themselves. The problem has not been solved in that country and there are still many reports of failures in aged care.

Professor Ian Maddocks, Senior Australian of the year in 2013, proposed a similar doctor led oversight system⁸ for Australia in 2014. It did not find favour and by itself may have struggled. There are powerful commercial and cultural perverse forces at work in the sector. It may require much more than this.

Ron Williams studied the corporatisation of health care in the USA for his doctorate. In 1992 he wrote a book⁹ warning Australians that *“compassion will give way at an increasing ratio to profit. Care for the patient will give way to care for the corporation”*. And that big corporations *“will not pay over their capital unless they can run their businesses along the free enterprise lines that they think fit”*.

That has now happened in aged care in Australia and government are now beholden to them and unable/unwilling to respond on our behalf. They cannot do it alone.

Williams indicated that *“The might of the megacorps is formidable; they are practised in the use of politics, and power and wealth, in getting their own way”*. He indicated that *“The only way that this nation can impose its will on any of them is to do so as a nation”*.

Those who gave evidence from Queensland and Victoria have been advocating strongly at multiple inquiries and to the Royal Commission. They are pressing for greater oversight by independent empowered visitors and advocates who visit regularly. We strongly support that but would like to see them brought even closer to the bedside.

⁷ Human rights and healthcare: changing the culture J Morris Age and Ageing, Volume 39, Issue 5, September 2010, Pages 525–527
<https://academic.oup.com/ageing/article/39/5/525/41761>

⁸ The Community Hub: a proposal to change the role of Residential Aged Care Facilities (RACFs) Family Medicine and Community Health 2014;2(4):20–25
Big challenge requires bold thinking: Maddocks Australian Ageing Agenda 11 July 2014
<https://www.australianageingagenda.com.au/2014/07/11/big-challenge-requires-bold-thinking/>

⁹ Remission Impossible : : the future of the Australian health industry by Ron Williams Brisbane : Jacaranda Wiley, 1992

We want the sort of oversight they advocate to be incorporated into the everyday management of aged care. This would be more effective and would do it less intrusively than other forms of regulation. It is the only really effective way to change deeply entrenched culture and practices.

We are pressing for a whole of community oversight process. This will be needed if we are to change the culture and insist that our elderly are protected in the way that we want. They will need support from government as well as from the medical and nursing professions.

2.7 Traditional responsibilities ignored

Aged Care Crisis argues that care of the vulnerable in our communities has always been and still is the responsibility of every citizen and every community. While we may no longer have the capacity to provide all that care ourselves, those who do it on our behalf are our agents and responsible directly to us when doing so. What the legislation in 1997 did was to take away our capacity to hold our agents to account, ensure that they do what we require of them and replace them if they fail to do so.

2.8 The most effective regulation

The powerful social control that citizens in functioning communities exert over one another confronts and stigmatises inappropriate thinking and practices so preventing problems from developing when self-interest conflicts with the rights of others or the 'common good'. It addresses problems as soon as they occur. It changes the thinking and culture of institutions and ensures that they embrace community values. Our capacity to do this was lost in 1997.

By opposing inappropriate policies, effective communities release lower order managers and employees from the commercial pressures of owners and senior management. This allows them to embrace their roles as part of the community when providing services. They are able to give expression to their humanity and express their social selves. They can form empathic relationships with staff, those they care for and their families. These are crucial for good care and essential for survival in a system that is totally transparent to the knowledgeable community it serves.

2.9 Structural changes needed

We are pressing for structural changes that embrace and build communities. We want the advocates and empowered visitors to be drawn from local communities, to be regularly on site and to become part of the day-to-day activities of care. They would oversee and help collect data. They would address problems when they occur. They would draw on local expertise. They would be responsible to their communities as well as the government that represents and supports these communities.

This will enable the communities, working with the visitors and advocates, to manage the care by working with their agents to see that they do what is required of them. They would be supported by local medical, nursing, financial and other community expertise, as well as the other advocacy and government bodies.

Those organisations that gave evidence to the inquiry would work with and through this local network. Central regulators and organisations would provide mentoring and formal regulatory backup. Such a system would be far more effective in controlling inappropriate restraint, whether physical or chemical. It would see that it is documented and reported.

It would boost volunteering, build civil society and generate social capital. It is government's role to support and build society and not to erode it – as has happened with current policy.

The intent is not to exclude markets but to harness their endeavours by creating the necessary conditions for them to work. These are an informed and effective customer and/or an involved community that watches over its vulnerable members, sets the limits of acceptable conduct, and is backed by regulators who can enforce compliance when breeches occur.

Father of economics, Adam Smith explained the problems that we address over 200 years ago:

It is not from the benevolence of the butcher, the brewer, or the baker, that we expect our dinner, but from their regard to their own interest.

The interest of [businessmen] is always in some respects different from, and even opposite to, that of the public ... The proposal of any new law or regulation of commerce which comes from this order ... ought never to be adopted, till after having been long and carefully examined ... with the most suspicious attention. It comes from an order of men ... who have generally an interest to deceive and even oppress the public.”

Source: Adam Smith: The Wealth of Nations, 1776.

Again and again, Smith warned of the collusive nature of business interests, which may form cabals or monopolies, fixing the highest price "which can be squeezed out of the buyers". Smith also warned that a business-dominated political system would allow a conspiracy of businesses and industry against consumers, with the former scheming to influence politics and legislation

See **Adam Smith** under heading "The Wealth of Nations" https://en.wikipedia.org/wiki/Adam_Smith

Our knowledge of markets going back over 200 years was inverted when politicians stepped through the looking glass in 1997. What we are suggesting takes us back into the real world to addresses these issues. We describe them and suggest how they could be addressed in greater depth in the material we are submitting to the Royal Commission.