

Submission to Standing Committee on Health, Aged Care and Sport

Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia

March 2018

Introduction

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's¹. 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 regulation². Even when reviews have found problems and made recommendations, they have often not been implemented. There has also been an unwillingness to address the challenging structural problems responsible for the failures they were responding to.

This inquiry shines a light specifically on the mistreatment of residents in aged care and the mechanisms that purport to protect them. Nursing is the most important determinants of care and reports suggest a steady decline in nursing skills and regression back to the conditions that Senator Giles identified³ in the early 1980s.

Staffing is vital

Unlike Australia, the US government openly acknowledge that staffing levels and skills are the most critical determinants of care⁴. They also recognise the significance of employee turnover and tenure as a “*vital component of quality care for nursing home residents*”. **They set out recommended minimum staffing levels that are required for safe care if residents are not to be harmed - based on careful research and expert opinion.** It has made staffing and care data available for nearly 20 years.

¹ Hansard, 14 Feb 2002: <http://bit.ly/2BLc2Eg>
The Riverside Scandal Corporate Medicine website http://www.corpmedinfo.com/nh_riverside.html

² **Aged Care Crisis Publications** <https://www.agedcarecrisis.com/publications>

³ Giles, Patricia Jessie (1928–2017) Australian Senate Biographies <http://biography.senate.gov.au/giles-patricia-jessie/>
Select Committee on Private Hospitals and Nursing Homes - Report (22 Feb 1985): <http://bit.ly/2rThtRd>

⁴ CMS.gov (Centers for Medicare & Medicaid Services) - Staffing Data: <http://go.cms.gov/2frxXuQ>

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Australia has fought a 20-year battle to keep this information away from those who need to know it. People don't have the data they need to manage staffing and care, to deal with complaints, to investigate and regulate effectively or to make policy.

For example, pressure injuries are one of the important markers of good or bad nursing care and should be assessed to determine whether staffing levels and skills are adequate. One of us has worked as a doctor in hospitals for most of his life.

Pressure injuries are almost always preventable and treatable if detected early. 'Poorly treated pressure injuries⁵ are serious and in this group of people can and often do cause death. This is a red flag. Someone has to go, look and ask why it has happened. One nurse was appalled when complaining to the Complaints system about care of a family member, when an assessor, insisted they were not preventable⁶.

Our inquiries reveal that prior to the competitive pressures on staffing by the marketisation of aged care in 1997 and the replacement of data collection and effective regulation with accreditation, **studies showed that the incidence of pressure injuries was 4.4%.**

More studies done 8 years after the system was changed suggested that the incidence had increased eight times to 34%, which is alarming. No action was taken to confirm this, to do anything about it or to track it regularly. Staffing issues were not addressed. We can only wonder what the incidence is now.

A flawed system

In our view the problems revealed in the deeply flawed accreditation and complaints framework are symptomatic of a wider structural problem in aged care that must be addressed.

There were fundamental flaws in the ideas that underpinned our aged care system when it was 'reformed' in the late 1990s. These have been elephants in the room at every review or inquiry with no one prepared to confront them. It is not surprising that the situation has steadily deteriorated and subsequent 'reforms' based on the same thinking have only made things worse. There have been multiple failures in homes despite quite recently achieving full accreditation.

Warnings

There were many warnings in the 1990s and when the bill was introduced in 1997 Senator Gibbs gave a telling and prophetic speech⁷ in parliament in which she aptly referred to George Orwell's book '1984' as she described the way the words 'nursing care' had disappeared from the discourse about aged care. She spoke of *'managers with no nursing experience. No longer do nursing homes have to employ a qualified director of nursing who will ensure that professional standards are met'*. She referred to *'dramatically decreased guarantees of the level of care that residents will receive'* in a system where there would *'no longer be the checks and balances'*.

Gibbs was describing a system where those who make policy, those who make decisions and those who manage care not only lack the information needed but have no practical experience in the provision of care. She was describing 2017/18.

⁵ Pressure injuries: <https://www.agedcarecrisis.com/care-issues/pressure-injuries>

⁶ Aged Care complaints kept secret, SMH, 27 Sep 2014: <http://bit.ly/2CQQA0Q>

⁷ Aged Care Bill 1997, Hansard, Senator Gibbs, 24 Jun 1997, page 5042 <http://bit.ly/2rfThau>

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Gibbs asked *'who is going to ensure that the taxpayers' money that the government allocates to these nursing homes is properly spent on nursing care?'* Even at that early stage the *'minister is going around claiming that accreditation will take care of everything'*.

This is a claim that 20 years later is still repeatedly trotted out in the face of evidence that the system is failing. The flawed regulatory process is used for marketing the system and is the first line of defense when failures in care are publicly criticised.

In the Bill there was *'a deliberate budget driven omission which fails to appreciate the health risk to residents in reducing or removing nurses.'* We now know that levels of staffing and particularly skilled staff have steadily decreased at the same time as resident acuity has dramatically increased since the introduction of the 1997 *Aged Care Act*.

We have a system where no reliable objective verifiable data about failures or actual standards of care is collected and published. We do not have any objective data to tell us whether care has improved or deteriorated, but there is other data that gives a very clear indication.

Senator Gibbs urged that *'aged care should never regress to the situation before 1984, as highlighted in the Giles report. This report highlighted a range of complaints against nursing homes. In fact, some of the photographs of neglected patients with bed sores you could put your fist into were horrifying.'*

Gibbs concluded her speech prophetically saying *'I believe this legislation will start a move which will work to the disadvantage of many of our most vulnerable senior citizens'*.

Those whom our aged care system has failed including many staff, would agree that Gibbs was prophetic in describing 2017.

Regulatory authority John Braithwaite and his team studied the aged care regulatory system in 2005, 8 years after the act was passed in 1997. Their warning was also ignored:

" - we fear from our observation of Australian business regulation over four decades that today business values are capturing regulatory values more than the reverse. When those regulatory values are about protecting the most vulnerable members of our society from abuse and neglect, the community should be concerned".

A protective wall around providers but not residents

The government's instinctive response to the intense criticism and the unpopularity of its policies was to put a protective wall around them by controlling the collection and publication of data, abolishing probity requirements, neutralising the potential threat posed by visitors and advocacy schemes, removing all accountability for how money was spent and creating a regulatory system to manage and control the political consequences of failures. It is only when failures like Oakden escape this system that public scandals occur and governments are forced into damage control.

Since 1997 there has been extensive rhetoric and impression management to create the perception that aged care has been improving. Luxury facilities have been built and glossy advertising brochures and impressive websites developed. Most have accepted this claimed improvement uncritically. At the same time staffing levels and skilled staff have declined.

The changes in 1997 left the community, the elderly and their families ill-informed and ineffective so creating a large imbalance of power between providers on the one hand and anxious family on the other. Civil society could no longer contribute to policy.

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Many providers are well resourced and often have dedicated complaints staff and risk management strategies in place⁸ - they also hold the overwhelming majority of any written documentation. Residents and families lack knowledge and the confidence to complain or to exert their rights. There are few sectors where family or staff whistleblowers have been so viciously attacked, discredited or mistreated and received so little support. The victimisation and adverse consequences for those who speak out to expose failures ensures that they remain hidden.

This large imbalance in power has been an effective barrier to lodging and investigating a complaint, leaving the disaffected even more disillusioned.

Protecting residents rights

We support the sentiments and proposals in the submission to this inquiry made by Rodney Lewis, Senior Solicitor and **ACC** Legal Issues Columnist⁹, who is well versed in elder law. These proposals include changes to the law and the introduction of a pathway through arbitration to affordable and accessible legal redress for aged care complaints at the option of the resident.

Rodney Lewis states the Complaints system is *“unable to address the issues of individuals but is oriented towards addressing systemic issues affecting a group, or the whole of the residents in a particular aged care home.”* He goes on to say

“... the extent of the consumer’s or resident’s rights which are found in the second schedule to the User Rights Principles – a very low spot on the ‘totem pole of importance’ in the legislation. Indeed, it could hardly be lower. That is so perhaps because these rights are not intended to be enforceable, despite the lofty descriptions they bear...”

“... In each of the variables the aged care system offers only advice about complaints. There is no redress for the individual, no improvement of the level of attention to their health needs, no overt recognition of harm and causation...”

Current laws not only fail to address mistreatment but also, are too costly and inaccessible for most. When presenting his paper at the 5th National Elder Abuse Conference¹⁰ earlier this year, Rodney expressed the view that: *“The law has given us carpenters tools to fix a computer”*.

A multifaceted approach

Michael Bachelard’s research and interest in the sector over several years led him to write a set of insightful articles in 2017¹¹. These explored the problems. They were much more than horror stories about the treatment of individuals or poor nursing homes. He looked at the “systemic issues behind them” and has aptly described our aged care system as a *“diabolically complex, hidden and compromised system”*¹².

⁸ Presentation: Dealing with difficult families - rights, obligations, strategies <http://bit.ly/2FxEAUa>

⁹ Legal Issues Column: <http://www.agedcarecrisis.com/opinion/legal-issues-column>

¹⁰ 5th National Elder Abuse Conference: “Together making change”, Feb, 2018 <http://togethertakingchange.org.au/speakers/>

¹¹ Aged care disgraces show need for urgent reform as thousands suffer needlessly The Age 23 Sept 2017 <http://bit.ly/2t66hSL>

Dawn’s final days reveal aged care horror SMH 21 Sept 2017 <http://bit.ly/2FdTMcB>

Nursing home accused of being like Guantanamo Bay SMH 24 Sept 2017 <http://bit.ly/2FdJKZ3>

Is this how it ends?: How we can make aged care better Brisbane Times 25 Sept 2017 <http://bit.ly/2F5nH7r>

¹² From the Newsroom - October 2017, The Age 7 Feb 2018 <http://bit.ly/2CSCrk3>

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It is clear that the model adopted is not working and that government is not capable of managing or regulating a widely dispersed service to such very vulnerable people. It does not have the resources or the capacity to deliver what is required.

Preventing mistreatment of aged care residents will require a well-integrated multifaceted approach. In addition to essential legal remedies, we are proposing a co-operative approach involving supportive local communities.

Aged Care Crisis is pressing for the re-involvement of community by the creation of local organisations as intermediaries between government and provider. This would guide residents and their families through the intricacies of the system, watch over and protect them and assist them in asserting their rights.

Currently fragmented government activities would be delivered and integrated locally. In what we have called 'Community Aged Care Hubs', communities would be involved in advising and supporting residents and families, mediating disputes and working with providers in a number of ways to collect data and act on it. Government would train, mentor, support and provide backup. Studies have shown that engagement builds trust. There are already initiatives in this area that can be built on. Active members would be drawn from families of past and present residents, retired nurses, medical practitioners, volunteers and representatives of community organisations.

The empowered Queensland adult community visitor function which the Office of the Public Guardian (OPG) proposed for aged care in its submission to the Senate Community Affairs¹³, is a good example of the direction that we see aged care taking, but we would like to see it implemented within local communities.

We note that the visitors scheme in South Australia was not local and visited monthly. It did not detect any problems for 5 years. It was only when a family member came to it that it identified the many problems and acted leading to the investigation that exposed the problems. The visitors did not go to the residents and the families and they were not there when other residents and their families needed them. There was no regular contact between visitors and the residents/families they were there to protect.

The ICAC investigation in South Australia was very critical of the visitors scheme¹⁴ because the scheme had the powers to be effective but did not use them and was not there often enough. Instead of doing unannounced visits, visitors tried to keep on side with staff doing only announced visits where they were guided by a member of staff and so could be steered away from any problems. In our proposal the visitors would have the powers, be local and be dealing with residents, families and junior staff making it very difficult to hide problems.

Such a visitor's scheme, provided in local communities, would provide a community platform that could be built on to increase community involvement in data collection, local management of the service, oversight and regulation. It would be in a position to address existing and emerging problems in the system rapidly and effectively. This would create a supported customer and an effective community. Both are needed to create a level playing field if this failed market is to work for society.

¹³ Office of the Public Guardian (OPG), Queensland, Submission to the inquiry into the effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised, August 2017: <http://bit.ly/2DRSPCT>

¹⁴ Oakden A Shameful Chapter In South Australia's History - A Report By The Hon. Bruce Lander Qc Independent Commissioner Against Corruption 28 Feb 2018 Page 175, 193, 226, 259 <http://bit.ly/2F9rsEL>

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The visitor's scheme advised by the ALRC in their report on elder abuse lacks the necessary powers and instead feeds into the existing unsatisfactory regulatory system. We note that the 1989 Ronald report wanted an empowered visitors scheme in aged care but the "*scheme lost the empowerment edge advanced in its conception*". There was "*vigorous opposition from private industry associations to what they dubbed the 'community busybodies scheme'*"¹⁵.

What we propose is a service which is local and on site regularly, participating and working with management and staff in an ongoing manner so that it ceases to be external and intrusive but instead constructive oversight becomes part of a cooperative effort in everyday life in nursing homes and the community.

A whole of system solution

Effective regulation is almost impossible, when the system is dysfunctional and when all of the pressures within the system are directed to circumventing that regulation.

Fixing a system that is flawed is more important than fixing its regulation, particularly when that regulation is not working in large part because of its relationship with the flawed system it is regulating. They must be addressed together. That is what we are pressing for.

We need an aged care system that is underpinned by an understanding of human nature and our capacity to empathise. We must recognise the importance for the sector and society more widely, of developing social selves through relationships and responsible citizenship within society.

A market within this system must genuinely acknowledge its social responsibility to the community it serves and foster responsible citizenship among its staff. Communities must be in a position to insist on this. To do so they need control of the aged care services in their communities – to own (ie identify with) them as their own.

We have been forced to recognise the benefits of 'owning' for providing community services for other cultures (eg. Aboriginal services¹⁶ and in combating poverty and deprivation in the third world¹⁷), yet deny it for the majority of our citizens. Instead we turn them into customers shopping for commodified products.

Professor Michael Fine's work explores the way good care is built around caring personal relationships¹⁸. The value for both carer and 'cared for' lies in those relationships.

Our recommendation to the Inquiry is that in looking at the proposals made for addressing mistreatment, it considers whether they can be best implemented through a partnership with a local community structure, in a way that will build on this body of knowledge and research. In doing so, we hope that it will see the merit in what we are proposing in our submission and make recommendations accordingly.

Under the community driven model, a 'Community Aged Care Hub', government would work with the community, which would then help manage the oversight of nursing homes, advocacy for residents and complaints handling. Family members, retired nurses, volunteers and community members should be at the centre of the solution.

¹⁵ Braithwaite J et al *Regulating Aged Care* Edward Elgar Publishing Limited 2007 page 186

¹⁶ **Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services** Productivity Commission Draft Report June 2017 pages 21-26 <http://www.pc.gov.au/inquiries/current/human-services/reforms/draft/human-services-reforms-draft.pdf>

¹⁷ **Partnering with consumers: national standards and lessons from other countries** Stephen D Gill and Melinda Gill. Med J Aust 2015; 203 (3): 134-136 <https://www.mja.com.au/journal/2015/203/3/partnering-consumers-national-standards-and-lessons-other-countries>

¹⁸ **The Nature of Care** Inside Aged Care web page <https://www.insideagedcare.com/aged-care-analysis/theory-and-research/nature-of-care>

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The community would work with the nursing homes, collecting accurate data about staffing, standards of care and quality of life, then encouraging staff and management while also transparently passing that on to families and potential residents. Any problems that arise could be dealt with at the local level initially, and with local support, but elevated to formal regulatory action when necessary.

Will this inquiry finally come up with a solution?

This inquiry is hopefully the final inquiry that follows the multiple recent inquiries and reviews by states, productivity commission, ALRC, anticorruption bodies, ministerial appointees, consultants, senate committees and now the House of Representatives. These have addressed elder abuse and neglect, workforce issues, competition policy, advocacy, quality, the progress of the LLLB program as well as aged care regulation by the Quality Agency, the Complaints System and the Health Department. The exposure of the massive failure at Oakden has focused our attention on the many failures in the regulatory system that have been occurring.

These fragmented reviews examine only parts of a complex system on which care depends, but only the ALRC has looked at failures in care among many other abuses. The Standing Committee on Health Inquiry focuses on care and methods of addressing it. Each of these other reviews addressed one or more of the processes that underpin care. We are hopeful that your committee will, like the Francis Inquiry into the Stafford hospital scandal in the UK, bring all this together to see what is happening in the system as a whole and look for whole of system answers.

Aged Care Crisis has made submissions to most of these inquiries. Its submissions are researched and fully referenced. It has studied the sector from multiple perspectives in order to come up with solutions for the problems identified by its analysis. It is clearly not possible to compress this supporting material into this submission.

We will address only key issues in the body of the submission, but include additional material in appendices. We also indicate where other material can be found in our previous submissions. In this submission we draw attention to some matters that have not been fully addressed elsewhere.

We hope that this committee will look at data and what it says and not be swayed by the weight of self-interested opinion, its volume or its assertiveness.

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Glossary and abbreviations

ACC	Aged Care Crisis
ACCC	Aged Care Complaint Commissioner
CVS	Community Visitor Scheme
PCV	Principal Community Visitor
Quality Agency, The Agency	Australian Aged Care Quality Agency (formerly known as the Aged Care Standards and Accreditation Agency)
The Department	The Department of Health (formerly known as the Department of Health and Ageing)
Pressure injuries	Alternative names: Decubitus Ulcers, Pressure Ulcers, Pressure Sores, Bed Sores, pressure injuries, Dermal Ulcers, Pressure Wounds
RN	Registered Nurse (equivalent in the USA and Australia)
AIN	Assistant In Nursing
CNA	Certified Nursing Assistant
CNA, NA	Certified Nursing Assistant, Nursing Assistant
LVNs/LPNs	Licensed vocational/practical nurses (USA) <i>(Equivalent to enrolled and certified nurses in Australia)</i>
PCW, PCA	Personal Care Worker, Personal Care Attendant, Personal Care Assistant (Level III or less)
hprpd	hours per resident per day
CMS	The Centers for Medicare & Medicaid Services (CMS) , previously known as the Health Care Financing Administration (HCFA) , is a federal agency within the United States Department of Health and Human Services (HHS) that administers the Medicare program and works in partnership with state governments to administer Medicaid, the State Children's Health Insurance Program (SCHIP), and health insurance portability standards. <i>In addition to these programs, CMS has other responsibilities, including the administrative simplification standards from the Health Insurance Portability and Accountability Act of 1996 (HIPAA), quality standards in long-term care facilities (more commonly referred to as nursing homes) through its survey and certification process, clinical laboratory quality standards under the Clinical Laboratory Improvement Amendments, and oversight of HealthCare.gov.</i>
OSCAR CASPER	The Online Survey, Certification and Reporting (OSCAR) system was an administrative database of the Centers for Medicare and Medicaid Services (CMS) for many years (in the USA). Effective July 2012, the OSCAR system was replaced by the Certification and Survey Provider Enhanced Reporting (CASPER) system and the Quality Improvement Evaluation System (QIES) .
Kaiser Foundation	The Henry J. Kaiser Family Foundation (KFF), or just Kaiser Family Foundation, is an American non-profit organisation, headquartered in Menlo Park, California. It focuses on major health care issues facing the nation, as well as U.S. role in global health policy.
Nursing Home Compare	Official USA government website that allows consumers to compare information about nursing homes. It contains quality of care and staffing information for all 15,000 plus Medicare and Medicaid participating nursing homes.
SB	StewartBrown

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Executive Summary

Part 1: There is a real crisis in care

Terms of Reference and the lack of data

Widely conflicting views about aged care are fueled by the lack of data about care. This makes the actual “*incidence of mistreatment and failures*” in care impossible to determine. As a consequence there is also no information about “*residents who do not have family, friends or other representatives*”.

The failure to collect and report data is alarming. This in itself confirms the widely held perception that “*reporting and response mechanisms*” are ineffective as are the processes that are claimed to monitor aged care and investigate complaints. That government don't collect data can only be because they would rather not know – an example of willful blindness. Why else would they do this?

The reasons why no data has been collected can be traced back to 1985 where the appalling standards in for-profit aged care was exposed by the Giles inquiries. The failures together with graphic photos were splashed across newspapers. The industry were still smarting from this when industry mogul, Doug Moran and John Howard's team designed the aged care system that was put in place in 1997. They took care to insulate it from any risk of something similar occurring. Their plans were bitterly opposed.

We can understand why the “*reporting and response mechanisms*” introduced at the time including the accreditation and complaints processes were and still are ineffective. They were designed to support government and industry whenever possible – not citizens. Whistleblowing was also inhibited and discouraged by the system.

Indirect Evidence

There are two sources that provide useful indirect evidence of poor performance. Together they show very clearly that the system is failing elderly citizens badly, but not the true extent of this.

Stories from the bedside

Since 1997 and particularly since 2000, there has been a steady stream of critical comment with descriptions of failures in care coming from staff at the bedside and from the families of residents who had the knowledge to see what was happening. Few were prepared to listen to this, but it was there for those who were.

In **Appendix 1** we provide a selection of quotes from some of this material over the last 20 years. It is clear that these problems are ongoing and have not been corrected by repeated tinkering with the legislation.

Poor care confirmed by Australian staffing data

Recently some data about staffing has become available. This shows that at the same time as the acuity of residents (ie sicker so requiring for more skilled care) has increased by 53%, the proportion of trained staff needed to care from them has fallen by 35%.

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The staff levels needed for safe care have been extensively studied in the USA. US residents get double the amount of care from trained staff compared with Australia. Overall US residents get an hour (one third) more total nursing care each day.

It is not possible to provide safe care with the sort of staffing we have in Australia. The staffing data clearly shows that there are serious issues in care across the sector. It shows that the information coming from staff and residents is accurate and the denials from industry self-serving.

To understand how this was allowed to happen we need only examine the performance of the aged care sector in achieving accreditation. At the same time as acuity was increasing by 53% and trained staff numbers were falling by 35% accreditation results improved by 53% so that 97.8% (nearly everyone) got perfect scores.

This becomes even more obvious when we compare this with the USA. In spite of having vastly superior staffing 93% of nursing homes had some deficiencies and 20% of these were serious. Only 7% got full marks. In Australia nearly 98% got full marks and only a fraction over 2% have any deficiencies. Figures from the complaints system do not suggest that complaints are rigorously pursued.

It is clear that there must be extensive failures in care. The regulatory system in Australia is little more than a marketing and branding tool for the industry and a supporting service for aiding government's ambitions to sell our aged care in Asia. It is there to protect these groups' interests ahead of the citizens who need care.

We recently discovered that our assessment of the system is congruent with what regulatory authority John Braithwaite and his team found when they reported on their study of the system in 2007. His strong warning was ignored.

We conclude that aged care provided in Australia is very poor and that the regulatory system serves government and industry not citizens. But the problem lies in the system itself as much as in its regulation. It is a whole of system problem. In the remainder of this submission we explore how this happened, the social processes at work as well as the social and psychological factors that are responsible for what has happened. We use the insights gained in order to develop a strategy that could lead us out of the blind alley within which the system is trapped.

Part 2: Understanding the crisis in care

The sensitivity of data

Data and decision makers

The incidence of pressure injuries is an example of how sensitive politicians are to data that reveals poor care or deficient staffing. This also reveals a lack of knowledge in the department as well as among the minister's advisers. The dearth of information about the frequency of pressure injuries in Australia is exposed. This is a critically important pointer to poor staffing.

What is revealed is that no one in the upper hierarchy of aged care knows what the real incidence of one of the most important pointers to inadequate staffing is. The available figures quoted by the department in 2016 suggest an 8 fold increase in incidence within 8 years of the 1997 'reforms' yet no action was taken to confirm this, track the incidence further or take any action. This suggests not only ignorance of its significance but an aversion to any sort of action or data that might challenge policy and the beliefs on which it is based.

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A broken promise

The (then) Aged Care Standards and Accreditation Agency¹⁹ was criticised in 2003 by the National Audit Office for not collecting objective data about care. At a subsequent parliamentary hearing the industry promised to do so indicating that many were already collecting data including the incidence of pressure injuries. The health department confirmed that they were already doing so.

This never happened and one can only assume that this was because of what the data they started collecting revealed about care. Four years later in 2007 the Accreditation Agency came to their rescue when they did not meet their promise. They appointed an outside consultant to review the process. The review found that it was not appropriate to collect and use this objective data to measure performance. The public were not told.

Who makes the decisions and where do they come from?

The neoliberal discourse created an enhanced role and a whole new set of paradigms for managers. They were given a controlling role in industry, government and society and spread the neoliberal discourse across society influencing how we all think. Critics call this movement 'managerialism'. Management and the processes it used were considered to be an independent skill which was universally applicable to all sectors. The need for knowledge of the sector being managed was ignored.

These managers and similarly trained businessmen have taken control of and assumed senior management roles in aged care in spite of their lack of knowledge and experiences of the system. Despite their lack of knowledge there has been a revolving door between government and industry. A government without knowledge or experience is advised by 'experts' who are as ignorant.

A top/down management structure has prevented knowledge from the bedside getting to and challenging management. Distant management is shielded from challenge. They have been able to apply their policies and processes without insight into the consequences. Accreditation and Complaints systems have not had the knowledge to evaluate their performance. Tokenism and wishful thinking have been institutionalised and unchallenged. Experienced staff have described what they saw.

Blame it on belief not people

The neoliberal discourse saw regulation as harmful and unnecessary. In 1997 accreditation was not intended to be a regulatory process. This was imposed on the agency as a consequence of pressures on government and industry. The agency was a reluctant regulator.

The roles of accreditation and regulation conflict and are very poor bedfellows. Each impedes the successful implementation of the other. It is very difficult, if not impossible to do both at the same time. In 2011 the agency was unsuccessful when it asked to be relieved of its regulatory role. Accreditation rather than regulation remained its primary focus. We explain how, because of this, regulation became tokenistic.

Getting an ever-increasing number of facilities to pass all accreditation standards became a measure of the agency's performance and a demonstration of its commitment to continuous improvement. This rather than the actual performance of nursing homes became their goal. Staff described the consequences for care.

¹⁹ Renamed from Aged Care Standards and Accreditation Agency (ACSAA) in 1 Jan 2014 to Australian Aged Care Quality Agency (AACQA)

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We point out that the most effective control is the social control that citizens in a civil society exert over its members during everyday interaction. The market based system introduced in 1997 created a silo within civil society which prevented this from happening. Centralised regulation and accreditation was an ineffective substitute.

Calls to collect data about care ignored

Government pursued a policy of privatisation, market competition, for-profit care and corporate consolidation in aged care in the face of Australia's own experience with for-profit care exposed in the 1985 Giles report. It ignored extensive international evidence from countries that collected data. This showed that the sort of providers, which this policy encouraged, staffed poorly and provided substandard care.

They could not have been unaware of any of this. We can understand why repeated calls to collect data over the years have fallen on deaf ears. We can imagine what they would have found when they did collect data and understand why they shied away from the promises they made.

International data shows wide differences in staffing and performance between different types of owners. There is a clear correlation between the pressure for profit in different types of owners and both staffing levels and failures in care. In **Appendix 2** we provide more recent international data about the adverse impact of increasing profitability and also the limited data from Australia that indicates a similar situation existed, at least until 2014 when additional pressures were placed on nonprofits. In the face of evidence politicians and industry have repeatedly denied that ownership or ownership characteristics have any impact on care.

Leading figures in the sector have commented on the absence of data and called for it to be collected. Descriptions by staff show that staffing and care are being squeezed to boost profits.

We were warned many times

To understand how all this came about we need only look at the history. The patterns of thought and policies based on them that were introduced in Australia after 1996 originated in the USA in the 1970s and spread across the USA, then the UK and finally Australia in the 1980s. Prominent social scientists and medical academics in both countries warned of their consequences for health care. At that time this generally included aged care. Multiple warnings and strong opposition from the medical profession were ignored.

Some citizens were alarmed when giant health care multinationals were welcomed into Australia during the 1990s. Activists collected data showing that these companies were involved in extensive fraud and patient care scandals. State departments acted using their state probity regulations. Several large multinational health care and one aged care company were expelled or deterred from operating in Australia.

The medical profession won a battle with government in 1998 to retain their market power. They used this to put a large Australia health care company that attempted to adopt US style practices out of business. While health care is affected by these policies the consequences could have been much worse.

There were international warnings about aged care too. Data about the problems in the aged care marketplace in the USA were provided to politicians in the late 1990s. Doctors had no power and little influence in aged care.

Executive Summary

In Australia the prophetic 1993 Gregory report had warned that it would be impossible to protect staffing from profit pressures if we adopted this approach. It is now clear that Gregory was right. Critics used the Giles report to warn of the consequences in parliament. They derided the utility of accreditation as a regulator.

The federal government in 1997 took steps to ensure that their policies could not be thwarted as they had been in health care. They responded by abolishing probity requirements in aged care and along with it, all accountability for how government funds were spent. Control of oversight and regulation was taken away from states and replaced by federal accreditation and complaints systems, which also became responsible for data collection and reporting about care. These changes closed off the avenues that advocates could use in aged care. They were designed to insulate government and industry from criticism and contain the impact of any failures in care.

Refusing to acknowledge when we get it wrong

In a critical article retired politician Carmen Lawrence wrote about the way we have airbrushed the past and ignored human psychology, human behaviour and social structures when making policy.

Extensive work has been done in the social sciences exploring why we are so vulnerable to ideas that fly in the face of logic and evidence, and ignore what we know about human behaviour and social processes and structure. They have explained why these ideas become so important to us as well as why and how we defend them from challenge. We summarise the implications of this and the role this knowledge can play in guiding policy in the submission. We expand on this and explain some of the insights gained in Appendix 7.

Part 3: Using our knowledge to find a way forward

Objectives

Examining why we have gone wrong is more than an academic exercise. We can see where the problems lie and understand the merits of a system that learns from this analysis and is structured to avoid making the same mistakes all over again. If we don't understand what has happened, we can do it all over again.

A new direction

We suggest that systematically moving and integrating the management, oversight, collection of data and regulation of aged care into local communities and involving the community in this would address the majority of the issues exposed in our discussion. A central representative community body would represent the community centrally and on government bodies. Instead of controlling and managing, government and other agencies would support, mentor and provide backup to locally controlled and managed services. We expand on this in Appendix 4.

In a table we summarise the eight problems we see in the marketplace, in the discourse on which it is based, in the way data is collected, in how it is used, in regulation, in management, in the way illusions allow dysfunctional thinking, and in working conditions for staff. We briefly outline how our proposal will address these problems. This will not be an easy task as civil society will have to be rebuilt around aged care.

We append to this submission a document "Community Managed Aged Care" in which we analyse the issues raised at the senate Adelaide hearing into Oakden in Nov 2017, the Nous report and the Carnell/Paterson report and show how what we propose would address the problems much better.

Executive Summary

Part 4: Recommendations

We make 4 long term recommendations for a restructured system but this will take time and effort. We make 3 additional interim recommendations that might be introduced to protect the system while this happens, should the committee see their merit.

Part 5: Submissions to other inquiries

We have made many submissions to inquiries and reviews over the years. In some of our recent submissions we have explored the issues raised here in greater depth or addressed other issues.

We list some of these submissions and briefly describe some of the content that expands on what we have said in this submission should the inquiry wish to follow up on some of the issues.

Part 6: Appendices

Appendix 1: Contrasting industry with families and staff - sets industry claims against a large collection of comments by family and staff over many years.

Appendix 2: Ownership type, staffing and care - is an examination of data showing the impact of profit pressure on staffing and care internationally and in Australia

Appendix 3. We were warned many times - Describes the way in which many warnings were ignored

Appendix 4: A community based solution - expands on and explains our suggestion for a community-based solution as a path to lead us out of the intractable problems in aged care.

Appendix 5: Ignorance about direct care - is a more detailed description of the way incorrect staffing data was used by industry during the workforce inquiry

Appendix 6: About Discourses in aged care - is an explanation of the concept or discourses explaining the two broad conflicting discourses in aged care and their impact on nursing home culture

Appendix 7: Understanding why we go wrong (Belief, Ideology and Discourses) - An exploration and analysis of our vulnerability to embrace, apply and hold onto policies that are based on thinking that is attractive but not sound, even when these policies are obviously not working and are harmful. We apply those insights to aged care.

Part 1: There is a real crisis in care

Part 1: There is a real crisis in care

In aged care we have two wide and divergent points of view. One which includes government and industry leaders considers our system to be providing excellent care and to be world class. The other which includes families who have knowledge, staff who work directly with residents and outsiders who listen and look considers that care is lacking far too often. The two views are incompatible and only one can be correct.

There is nothing new about this situation. It has occurred in multiple other situations and as in these other situations this occurs when there is a lack of data, and an unwillingness to learn from what it reveals.

1.1 Terms of Reference and the lack of data

Reference 1. The incidence of all mistreatment of residents in residential aged care facilities and associated reporting and response mechanisms, including the treatment of whistle blowers;

Nobody knows the ***“incidence of all mistreatment of residents in residential aged care facilities”***. We don't collect that sort of data. Instead we have recurrent reviews and inquiries that, without accurate data, make recommendations based on their particular belief systems and even prejudices. To understand how this came about and plan something better we need to look at the system we have and how we got here.

The new government elected in 1996 had been supported and funded by the for-profit aged care groups. They were so closely involved in policy that Doug Moran, their leader, claimed he had written the new aged care legislation passed in 1997. It was written for the industry rather than the community and its members. 'Neoliberal' ideals dominated the discourse and the new system. Regulation and oversight were seen as harmful and to be kept to a minimum.

It is now 20 years since accountability, effective regulation and state oversight were abolished and replaced by a free market and a centralised regulation system that was keeping regulation to a minimum. It was intended to accredit rather than regulate and focused on processes rather than on data.

This was only 12 years after the Giles inquiry had exposed appalling care in for-profit nursing homes and received massive publicity with horrific photos in the media. These had resulted in the increased accountability and regulatory oversight that so irked the for-profit companies that government were by 1997 committed to support. The growing neoliberal movement believed that regulation impeded the effective operation of the free market which was capable of and should be allowed to regulate itself. The leaders in the sector had embraced this.

At the time the proposed changes were hotly disputed and not popular in the community. The public had not forgotten. There was a savage community backlash to this policy and the government was under intense political pressure. The government only narrowly won the next election.

We can understand that the system they set up would reduce regulation to a minimum. We can see why, at the time it would be structured to constrain any embarrassing stories and graphic photos exposing failures in policy. Data showing failures in care was a threat to government and industry. It sought to protect itself.

Part 1: There is a real crisis in care

More concerning is that no meaningful changes in collecting data have been made in spite of 20 years of recurrent scandals, ongoing unhappiness about the care provided to the elderly, multiple reviews and inquiries, and many calls for data to be collected and published.

After 20 years of periodic scandals and ongoing unhappiness we still do not collect the sort of data that would tell us whether adequate care is being provided. There is no data that will tell us the *“incidence of all mistreatment of residents in residential aged care facilities”*, the first of the committee’s terms of reference.

This history tells us a great deal about the patterns of thought and discussions (what we will call ‘discourses’) that have governed the sector but almost nothing about the care provided. The absence of data should alarm us. It indicates that all the parties involved realise, even if they do not acknowledge it to themselves, that there has been data that would have been embarrassing for them.

This is clearly data that they or the government they must serve would rather not know about. This tells us why the *“reporting and response mechanisms”* are ineffective. When you do not collect data about care then you do not know what you are doing and cannot provide it effectively.

Whistleblowers: The only real source of information about aged care comes from whistleblowers. Staff who speak up lose their jobs and no one else will employ them. It takes horrendous conditions and great courage for staff to speak up. Families who want to speak out lack power, are looked down on by providers, fear retaliation against their family member in care, face an opaque regulatory system that is not responsive to them and can be threatened with defamation. It takes great courage to go to the press, expose what happened and then become an advocate for others. As was revealed by Oakden many, who would like to speak out about what they experience or see, decide not to do so.

Reference 2. The effectiveness of the Australian Aged Care Quality Agency, the Aged Care Complaints Commission, and the Charter of Care Recipients’ Rights and Responsibilities in ensuring adequate consumer protection in residential aged care;

The history of aged care also tells us about ***“the effectiveness of the Australian Aged Care Quality Agency, the Aged Care Complaints Commission, and the Charter of Care Recipients’ Rights and Responsibilities”***. Not only have they not been calling for objective data about care but they have actively avoided collecting it. Many families and nurses are unhappy about the lack of response and action following their complaints.

The issue here is that the regulators are more concerned about supporting the system than the residents. John Braithwaite, an international authority on regulation, described this when he investigated aged care regulation in Australia and published his findings in 2007²⁰. Little has changed in the 10 years since then. If we are to address this then we need to understand why and how it happens.

1.1.1 Protecting government

The protective role the Quality Agency plays in supporting government policy is illustrated by the way it has reported out its data over the years. It creates a deceptively rosy and inaccurate picture of performance, using a strategy to underreport the incidence of failures.

²⁰ Braithwaite J et al *Regulating Aged Care*’ Edward Elgar Publishing Limited 2007 (Section on Australia)

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Concealing failures: We discovered for example in 2008 that the agency had developed a strategy for under-reporting success in achieving full accreditation. In her annual report based on accreditation data the minister boasted that only 46 (1.6%) had failed a standard when in fact 199 (7%) had failed over the year²¹. The figure reported represented only those who had not succeeded in correcting failures and becoming reaccredited by a single date each year. Four times as many had failed during the previous year and only one quarter had not corrected this in time.

In addition, the agency had analysed and reported out failures in achieving full accreditation without taking account of obvious variables. In doing so it obscured differences between different types of owners.

When properly analysed taking account of the impact of the difference between metropolitan and rural areas (where for-profits did not operate), it was clear that facilities with comparable nonprofit owners performed very much better than those owned by for-profit owners – something confirmed by many international studies. This should have been obvious, even from the raw figures to anyone who understood the sector and had basic data handling skills.

There were several agency board members with these skills. The government had abolished probity regulations on the basis that owners had no impact on care. They called them ‘passive investors’. This information would have challenged the explanations the government had used to justify its policies and persuaded families to favour nonprofits when making decisions. This we believe is why it was not properly analysed.

Research in 2014 by Dr Richard Baldwin challenged government policy by showing that for-profit owned facilities were more than twice as likely to be sanctioned than nonprofits. The agency responded in a presentation that was reported in the aged care press. They confronted this research claiming no difference in performance using accreditation data reported in exactly the same deceptive way as in 2008.

When challenged by Aged Care Crisis in the comment section of the article and also directly by phone and email, the agency refused to respond. Charts showing the results of these studies and links to sources are given at the end of Appendix 2. They were well aware of our findings and criticisms in 2008 but had elected to ignore them and were still reporting data in the same way.

That the agency was prepared to distort figures and ignore data challenging government policy in its public reporting illustrates the strength of its commitment to government policy above the interests of the public.

It is clear that we cannot accept claims made or data provided by the Quality Agency as valid. If we are prudent we should always fear the worst and check everything it says or does.

Reference 3. The adequacy of consumer protection arrangements for aged care residents who do not have family, friends or other representatives to help them exercise choice and their rights in care.

We don't have data that tells us whether these processes are working so we do not have data that tells us more about “***aged care residents who do not have family, friends or other representatives***”.

²¹ Aged care report card Aged Care Crisis 2008 <http://www.agedcarecrisis.com/news/research/108-aged-care-report-card>

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It seems clear though that if care is poor and abuse is occurring then, in a market system driven by strong commercial pressures, those who do not have anyone to protect them will be at much greater risk.

1.2 Indirect evidence

While there are no credible measures of care or quality of life that enable anyone to estimate the actual incidence of poor care or abuse, there are two sources that give us some idea of just how bad it is. The first of these is information from staff and families at the bedside over the years. The second is recently available data about staffing levels in Australia.

These both give us a very good idea about how bad care is and how extensive this is. They show quite clearly that our regulatory system has failed our elderly residents and failed them very badly. We have explored the reasons for this in several recent submissions that we have made to other reviews and inquiries and we will refer to them in due course.

1.2.1 Stories from the bedside

When you look at what staff at the bedside, family and residents are saying about the care they are receiving you find that there is a long story of anger and despair going back nearly 20 years. These devastated and very critical people are those who actually see and experience what is happening in aged care. They are not the industry believers who sit in their offices and commission positive stories to counter what they see as sensationalist press and rare exceptions.

This unhappiness has been ongoing since about 2000 and it has been steadily increasing. This has been accompanied by an increasing number of press reports of failures in aged care and periodic major scandals. Initially the reports we saw were often from nursing homes belonging to the smaller for-profit groups owning only one or two nursing homes. Later they came from the larger for-profit corporations.

The 2014 Living Longer Living Better (LLLBB) reforms introduced strong competitive pressures driving the sector to consolidate. There has been a takeover frenzy with several companies listing on the sharemarket. We are hearing more complaints and seeing more failures first in nonprofits and now in government run facilities, perhaps because like Oakden they are threatened by privatisation. Nonprofit and smaller for-profit providers are the most threatened by acquisition²² and most under pressure. We suspect that they have been forced to divert funds to profits, either to protect themselves from predators or to secure a good price as they exit the sector.

In **Appendix 1** we have printed a large selection of short quotes from comments by staff and families from multiple sources from 2005 to 2017. They are all saying the same things. On that page we have also provided links to pages where a vast amount of additional material is referenced. This describes what has been happening in the sector.

There are also links to information about the USA where similar problems developed in the 1990s. An update page describing the situation in the USA between 2001 and 2003 could have been about Australia today.

²² **Examples:** St Vincent de Paul NSW 2006, Masonic SA 2012, Masonic QLD 2016 and finally Presbyterian Care Tasmania closing/divesting a facility in 2015 then acquired by Regis in 2017
Aminya Centre: Potential operator could secure future for Scottsdale aged care facility ABC News 29 Aug 2015
<http://www.abc.net.au/news/2015-08-29/new-operator-emerges-for-north-east-aged-care-facility/6734584>
Regis moves into Tasmania with Presbyterian acquisition Australian Ageing Agenda 24 May 2017
<https://www.australianageingagenda.com.au/2017/05/24/regis-moves-into-tasmania-with-presbyterian-acquisition/>

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1.2.2 Failures in care confirmed by Australian staffing data

We have recently become aware of staffing data collected in aged care in Australia. We have been in a position to compare it with accreditation performance and with international data. What it reveals is startling and challenging. It confirms everything that the nurses and residents have been saying and shows that the regulators have been deceiving everyone – and we suspect themselves as well. It confirms the findings of academic criminologist John Braithwaite and his team when they studied Australia’s regulatory performance in Australia in 2005 and were very critical. This criticism was published in their book “Regulating Aged Care” in 2007.

It is worth noting that although the Carnell/Paterson investigation of failed regulation after Oakden and their report referenced Braithwaite’s work and supported his theories they entirely ignored this book, the assessment he made, the critical comments and the warning he gave about the risks for the system. This was the system whose failure they were investigating. He was the most experienced and insightful authority in the country. He had spent many years investigating the regulation of aged care and writing about it. He was very critical and they ignored it!

In our submission to that inquiry, we quoted extensively from the findings, the criticisms and the dire warning in Braithwaite’s book. We also supplied some data similar to that below, which was ignored.

The prescribed form we were required to complete limited what could be said but we were able to attach an additional document describing Braithwaite’s work and providing data on staffing. It is difficult to believe that, if this attachment was actually given to them by the department (and they bothered to read it), they would not have understood the significance of the material. Had they done so they would surely have been compelled to consider the implications.

As in this submission we were challenging the concept of accreditation as regulator and its close association with the discourse on which the system and its regulation was built in 1997. We conclude that these issues and the data were ignored because the review was too close to government to be objective and independent. The only solution for them was to ignore criticisms that would challenge policy.

1.2.2.1 The regulatory system has been concealing failures

The early 2007 failures at Oakden were during and soon after the period when Braithwaite observed that the regulators had been captured by the market, that regulation was ineffective, that on site assessors adverse findings and recommendations were often overruled by management. That things “*have to be bad for non-compliance to be recorded or strong criticisms to be made in an accreditation report.*”

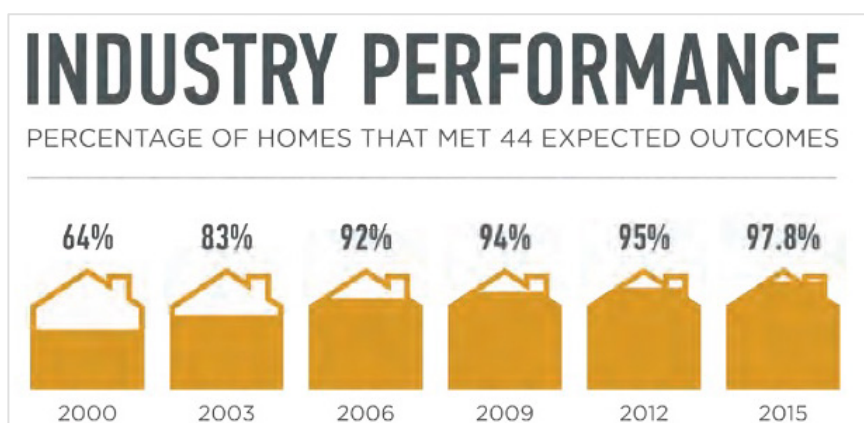


Figure 1: Quality Agency Annual Report 2015/16

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Braithwaite found that Department of Health used “percentage compliance as a performance indicator that must be seen to improve each year, driving compliance to ridiculously, artificially high levels over the years” and that department officers “argued to us quite unselfconsciously that ‘98 per cent of homes are fully compliant, up from 92 per cent in 2004’”.

What this suggests is that the improvement in performance of the sector in achieving accreditation had everything to do with achieving these performance goals and little if anything to do with the quality of care provided to residents.

In 2003 the industry promised to collect objective data, but in 2007 the agency commissioned a review of accreditation that absolved the industry of the need to collect objective data about standards of care. This enabled both the agency and the industry’s to renege on their 2003 undertaking to do so. This would have made passing accreditation much easier. It is difficult not to connect the dots and draw conclusions.

We think that it is highly significant that in the review of the performance of the regulators the Carnell/Paterson report did not at any point refer to or reference Braithwaite’s critical book ‘Regulating Aged Care’ or the many quotes in our submission describing his findings. Had they done so they would have been compelled to consider the implications. We worry that they had an agenda, whose legitimacy, would have been challenged by Braithwaite’s careful research.

1.2.2.2 Staffing data

Data showing increasing acuity (frailty and incapacity requiring more care) and decreasing levels of the trained staff needed to care for them is available for comparison with accreditation performance over the years. The chart shows percentages of direct care nursing staff and the percentage of high care residents.

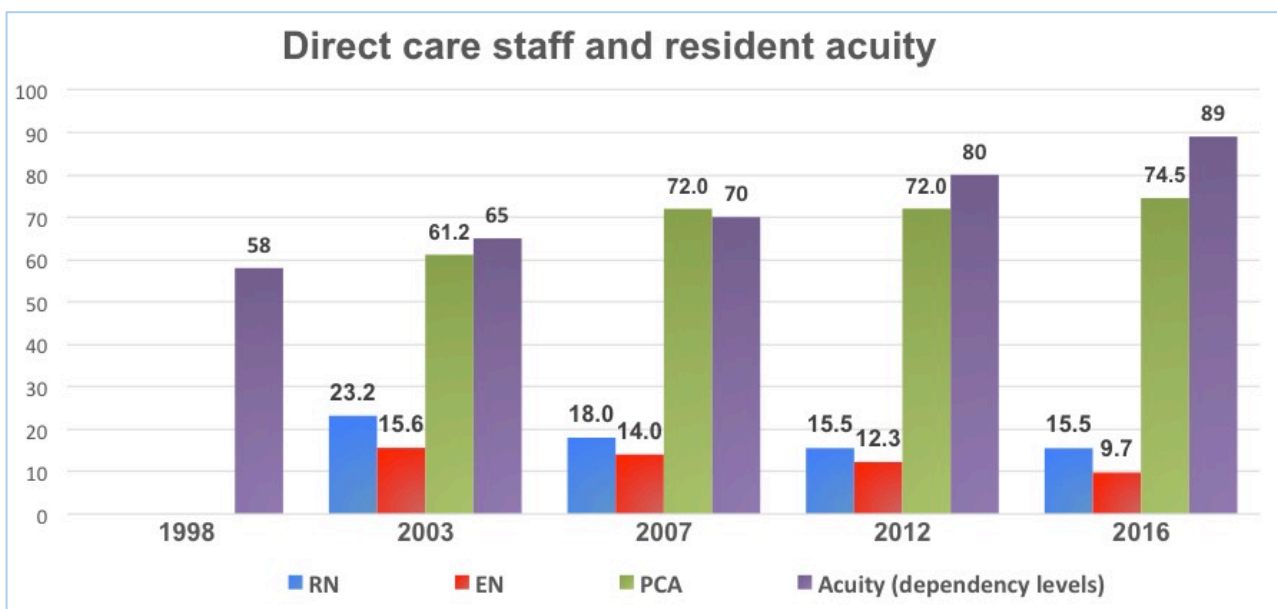


Figure 2: Nurses and resident acuity in Australia²³

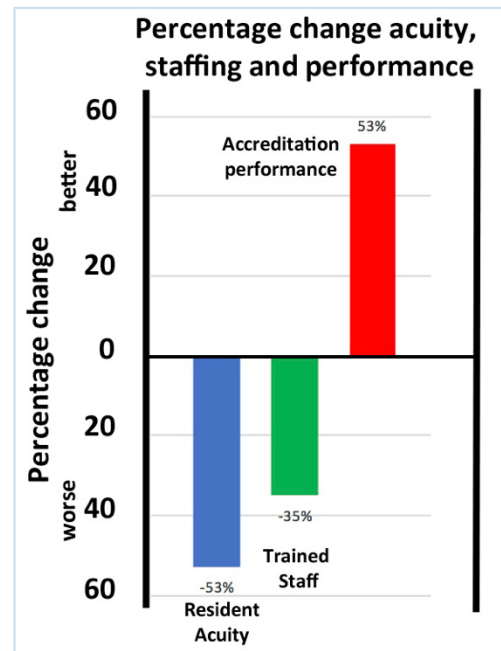
²³ Figures from the ANMF fact sheet website in 2016: http://anmf.org.au/documents/reports/Fact_Sheet_Snap_Shot_Aged_Care.pdf

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When we look at the ongoing unhappiness from staff and many residents’ families we are left wondering how much of the improvement from in 64 to 98% accreditation success between 2000 and 2015 was due to departmental policy. This was a 53% increase in performance to near perfection.

This was a system where during this same period the acuity of residents deteriorated by 53% from 1998 and the number of trained staff (RNs and ENs) needed to care for these sicker and more difficult to handle residents fell by 35% (from 38.8% in 2003 to 25.2% in 2016). Minimally trained PCA’s increased by 20%.

Note: *The 53% increase in acuity (needing high care) has been plotted as a negative below the line to highlight the significance of what has happened.*



We are left wondering how there could have been overall improvements in the care when the staffing figures show that the opposite must have occurred. It is not possible for care to get better when 50% of the residents are sicker and need much more care, and there are over a third less staff to care for them.

This is simply not credible. It could not have happened. Care must be a lot worse which is what nurses and families have been saying. The only logical explanation is that facilities were being accredited to meet a target of 100% and not to protect residents. This was impression management and a branding exercise for the industry on a massive scale and it was done in the face of deteriorating care.

1.2.3 Confirmed by international comparisons

Staffing: As we revealed to the senate workforce inquiry and to the other inquiries following Oakden there are not enough staff to provide care when we compare our staffing with that in the USA where extensive studies of the relationship between staffing and care have been done to determine safe staffing levels and where minimum levels based on these careful studies are advised.

	USA: CMS Recommended Minimum	AU: SB Recommended Benchmarks	USA: US Average	AU: SB Average
Registered Nurses	0.75	0.36	0.8	0.37
Enrolled Nurses (equivalent)	0.55	0.34	0.8	0.33
Nurse Aids (equivalent, eg PCAs)	2.8	2.22	2.4	2.08
Total nursing time:	4.1 hrs	2.9 hrs	4.0 hrs	2.8 hrs

*Total rounded to 1 decimal point.
CMS²⁴ = Centre for Medicare and Medicaid Services (15,000 facilities) SB²⁵ = SB (800 facilities)

²⁴ Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2009 Through 2015. Henry J Kaiser Foundation July 2017 <http://files.kff.org/attachment/REPORT-Nursing-Facilities-Staffing-Residents-and-Facility-Deficiencies-2009-2015>

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US nursing home residents on average receive twice as much care from trained nurses and one hour (a third) more care from nurses each day than residents in Australian nursing homes.


Independent US studies over the years show that the levels of care in Australia expose residents to risk. We cannot be providing good care with staffing levels like this.

The benchmarks our nursing homes use in determining staffing requirements are based on commercial considerations and not research. They are developed by a financial company that supports the providers and lobbies government on their behalf. They are set at levels that make this very poor staffing look legitimate.

1.2.4 Confirmed by regulatory ineffectiveness

This gets worse when we compare regulatory failures in the two countries. What is revealed is even more startling. In spite of the differences in staffing, in the USA²⁶ 93% of homes had a deficiency and 20% were serious enough to cause harm or create jeopardy. In Australia 97.8% passed all the accreditation standards. Only 2.2% had problems.

 Red shows the number with deficiencies or failing standards

 Blue have no problems

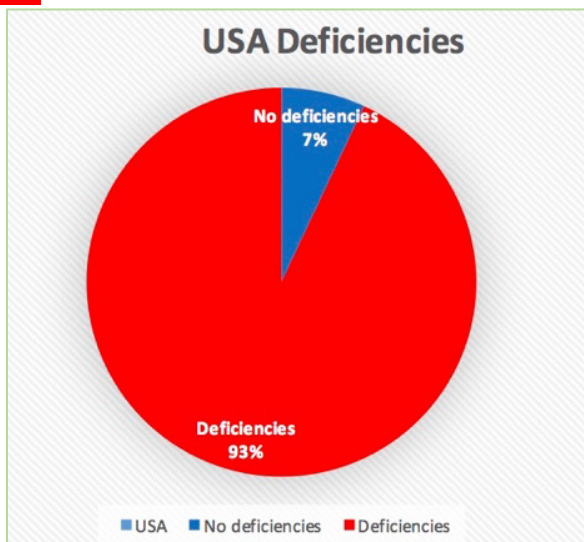


Chart 6: USA deficiencies = 93%

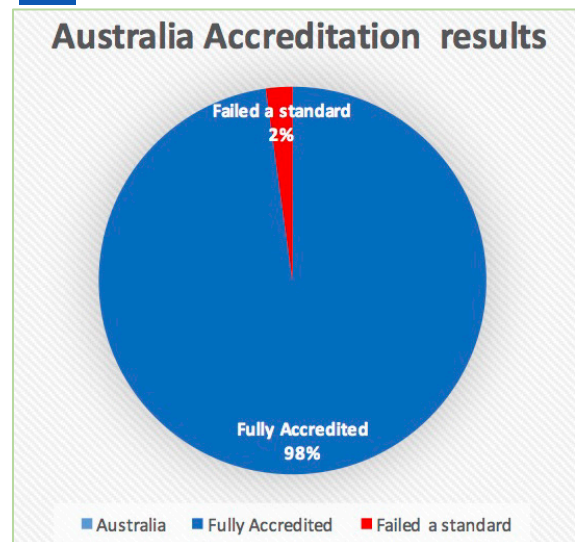


Chart 7: Australia deficiencies = 2%

Many comments from staff and family members confirm our assessment of the accreditation process.

For example a submission from a clinical consultant²⁷ to the 2017 Carnell/Paterson Review describes it as “deeply flawed”.

Comments include:

- *Sadly, the current audit process is a national disgrace. Substandard conditions are commonplace, with facilities easily passing accreditation and proudly displaying their certification as vindication that they are doing everything right.*

²⁵ Aged Care Financial Performance Survey Summary of Survey Outcomes StewartBrow December 2015 SB
Aged Care Financial Performance Survey Residential Care Report StewartBrown - June 2016 - SB

²⁶ Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2009 Through 2015. Henry J Kaiser Foundation July 2017
<http://files.kff.org/attachment/REPORT-Nursing-Facilities-Staffing-Residents-and-Facility-Deficiencies-2009-2015>

²⁷ Submission Response 617437173 to Carnell/Paterson Review: <http://bit.ly/2DZ6hrT>

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- *Any audit that gives you two months notice they're coming and is conducted by non-clinicians is farcical. It's known as the 'pre-accreditation shuffle': give the walls a fresh coat of paint, buy some new outdoor furniture, roster extra staff on the audit day, go back and fill in all the blanks on your paperwork and don't serve the cold party pies until the next week.*
- *The AACQA only publishes the final sanitised generic accreditation report. There is no information available regarding unannounced visits, areas where additional information has been requested or the documentation submitted to the agency when facilities have been found to be non-compliant. (Although, to be fair, this usually only consists of a hastily cobbled together 'action plan' that will never be implemented or followed up by the agency) Why, under The Act, is this classified as protected information? What are we hiding and why?*
- *The AACQA has failed to protect the frail elderly. The Aged Care Act allows them to continue. It attempts to maintain the facade of 'quality' through a variety of mechanisms, the most visible being 'Better Practice Awards'. Real nurses and savvy consumers view these awards with contempt; awarding providers for doing what they should be doing anyway as basic daily care. (Is the daily application of moisturiser on frail elderly skin really worthy of a special better practice award?)*

Note that the criticism here is that the Quality Assessors do not have the skills needed to do their job.

This clinical consultant indicated that *“The AACQA is unable to perform its charter effectively current audit process is a national disgrace conducting the site audits”*. Assessors would assess the data *“to ensure all data is completed, however, they do not have the skill to adequately analyse that data”*. And again *“The AACQA seems to be satisfied that a facility simply has to collect infection data. There is no consistent approach to ensuring data is analysed and actioned”*.

The point we emphasise here is that you cannot train people if you don't have data to base that training on. This is compounded when their managers do not have data either - or practical experience so cannot be role models or mentors and assist those who are doing the clinical assessing.

Conflicts of interests

In a smoke and mirrors situation like this the system simply buries its head in the ground, particularly when those who have been closely associated with the provider or their mates are in positions of power or on the board of the body doing the assessments. This may well have been a factor at Oakden regardless of whether the person on the board would actually have exerted any pressure. In a similar example in NSW the suggestion that the owner was a friend of the minister may have influenced the agency and its assessors over the years. The impression that they might be able to is enough.

Oakden: Two clinical advisers who claim that their efforts at Oakden were undermined by the accreditation agency in 2007 causing them to resign were very critical of the agency. They were replaced as clinical consultants by a group whose CEO had previously been on the board of the government body managing Oakden and who was soon appointed to the Quality Agency in 2008.

He has been on the board of the Aged Care Financing Authority and lists education from The Executive Connection (TEC 13) which provides coaching to CEOs so has economic and managerial expertise. He was awarded a fellowship to explore ways of developing roles and

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improving lives *“for people in their 70s, 80s, and 90s”* and his very commendable interest and research has been on quality of life²⁸.

We wonder if he had clinical training and fully appreciated the importance of clinical wellbeing and whether he might have unknowingly at times brushed clinical issues aside.

In evidence to the senate hearing into Oakden in Adelaide Carla and Neil Baron who had experience in South Australia and at Oakden were very critical²⁹ indicating that *“It is very difficult for an assessor to find noncompliance in an organisation when they know the CEO of that organisation is a board member of the agency”*.

Then again about Oakden *“there was a concerted effort by all concerned - - (including) - - the Aged Care Standards and Accreditation Agency—to maintain the status quo: keep it as it was; don't rock the boat. - - - the system did not work”*. And *“poorly worded standards -- inconsistencies at all levels and that I believe resulted in significant failures”*. When the consultants were pressing for improvements to poor practices *“the agency come in – (and tell staff) ‘You're doing a great job here—we can already see improvements”*, and so neutralise the consultants efforts. Staff *“Put the band aid in place for the agency and move on”*.

XYZ company: In another instance the founder of a problem nursing home and retirement village company XYZ was a friend of the minister for aged care and a political donor.

XYZ had many issues in the late 1990s and early 2000s. Nurse whistleblowers in its two nursing homes spoke out strongly and there was publicity. There were allegations of an *“environment of harassment, staff claims of verbal abuse by management, and a long history of underspending on the home”*. This was followed by problems and disputes in its retirement villages dragging on until 2010³⁰.

At the time the press reported that staff warned the assessors that their advice to close one of the nursing homes would be overturned because of the friendship with the minister. Nurses apparently warned assessors that they would not be allowed to close a facility and when the assessors advised that it be closed they were overruled. Both the Agency and the minister later denied that this was due to their influence. The two nursing homes involved at the time remained accredited over the years.

The minister resigned from parliament under a cloud in 2016. In 2017, XYZ's two nursing homes were finally closed down³¹ with minimal publicity in a local newspaper in December shortly before the holiday season. They had failed 30 and 24 respectively of the 44 accreditation standards. Staffing was a core problem. A news article at the same time reported that XYZ's founder and owner donated almost \$20 million to a charity in Israel³².

XYZ nursing homes had been fully accredited for about 14 years. We are left wondering how they recovered so well after years of problems and how so much could have gone wrong so quickly. There are remarkable similarities with Oakden but XYZ was handled very differently and with minimal publicity and political consequence? It is difficult not to conclude that the regulatory system was working in the way government had intended it to – keeping it under wraps.

²⁸ The Winston Churchill Memorial Trust Of Australia 2012 fellow <http://bit.ly/2oBJOrS>
Shifting focus to quality of life Australian Ageing Agenda 10 Sept 2014 <http://bit.ly/2oKre02>
Call to action on quality of life in aged care Australian Ageing Agenda 9 Sept 2016 <http://bit.ly/2t9U1k3>

²⁹ Senate Inquiry - Public Hearing, 21 Nov 2017, Adelaide <http://bit.ly/2CQ5Ddj>

³⁰ XYZ Health Care, Corporate Medicine web site <http://bit.ly/2A1a6wz>

³¹ Failed nursing home loses accreditation Blue Mountains Gazette 4 December 2017: <http://bit.ly/2A7yszu>

³² \$20 ZZZ -on donation, Jewish News, 7 Dec 2017: <http://bit.ly/2AKe5rz>

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If this had been more prominently reported in the press, would another flood of families have come forward to tell us of their experiences? Was Oakden really different in that it was also regulated by a state visitor's scheme that was able to escape the government's protective regulatory system and overcome a political and bureaucratic brick wall by making its concerns public.

A CEO of a nonprofit organisation who previously worked for government is also very critical of the regulatory system. On the LinkedIn site³³ he wrote:

“... With the recent closure of two homes in Sydney, the fact it took the Department over 15 years to rid the sector of a provider everyone knew was a disgrace is appalling. That provider was on the list of undesirables back in 2000 when I first joined the Department and was still there when I rejoined the Department in 2011 and when I left again in 2015 ...”

He was scathing about the Quality Agency, comparing the UK regulator where “*343 homes were found to require improvement and a further 92 provided inadequate care or services*” (total 435) with Australia's 5 sanctioned homes and 79 services that had not met outcomes (total 84). He concluded “*I think someone has painted on eyes*”

On another occasion he wrote:

“... you would be outraged to know how difficult it is to be sanctioned under the Aged Care Act

Unless the Quality Agency calls serious risk at an audit, the process is mind-numbing slow and usually takes months.

There are previously sanctioned providers given additional allocations and grants and providers previously charged with commonwealth fraud allowed to build new homes and continue operating.

The departments ability to rid the sector of underperformers and crooks is an absolute joke ...”

and in another post:

“... While I am calling on each and every person associated with aged care in Australia to challenge the status quo and make a difference in the aged care sector, most importantly I am challenging our sector leaders the supposed movers and shakers, the people with influence, the people with the power to force change ...”

That is what Aged Care Crisis is doing, but we think that the data we have researched shows that the problem of staffing and care is more widespread than the writer realises.

³³ LinkedIn: The True Cost of Providing Quality Aged Care <http://bit.ly/2BVYHww>

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1.3 Quality Agency assessments

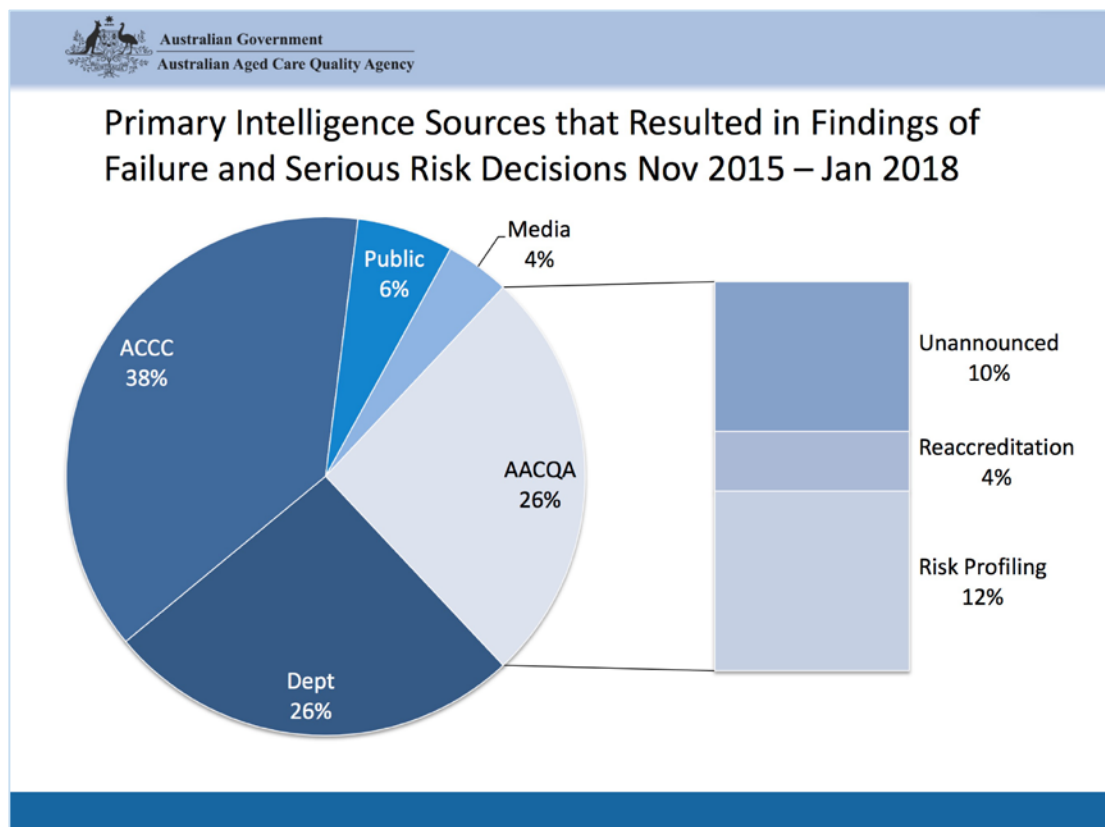
The Quality Agency’s own data shows the lack of utility of the inspections performed by the Agency.

The source of information that resulted in adverse findings

Data drawn from Nov 2015 to Jan 2018 (just over 2 years) were presented to industry at a LASA conference by the Quality Agency in 2018³⁴. This shows that in the vast majority of cases problems were only found when the agency had been told about a problem. They did not discover it themselves.

The **Primary Intelligence Source** for 74% of the “findings of failures and serious risk decisions” came from other outside sources including the Complaints Commissioner (38%), the department (26%), directly from the public (6%) and the Media (4%).

All of this information would have come indirectly from someone (families, friends, staff etc.) who knew or saw what was happening and who lodged a complaint, spoke to the department or perhaps to a politician.



Source: Lessons from Regulatory Case Studies, Quality Agency, presentation to LASA conference Feb 2018 <http://bit.ly/2FeMeWT>

Only 26% of the findings were initially identified by the agency. In 12%, risk profiling and not their inspection alerted them to problems. Only 4% were detected at re-accreditation visits and 10% at unannounced visits.

The loudly trumpeted Carnell/Paterson reform to move all oversight to unannounced visits, which discovers only 10% of failures is not convincing.

³⁴ Presentation: Lessons from Regulatory Case Studies - Ann Wunsch, Quality Agency to LASA conference, Feb 2018: <http://bit.ly/2FeMeWT>

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Detection of problems by agency visits

Data from this same presentation gave the number of visits and the number of occasions when a problem was identified.

Another report titled *Regulatory Performance Data*³⁵ supplied to the Senate inquiry into Oakden gave more information for the financial years 2013/14 to April 2017 - just under 4 years so almost double the time although the two sets of data overlap. The percentage of failures found has been calculated for both in the table below:

Type of visit	Presentation (Nov 2015 to Jan 2018)		Report (2013/14 fin yr to Apr 2017)	
	Number	Failure detected	Number	Failure detected
Reaccreditation	1001	33 (3.3%)	3146	69 (2.2%)
Review audits	70	40 (57%)	90	70 (78%)
Announced contacts	816	11 (1.3%)	3507	46 (1.3%)
Unannounced contacts	4616	84 (1.8%)	11362	169 (1.5%)

- Note that **Review audits** are performed in response to information supplied to the agency and here the finding of failure was much higher 57% and 78% respectively.
- In contrast, re-accreditation audits yielded 3.3% and 2.2%
- Announced assessment contacts yielded 1.3% in both
- Unannounced assessment contacts yielded 1.8% and 1.5%

When visits were unannounced this increased the chances of detecting problems by only 0.5% and 0.2%. Compare these figures with the 93% detection annually in the USA - and 20% were serious.

The *Regulatory Performance Data* report also gave the number who had failed each standard. We have expressed them as a percentage of the total of all assessment visits made including audits (18,105) during the four-year period.

We concentrate here on important clinical indicators because there seems to be so little interest in and knowledge of clinical issues at all levels of the regulatory process. There are claims that assessors have little, if any clinical knowledge, that *“dozens of aged-care executives are moonlighting as inspectors”* and that many others assessors are also consultants to the industry³⁶. We wondered why the Quality Agency had recently removed assessor’s names from their public reports.

There is no data about clinical outcomes that these untrained assessors can use as a benchmark when deciding what is acceptable. Clinical issues and clinical outcomes are simply ignored and there seems to be a dearth of clinical knowledge and skills. Some examples illustrate this.

³⁵ “Regulatory performance data” part of AACQA submission (number 42) Aug 2017 to Senate Inquiry “Effectiveness of the Aged Care Quality Assessment and accreditation” <http://bit.ly/2Fex0Bk>

³⁶ Aged-care executives two-timing as auditors, in potential conflict of interest Courier Mail 20 Feb 2018 (paywall) <http://bit.ly/2oHwzVF>

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Standard	Number in 18,105 assessments	Percent detecting a problem	Clinical incidence
Medication Management	86	0.47%	
Pain Management	29	0.16%	
Nutrition and Hydration	24	0.13%	40 to 80% malnourished
Skin Care	31	0.17%	Pressure injuries in 2005 = 26 and 44%

Medication and pain management are two of the most criticised outcomes and are dependent on staffing skills and numbers, which we know are deficient. This claimed low incidence of failures (0.47% and 0.16%) if real would be way beyond any other country - world-class care beyond what is possible.

But this is not what is being measured here and one wonders at the utility of these measurements – other than as a marketing and branding exercise for the industry.

Pressure injuries and malnutrition are interdependent clinical issues. Malnutrition predisposes to pressure injuries and the loss of fluid, inflammation and sepsis associated with pressure injuries have a “catabolic” effect (breaking down tissues) which increases malnutrition and makes it much more difficult to treat. Both have a devastating impact on quality of life and mortality. The incidence of both can be markedly reduced by sufficient staff with knowledge and motivation.

Pressure injuries are largely preventable with adequate trained staffing and **Malnutrition** can be kept to a minimum with good tasty food and enough attentive staff. Clearly the assessors are not looking at the residents or their charts and/or have not got the basic clinical nous to look at what is happening. To be even remotely credible, an assessment of care must include a clinical assessment of the residents receiving it and that cannot be happening.

1.3.1 Example: Pressure injuries

To appreciate the problem, we need only ask about the incidence of pressure injuries, one of the strongest indicators showing that nursing care is deficient.

In giving a speech in 2017, the Minister quoted an incidence of 32%³⁷. When his speech was transcribed on the department website, it appeared as 10.3%³⁸. When his advisers were asked for the source of these varying figures, the 10% figure was removed from the transcript³⁹.

When pressed, they then referred to figures between 3.4 and 5.4%⁴⁰ that were quoted in 2006. These were in fact, figures taken from the 1990s when staffing was better (and tied to funding) and state regulators were rigorous.

The most recent figures Aged Care Crisis could find were quoted in 2009 but came from studies done in 2004 and 2006 that examined data from 2003 and 2005. The actual figures 8 years after the 1997 reforms were 26 and 46% (average 34% close to the minister’s figure of 32%).

³⁷ Minister’s speech - AACQA - Better Practice Conference, Oct 2017 - find video excerpt: <http://bit.ly/2CFnkQ1>

³⁸ Minister’s speech - AACQA - Better Practice Conference, Oct 2017 - original publication (pg 4): <http://bit.ly/2AozvdL>

³⁹ Minister’s speech - AACQA - Better Practice Conference, Oct 2017 - updated speech transcript: <http://bit.ly/2IU6iDj>

⁴⁰ 2006 RACGP Silver Book: <https://www.racgp.org.au/your-practice/guidelines/silverbook/common-clinical-conditions/pressure-ulcers/#216>

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If these figures are correct, then the 8 times jump from 4.4% to 34% only 8 years after the system was changed is alarming. We can only wonder what they are now. But alarm bells did not ring and instead of addressing it and monitoring progress it was ignored.

In the USA they collect data from 15,000 nursing homes each year and the average is currently 6%. There is a vast database of information in the USA that we can learn from but we need to know what our own figures are to do that. The only conclusion a sensible person can reach is that the industry knows but is not telling.

Pressure injuries are one of the voluntary quality indicators being collected but not published. It depends on enough staff who recognise its significance and know how to prevent it which can be done most of the time. Someone must know what the average number in this selected group are, but no one is saying. The nurses are telling us about it but no one is listening.

For example, in a submission to the Carnell/Paterson Inquiry a nurse who was a clinical consultant was very critical of the care given and of the failure of the accreditation process, which was described as ‘*deeply flawed*’⁴¹.

The consultant wrote “*I witness appalling standards of care on a daily basis*”.

In writing about Skin Care:

I attended a recently accredited facility. While all their wound care documentation was satisfactorily completed, further investigation revealed that:

- ***Over 60% of bed-bound residents had serious pressure injuries***
- *Over 90% of incontinent residents had skin rashes and fungal infections*
- *They were using inappropriate wound care products and techniques*
- *All wounds had deteriorated since they were first identified due to incorrect care practices*
- *Simple skin tears became chronic ulcers. Pressure injuries deteriorated into wounds that are commonly found in third world environments.*
- *The facility simply accepted their high rate of these preventable injuries and had not actioned any alternative strategies*
- *I'll wager \$1000 that in any facility I attend, at least 50% of the air pressure mattresses will be either set incorrectly or malfunctioning. Most of them will have broken parts and have not been serviced for many years. Care staff have not been trained in their correct use.*

The Agency's own data reveals that in a little under four years from the 2013/14 financial year to April 2017 the Quality Agency did 18,105 assessments of nursing homes.⁴² During this period the Agency detected 31 problems in skin care – just 0.17% of visits.

Pressure injuries have dressings on them and are recorded in the notes so are easy to detect and evaluate. Facilities are accredited without looking at either. This is a vast amount of effort and money wasted for no purpose.

⁴¹ Submission Response 617437173 to Carnell/Paterson Review: <http://bit.ly/2DZ6hrT>

⁴² **Regulatory Performance Data April 2017** attached to Quality Agency submission to Senate Committee Inquiry into the Effectiveness of the Aged Care Quality Assessment and accreditation framework. . August 2017 <http://bit.ly/2Fex0Bk>

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1.3.2 Example: Malnutrition

Malnutrition is a good example of what is happening and the ineffectiveness of our regulation. There has been recent publicity about malnutrition and research to support its incidence.

The importance of malnutrition in undermining wellbeing, predisposing to multiple medical problems and limiting quality of life has been largely ignored. In 2010 the Dietitians Association of Australia indicated⁴³ that:

Nutrition status largely determines quality of life, independence and overall health of older adults - - - . Despite the importance of nutrition, there is no current food and nutrition policy for Australians, let alone for older Australians.

- - unintentional weight loss places individuals at greater risk for clinical complications such as increased risk of falls and fractures; increased risk of osteoporosis, infections and pressure ulcers; increased rates of depression; decreased mobility, morbidity and mortality; delayed healing from acute episodic events, prolonged and increased frequency of hospitalisation and decreased quality of life

The association indicated that *“Malnutrition is recognised by DAA as the major nutritional concern amongst older Australians”* and that it was *“associated with adverse clinical outcomes and costs”*. In spite of this *“there is no coordinated approach to addressing the issues of older Australians”*. They recommended that *“the Commonwealth monitor nutritional status across the aged care system and report on the prevalence of malnutrition”*. This has not happened.

Measuring Malnutrition: The incidence of malnutrition varies with the type of assessment used but the most reliable seems to be to record the *“percentage of weight loss over a specific period”*⁴⁴ with over 5% in a month or 10% in 6 months raising concern. That should be readily accomplished. A literature review shows wide variation in incidence but indicates that approximately 20% of residents in nursing homes have malnutrition⁴⁵.

Factors influencing malnutrition included *“food budget, staffing, social activities, and family bringing meals to residents”*. The *“association between malnutrition and mortality among nursing home residents is especially clear”* and the literature *“clearly indicates that malnutrition leads to earlier mortality”*. In addition *“staff training studies demonstrated clear benefits on malnutrition indices.”* Low staffing levels are associated with malnutrition⁴⁶.

Incidence in Australia: The incidence varies across Australia. Most accept that about half (50%) are malnourished. A poster presentation in 2005⁴⁷ suggested a prevalence *“of malnutrition in the elderly appears to be disturbingly high: between 40% to 60% and as high as 85% has been reported”*. Those recently hospitalized, living alone or in residential care are at most risk. They found that *“Less than 10% of residents were seen by a dietician and 19% were seen by a speech pathologist”* and *“only 20% were weighed monthly”*. They commented on the lack of skill among staff and time pressures as problems.

⁴³ Submission from the Dietitians Association of Australia to the Productivity Commission: Caring for Older Australians 10 Aug 2010 <https://www.pc.gov.au/inquiries/completed/aged-care/submissions/sub371.pdf>

⁴⁴ Prevalence and Measures of Nutritional Compromise Among Nursing Home Patients: Weight Loss, Low Body Mass Index, Malnutrition, and Feeding Dependency, A Systematic Review of the Literature C.L. Bell et al. / JAMDA 14 (2013) 94e100

⁴⁵ Malnutrition in the nursing home Bell C L, Lee A S W, Tamura B K www.co-clinicalnutrition.com Volume 18 Number 1 January 2015

⁴⁶ Low staffing level is associated with malnutrition in long-term residential care homes J Woo, I Chi, E Hui, F Chan and A Sham European Journal of Clinical Nutrition (2005) 59, 474–479

⁴⁷ Aged Care Nursing and Nutrition Issues Gaskill D et al. (2005) Aged care nursing and nutrition issues. [poster]

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A 2007 study of 6 nursing homes in Queensland found “a median of 50.0% and 49.2% of residents of aged care facilities were found to be malnourished” in two separate audits. Another in 2008 of 8 nursing homes and 350 residents found “43.1% moderately malnourished and 6.4% severely malnourished”.⁴⁸

A 2014 study of nursing homes in Canberra⁴⁹ found a lower figure reporting “20% as moderately malnourished, and 2% severely malnourished” but this study excluded high-risk residents including those who were cognitively impaired and medically unfit. This is a significant proportion of residents who are likely to be malnourished, so that the studies are not really comparable. What is clear is that the incidence in Australia is higher than the 20% found in comparable countries.

Profit, food and nutrition: Groups of dieticians and citizens such as The Lantern Project⁵⁰ have taken a proactive approach by trying to encourage and persuade providers to do the right thing and motivate them to improve the diet for residents by making it more nutritious and attractive. They are well aware that motivation is constrained by commercial imperatives.. Their own study⁵¹ working with SB has examined just this issue. It reveals that in Australia nursing homes on average spend only \$6.08 on “the raw food and ingredients budget”. This was much less than in other countries as well as the budget for food in prisons.

As cost of living and so food increased over the two years of the study the budget for fresh food had decreased by 30 cents per person per day. This has been accompanied by an increase in food supplements which are less effective in addressing malnutrition. The authors indicate that “Increasing the aged care profit margin by reducing food spend impacts the quality of resident care and can contribute to malnutrition rates in aged care”.

The incidence can be reduced: In another study⁵² affirming that half of all residents were malnourished and that this was in part due to inadequate dietary intake, the authors showed that a variety of strategies “can help prevent decline in residents’ nutritional status. Food and nutritional issues should be identified early and managed on admission and regularly in the RAC setting”. They affirmed that nursing staff’s inability to “identify and recognise malnutrition as a formidable problem in the RAC setting results in them not prioritising nutrition care for the residents”

Publicity: The report that only \$6.08 was spent on food each day was picked up and ran in the press⁵³ stimulating the president of the AMA to comment that “My children’s guinea pigs get fresh

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- ⁴⁸ Prevalence of malnutrition in adults in Queensland public hospitals and residential aged care facilities Banks M et al Nutrition & Dietetics Volume 64, Issue 3 September 2007 Pages 172–178
Malnutrition prevalence and nutrition issues in residential aged care facilities Gaskill D et al, Australasian Journal on Ageing Volume 27, Issue 4 December 2008 Pages 189–19
- ⁴⁹ Malnutrition prevalence and nutrition issues in five Australian Residential Aged Care Facilities. Kellett J et al 13th National Conference of Emerging Researchers in Ageing Conference Paper Nov 2014
- ⁵⁰ The Lantern Project <http://thelanternproject.com.au/>
- ⁵¹ The Lantern Project’s Value Study <https://vimeo.com/237917664>
What does it cost to feed aged care residents in Australia? HUGO C et al, Nutrition & Dietetics 2018; 75: 6–10
- ⁵² Agarwal E. Optimising nutrition in residential aged care: A narrative review: Retrieved from <http://dx.doi.org/doi:10.1016/j.maturitas.2016.06.013>
- ⁵³ Prisoners and pets fed better than people in aged care homes Courier Mail 11 Feb 2018
Nutrition in aged care facilities. AMA President, Dr Michael Gannon, Channel Nine, Today Show with Louise Momber, 12 February 2018 <https://ama.com.au/media/transcript-dr-gannon-channel-9-today-nutrition-aged-care-facilities>
Fish nuggets, sloppy beef stew, liquid lemon jelly and chunks of sausage with gravy: Nursing home workers share appalling photos of \$6 meals dished out to elderly residents Daily Mail 13 Feb 2018 <http://daily.mai/2CB779v>
Weighing Up The Aged Care Costs Letters to the editor: Courier Mail 15 Feb 2018
Aged care providers must prioritise care over cash The Daily Telegraph 20 Feb 2018: (paywall) <http://bit.ly/2sluLkC>

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ingredients and more money spent on them. It's a national disgrace the way we treat our aged." Others compared this with company profits.

Many supplied photos which were published. Some family members described their own experiences including their first meal.

"Then the evening meal arrived. It comprised two cheerios, with nothing else on the plate. Perhaps Mum no longer cared much about what she was given to eat. Certainly, she did not complain.

I saw many other woeful meal offerings there, but the image of that first dinner still brings me to tears. Food to meet the nutritional needs of residents? Hardly.

Despite our efforts to find an appropriate facility, I felt we had failed Mum".

The response: The industry response⁵⁴ was interesting drawing on the infallibility of the Quality Agency where *"nutrition is a key consideration in this process"*, indicating that *"Malnutrition Screening Tool (MST) is employed in all facilities"*, that elderly women *"have a much lower calorie requirement"* than prisoners, and that it is *"not true to say that aged care providers are making huge profits"*. We have repeatedly stressed the very different interpretations put on facts by those whose view of the same events is based on very different 'discourses' (patterns of thought). This illustrates the point well.

The Quality Agency and regulation: So where was the Quality Agency during all of this and what was it doing about this? During the just under 4 years when they performed 18,105 assessments of one sort or another, they only found 24 failures in hydration and nutrition. Although 50% of residents were malnourished, they found a problem in only 0.13 of these visits. This does not sound like a rigorous process that anyone could depend on! Was this because their staff have no clinical knowledge, because it was tick and flick, or because their job was to keep a lid on things and not rock the boat?

Explaining it to parliament: The issue of food, nutrition and cost cutting has been going on for years. There were university studies and press reports in 2010. The previous CEO of the agency was grilled about this by the Community Affairs Legislation Committee⁵⁵. When asked about *"accreditation standards for food"* he indicated that in the previous year *"we identified 40 homes with noncompliance in nutrition and hydration"*. When pressed he admitted that ***"No-one actually regulates what they can and cannot do eat"***. When pressed about *"who regulates foods, and who is responsible for this in nursing homes that receive subsidies"* the answer was that it was not the department or federal government.

The accreditation process assessed ***"performance against the standards which take into account nutrition and hydration"***. The questioning senator stressed that the research findings were quite explicit and revealed *"very serious circumstances."* She asked specifically *"Do you measure nutrition levels as part of the accreditation process, Mr Brandon?"*.

The answer was:

"No, we do not measure nutrition levels. We look at the standards which we expect will stop malnutrition actually happening".

⁵⁴ Aged Care Peak Body Says Food Claims Are Misleading LASA Media Release 12 Feb 2018 <http://bit.ly/2EJAigp>
Aged-care residents 'need less food' than prisoners The Courier Mail 13 Feb 2018

⁵⁵ Community Affairs Legislation Committee 02/06/2010 Health And Ageing Portfolio Aged Care and Standards and Accreditation Agency <http://bit.ly/2otvzET>

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Promises made to be broken: Only 3 years earlier in 2007, a consultant had advised the agency that measurable outcomes like nutritional state were “indicators” and not to be used as a measure of performance. The industry had promised parliament that they would collect this data but parliament had already forgotten this.

The senator had earlier asked *“What are you actually doing to make sure that stories like this do not appear in the newspaper?”* As cynics who have researched the regulatory background our answer would be *“making sure no one knows about it.”*

In spite of all this attention in 2010, not much has changed in the last 7 years. It is still business as usual. Unless we change the regulator, we will have to go through it all over again in another 7 years.

The CEO of a nonprofit, who resigned from the Health Department, struggles to provide good care and manages to provide 4.3 hours of nursing per resident per day, is critical of SB’s benchmarks. He wrote in LinkedIn⁵⁶ *“I have worked for providers that hit the SB benchmark for food and I would not eat there”*. He added that *“the accreditation process for ensuring meals are appropriate has been a joke for years and its about time we stop trying to defend the indefensible”*.

The lack of data: Oversight without data is like being in a dark room without a light. Without measuring nutrition and assessing its progress there is no means of telling whether the processes in place are working or whether the measures the agency requires providers to meet or the assessments done are of any value at all. The limited data available suggests that there is a large investment of people, time and money in these processes and that all of it is being wasted. It would be better spent elsewhere.

A local community solution: Most communities have trained nurses, doctors even dieticians and nutritionists who could help the empowered community visitors that we are pressing for to assess nutritional state. It does not require a university degree to check that residents are weighed and how much they are losing, see what is being done to maintain nutrition and then discuss it with a mentor to see if more can be done. This is what we believe should be happening.

We have a government that talks up innovation without having a system of data collection that can determine whether an innovation is beneficial or harmful. Managers can and do ‘innovate’ in aged care in order to ‘improve performance’ which is measured in cost savings while consequences for residents are ignored.

In our proposal we would be harnessing the skills of the local community to look at the actual failures in these areas and insisting that providers organize staffing and training. They would be reporting to community and government, and when needed calling on the accreditation agency to assist the providers which is their proper role.

Comment on the Quality Agency

The agency’s own data shows that the Quality Agency’s oversight process during accreditation is singularly ineffective. Vast amounts are spent with little regulatory benefit. Unannounced visits resulted in only minor benefit. The utility of the Carnell recommendation to move to only unannounced visits and its adoption by the minister is not supported by the Quality Agency’s data. It is no more than an attempt to placate critics and it reduces the burden for the industry, something they have wanted for years.

⁵⁶ LinkedIn: <http://bit.ly/2F0tlm4>

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The data shows that unless alerted to problems the accreditation process was an exceptionally ineffective regulator. The vast majority of problems were not detected by accreditation audits or assessment contacts. The assessors had to be told what to look for in 76 + 12(from risk profiling) = 88% of instances. The accreditation processes themselves detected only 14% of the problem cases – a vast waste of resources that could be devoted to care.

It takes knowledge, great courage and dedication for residents, families and staff to speak out and it is clear that they do not think that the problems they complain about are being addressed by the agency.

The agency's own data when set against staffing data shows that failures in care are likely to be widespread and that only a fraction of this is detected. This data has been collectable for 20 years. Why has it taken so long and only become available when public anger demanded it?

The accreditation data shows quite clearly that as a regulator of care and quality of life the Quality Agency is not fit for purpose. What is needed is a much better system that detects failures in care and then does something about them. The changes we suggest are intended to do just that. Far more problems would be identified and only review audits would be needed. These could be done by another agency or even the department itself after consultation with the community group. The agency could focus on training and support. The community organisation we propose would work with them to evaluate implementation and success. We do not know if accreditation is useful and if so how useful. We need data to set against what it is costing us.

The problem has been that making it a regulator has introduced incentives that undermine the entire process and encourage gaming. Our proposal seeks to relieve accreditation of its regulatory role and create a context which strongly motivates providers and makes gaming impossible. We can then see how well it works.

1.3.3 Complaints handling

The Carnell/Paterson report shows (Pg 41) that probably roughly 0.35% of about 3,500 formal complaints in a year result in a review audit by the Quality Agency.

The report documents (Pg 174) that in the 2016/17 year only 50 site visits (1.4% of 3500) were made by the complaints system.

This does not suggest that information supplied by staff and families is being vigorously followed up. A constant complaint about the complaints system over the years has been its failure to achieve any outcomes.

The report itself indicated that *“Many respondents had no confidence in the complaints-handling processes”*. (Pg 171)

In addition *“the lack of staff was a major contributor to the number of complaints made around quality of care. It was noted that this situation negatively impacts staff morale”* (Pg 173)

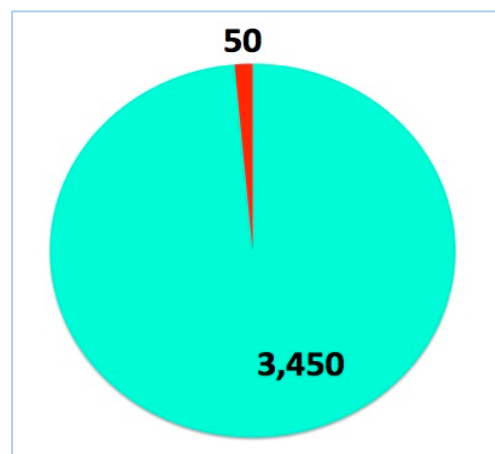


Figure: 1.4% of complaints resulted in site visits by Complaints system

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A lack of clinical expertise: In a submission to the Carnell/Paterson review, a clinical consultant who complained to the complaints system about the care being given described the experience⁵⁷,

“It took ten days for the complaints officer to contact me. They showed little insight into the situation we were alerting them to and were reluctant to take any immediate action. The complaints scheme provided details of the complainant to the provider which resulted in us losing our service contract with the provider. Frustrated with the process, we withdrew our involvement in the case and the matter was not pursued further by the department”.

The scheme divulged - - - all the details of the complaint to the provider. They also arranged for an onsite visit in two weeks! This gave the provider ample time to address the issues presented...”

Once again the problem is a lack of knowledge and experience among those responsible for responding to complaints and the patterns of thinking adopted in both the industry and the regulator.

In a recent case the coroner was very critical of the Complaints system’s investigation of the death of a patient beaten to death by a fellow resident with dementia⁵⁸ where a nurse behaved inappropriately then claimed the injury was self-inflicted and failed to act properly. While the full report is not yet available it is likely that this is another example of a lack of clinical skill and knowledge.

Nurses making complaints have complained about the lack of clinical knowledge in the complaints system for years. For example, an experienced nurse was phoned by a complaints officer who “*began lecturing me about bed sores not being preventable*”⁵⁹ – an attitude that comes from the free market managerialist discourse. Those who think otherwise are not credible and can be disregarded.

The difficulty for families: Problems for families include the complexity, the distance from the facility, fear of personal consequences and that the family member will be victimized discourage families from complaining. They lack power and confidence in a system created by turning care into a commodity and a discourse that promotes it’s excellence and discredits those who challenge that.

Family members of residents at Oakden described the difficulties in making a complaint “- *the confusion experienced about where to lodge a complaint, how to lodge a complaint and whether it's safe to lodge a complaint*” **During the 10 years of abuse and neglect not one family member complained to the complaints system.** A clinical consultant described how a nurse who wanted to complain was deterred from doing so by intimidation and said “*Look, I don't want to make any more troubles, it's bad enough.*”

Many simply give up and do not pursue their complaints. There is no one there to support the residents and families when they really need help and support in building confidence, advice when taking action and backing from those with clinical expertise when they confront those who have none. This is the sort of change that Aged Care Crisis is pressing for.

⁵⁷ Submission Response 617437173 to Carnell/Paterson Review: <http://bit.ly/2DZ6hrT>

⁵⁸ Nursing home resident lay dying in her bed for hours after attack by patient 9 News 26 Feb 2018 <http://bit.ly/2GQD9Rk>

⁵⁹ Aged Care complaints kept secret (Sydney Morning Herald, 27 Sep 2014) <http://bit.ly/2CQQA0Q>

Part 1: There is a real crisis in care

1.3.4 Conclusions

The available indirect data indicates that we would find extensive problems in the care provided to residents in nursing homes if we collected data transparently and did a thorough assessment. We simply do not know quite how extensive serious failures in care have been in the past or are now but there can be no doubt that they are widespread.

What these figures do show is that regulation in Australia has been totally ineffective and that care has generally been inadequate. They tell us why it has been so poor.

We have a system that has deceived us. It is protecting an industry that is not delivering and as a community we should be furious.

If we at Aged Care Crisis had not seen and studied similar situations we would be angry too. It is important to understand that this is not a unique situation. It is not about evil people but about the way normal, well-intentioned people behave when they are trapped in a system they believe in but which is flawed.

We have written more and at length in other submissions. We have shown that attempts to address the problems by tinkering with the system do not address core problems in the patterns of belief on which it is based and the processes that are based on them. Proposals such as more unannounced visits, Quality Indicators and Star ratings (both of which are self-reported so easily gamed) will have marginal if any benefit unless the underlying problems in the system are addressed.

Part 2: Understanding the crisis in care

The remainder of this submission is devoted to an analysis of what has happened and the processes responsible. This analysis is to understand so that we can develop a strategy for addressing the issues and not make the same mistakes.

We argue that the patterns of thinking in industry and government are based on a 'discourse'⁶⁰ that is disconnected from actual data and the real world of aged care. It is based on a belief system developed elsewhere that is inapplicable to the sector. It was never based on evidence or logic and it dealt with its critics by discrediting or ignoring them. Exploring it in depth is not to apportion blame but to understand and so help us decide what to do about it.

It is currently managed by those who are wedded to the belief system and have little if any experience in the provision of aged care themselves. They are unable to recognize and accept the consequences of their decisions. Both politicians and industry believe in what they are doing and it is because of this that neither can be trusted to change the system on their own. Asking the industry to develop a workforce taskforce to deal with the crisis in staffing was a regressive step but illustrates the way discourse operates in defining who is credible and believable and who is not.

Globally we can see how, over the last century and more, both governments and ideological believers of all sorts have resorted to claims based on illusion in order to discredit their critics. Instead of addressing the criticisms those challenged have turned to other believers seeking reassurance. That this has happened again in aged care should not surprise us. It is a very human response.

Unless we as a community can take this in hand ourselves we are not going to find out exactly what is happening or be able to do anything about it. As we explain later the only way to deal with a problem like this is to involve the community in a way that ensures total transparency and open discussion - to work with them in confronting the problems in the discourse and then rebuilding it to make it fit for purpose.

If we are to find a way out of the blind alley where aged care is failing so badly then we need to understand what is actually happening, how we got into this situation as well as the underlying social forces and psychological processes that have led us to follow this path in the face of strong warnings and criticisms. The remainder of this submission analyses these issues and then uses this analysis to suggest a way forward.

First we need to look more closely at the issue of data and at who is in control of the sector and its regulation.

⁶⁰ We use 'discourse' in the sense it is used by Michell Foucault and also by many social scientists. It is the pattern of ideas that influence and control our thinking and so our behaviour. Those who have power and credibility have the ability to control others by controlling what is acceptable and credible within the discourse and what is not credible so should be ignored or even derided. (For more see Appendix 6)

Part 2: Understanding the crisis in care

2.1 Data collection and its sensitivity

2.1.1 Failure to evaluate care in Australia

ACSA: In 2013 ACSA performed an analysis of sustainability in aged care. Under the heading “Balancing quality and financial performance” their report commented that *“The available data on performance and sustainability of the sector appears to be based entirely on an assessment of financial metrics”* and then the understatement that *“There appears to be a significant gap in our knowledge of the relationship between financial performance and of quality and between staffing levels and quality”*⁶¹.

Alzheimer and researchers: Carol Bennet, CEO of Alzheimer’s Australia described this as a gaping hole without *“a single measure of quality”*⁶². Researcher, Richard Baldwin was very critical of the lack of data in aged care, particularly studies comparing for-profit and nonprofit services because government was pursuing policies, which extensive international data revealed resulted in poorer care.⁶³

Carnell/Paterson Review: Strangely the Carnell/Paterson report was surprised to find that the *“absence of reliable, comparable information about care quality in residential aged care is a striking feature of the current system”* and then later *“Historically, there has been a significant lack of publicly available data and policy-relevant evidence on residential aged care”*. They urged that more data be collected but it was far from clear how reliably this would be done.

This should not have been a surprise because Carnell was on the board of the accreditation agency for several years from 2008 not long after it had advised providers to consider failures in care to be indicators and not a measure of performance. She should have known. She strongly denied that her past role created a conflict of interest for her in her role as reviewer⁶⁴. This is difficult to sustain when we consider the central role that the agency has played in supporting industry and hiding what has been happening.

Patronising consumers: It is interesting that, as recently as 12 May 2017 a suggestion by the minister’s representative on the Aged Care Advisory Committee⁶⁵ to release all accreditation data publicly was not welcomed by the industry and even seniors groups on the basis that *“these reports were more technical and, without explanation, may not provide useful information for consumers or their families”*. This is the data on unannounced visits and provider responses that those who advise and assist seniors do need to have access to. Critics see this as a graphic illustration of the patronising approach adopted by industry to the community.

Response to calls for data: The response to many calls for data over the last 20 years has been minimal with only a voluntary and confidential behind closed doors trial of a few self-reported Quality Indicators (QIs). When data is collected, it has focused on consumer views which can be easily manipulated or discounted and do not provide hard data.

⁶¹ The financial viability and sustainability of the aged care sector ACSA report 2013: <http://bit.ly/2tba110>

⁶² Better data needed to compare aged care ABC Radio pm 24 Nov 2015 (Bennett and Baldwin)
<http://www.abc.net.au/pm/content/2015/s4358621.htm>

⁶³ The Future of Aged Care in Australia: A Call for Evidence Based Policy - The Policy Space, 22 Sep 2015
<http://www.thepolicyspace.com.au/2015/22/55-the-future-of-aged-care-in-australia-a-call-for-evidence-based-policy>

⁶⁴ Oakden aged care home inquiry boss Kate Carnell denies conflict of interest ABC News 3 Aug 2017
<http://www.abc.net.au/news/2017-08-03/conflict-of-interest-for-kate-carnell-to-lead-oakden-inquiry/8771410>

⁶⁵ FOI release Aged Care Advisory Committee meeting May 2017 <http://bit.ly/2EYtZWj>

Part 2: Understanding the crisis in care

Risks to collecting data: In the current system any data collected will be self-reported and the industry will have to agree to this. We can see why they will be reluctant. If they are persuaded to agree there will be strong pressure to massage figures that show poor performance. The government's policy is also threatened by poor figures so there will be little incentive for them to pursue providers about this.

2.1.2 Sensitivity of data and censorship

2.1.2.1 Incidence of pressure injuries in aged care

In the previous section we wrote about a speech to the industry at the Better Practice conference in which the minister gave a figure for the incidence of pressure injuries saying *"in Australia we sit around a figure of 32%"* of residents comparing it to 6% in the USA⁶⁶.

But when the transcript of the speech was published, it said that the *"latest figures I have seen suggest that 10.3% is the estimated prevalence"*⁶⁷. When this was queried, the transcript was revised again, removing all the incidence figures saying that he was *"concerned about the number of people who meet with me in respect of pressure sores and issues of incontinence"*.

Instead, figures of 3.4% and 5.4% quoted in 2006⁶⁸ were claimed. But these referred to studies done in the 1990's before the marketisation of aged care in 1997. The most recent figures available quoted by the department in 2016 were 26% and 42% (average 34%) taken from a 2009 paper⁶⁹ referencing work done in 2003 and 2005. We suspect this was the minister's source of the 32%.



The figures themselves suggests an alarming 8 times increase in the incidence of pressure injuries from 4.4% to 34% within 8 years after the 1997/8 'reforms' which is what you might expect from the deterioration in staffing and oversight, but more data would be required to determine that. That is what should and would normally have been done by a knowledgeable sector but we do not know of any studies done since then. We think it is now becoming clear why.

It is likely that someone at the conference realised the significance and explained to someone in government just how bad the figure of 32% was and what that revealed about care. The government's PR machine did the rest and everyone ran for cover.

That both the department and the minister published this data without any indication that they understood its significance reveals an even greater problem and that is the lack of knowledge within the health department, the government and among its many advisers. We will return to that later.

The point is that this sort of information is not collected and monitored and those responsible for managing the system are unaware of it and don't use it when making decisions.

⁶⁶ Pressure injuries - Aged Care Crisis <https://www.agedcarecrisis.com/care-issues/pressure-injuries>

⁶⁷ Speech - Australian Aged Care Quality Agency - Better Practice Conference, 12 Oct 2017: <http://bit.ly/2Dsgg5Y>
Revised transcript: <http://bit.ly/2IU6iDj>

⁶⁸ 2006 RACGP Silver Book: <https://www.racgp.org.au/your-practice/guidelines/silverbook/common-clinical-conditions/pressure-ulcers/#216>

⁶⁹ Reducing pressure ulcer prevalence in residential aged care - Wound Practice and Research Vol17 Nu1 Fen 2009
https://www.agedcarecrisis.com/images/pdf/1701_02.pdf

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2.1.2.2 Censorship and community anxiety

In every dysfunctional system there is an instinctive attempt to protect the discourse by some form of censorship. But when there is little or no data then any available figures, even if they are not confirmed become hugely significant and the press seize on them. Even when the press is censored it spreads like wildfire through the community.

The gut response in the system is to increase censorship further and it is not surprising that government is now targeting community advocacy groups by threatening their funding⁷⁰.

As a community we have to accept this pressure injury data as probable while recognising that isolated studies like this can reflect variation. They need confirmation but in a dysfunctional system that does not happen and no action is taken to address the problems. They are simply buried.

In a functioning system, the discourse reflects the real life situation rather than an idealised image and is appropriate for dealing with it. Data is not threatening. Instead it becomes the subject of considered and constructive debate, is confirmed by further study and then acted on.

Politicians, the bureaucracy and the market share a common market based discourse and think in the same way. Instead of managing aged care, politicians and the bureaucracy have become all about managing image and perception. Data introduces the real world into the world of images and threatens to destroy it. We can see why it is avoided. When data cannot be ignored it is massaged and sanctified.

As the staffing and accreditation figures show this is where this system has gone so wrong and why it has betrayed Australia. The way the problem of pressure injuries was managed in the minister's office is another example.

2.1.3 A broken promise

An audit of accreditation by the Australian National Audit Office (ANAO) in May 2003 focused on the failure of the agency to collect data to evaluate its performance⁷¹. The agency promised to do so. At a hearing of the Joint Committee of Public Accounts and Audit soon after in 2003, the industry undertook to collect data⁷². At the time, those of us who were critics were reassured that after so many early failures had been airbrushed, the industry was finally acting.

- The industry (Mr Mundy) indicated a willingness to use a *“resident-mix-adjusted basis - - (to) - look at the incidence of quality failures. For example, -- the incidence of ulcers from pressure sores and so on”*.
- Another industry representative (Mr Young) indicated that they were already doing *“the sorts of things that Mr Mundy just mentioned – like the occurrence of infection rates, bed sore rates, medication errors and those sorts of things—are being recorded, in fact they form an integral part of those facilities' quality improvement systems for accreditation purposes”*.

⁷⁰ Government accused of trying to 'silence' charity sector with new commissioner ABC News 7 Dec 2017 <http://ab.co/2ERvylf>
Charities express alarm as long-time 'foe' Gary Johns is appointed as their regulator Sydney Morning Herald 7 December 2017 <http://bit.ly/2EWyKMm>

The Gary Jones appointment - The Saturday Paper, Edition 187, Dec 16-22, 2017 <http://bit.ly/2EsUqyX>

Plea for Premier to reverse disability funding cuts as pressure mounts (NSW) Sydney Morning Herald, 17 Nov 2017 <http://bit.ly/2mcBOeY>

⁷¹ Managing Residential Aged Care Accreditation Auditor General by Aus Nat Audit Office (ANAO) 2003 <http://www.corpmedinfo.com/agereport2003.html>

⁷² Joint Committee of Public Accounts and Audit - Review of Auditor-General's reports, fourth quarter 2002-03 - 18 August 2003 <http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=ld%3A%22committees%2Fcommjnt%2F6844%2F0003%22>

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- The department (Mr Mersiades) indicated that those who were not tracking their performance were exiting the sector. He said *“Those who are left are signing up to a process of continuous improvement using the sorts of statistics that Mr Young was referring to in terms of tracking how they are performing against things like bedsores, falls and medication processes”* and *“we do need to be able to make a better fist of being able to demonstrate that the accreditation system is having a positive effect”*.

Now that we know what was happening to staffing we can imagine what was revealed when they collected data. We can understand why they could become alarmed at the consequences for industry and government and soon reneged on this promise. While this threat might not have been articulated and recognised openly, a variety of justifications would have been developed and then asserted strongly through the discourse to justify rejecting it.

2.1.3.1 Making it legitimate

Now that we appreciate the extent to which the agency had been captured by industry and has been acting for it we can also understand why it accepted these justifications and then came to the rescue. They found a way to make this back-down look legitimate for both of them.

In 2007, the (then) Accreditation Agency employed Campbell Research & Consulting to review accreditation⁷³. This is the same year that John Braithwaite published his book describing the extent to which regulation had been captured by industry. The consultant’s report advised the agency to inform the sector that failures in care were not to be used as a measure of performance.

Campbell Research’s report acknowledged that prior to 1997 data had been collected but, despite the 2003 undertakings, not since.

“ There was no baseline data to enable direct comparison of quality of care and quality of life of residents in aged care homes today, compared with that which existed prior to the introduction of the new regulatory framework in 1997 ...”

The manipulation of language played a major role in this. Data about failures in care became ‘indicators’ and not a measure of performance and their report advised that the sector be informed of this.

The purpose of the indicators should be **confirmed to the sector** - the basis for the indicator development **was the clear understanding that they were being developed not to measure performance, but as tools to assist aged care homes to monitor and improve the quality of their care and services;**

Source: Campbell Research report, 2007 (page 99)

The public were never told that the industry had reneged on its promise and that a government appointed regulator was supporting them in doing this. The jargon in the long report would have repelled anyone except the most dedicated.

⁷³ Review - Evaluation of the impact of accreditation 2007 Corporate Medicine web site
<http://corpmedinfo.com/agereport2007c.html>

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2.2 Who makes decisions and where do they come from?

In 1995 Stuart Rees and Gordon Rodley⁷⁴ wrote about the new managers that were being trained to manage and control every sector of society. Management was seen as a new discipline that was universally applicable. The strategies would work everywhere. They warned that these highly trained managers, with their focus on changing culture within organisations, were being put in charge of sectors and activities where they had no or very little prior experience or knowledge. They were worried about the consequences.

Twenty years later the consequences are glaringly apparent in aged care. Owners and senior management seem to be largely drawn from the business and managerial sectors. Entrepreneurial skills are admired. Few have had real experience in providing care and those that do have already moved away and into management.

Later we give an example which shows how little understanding about staffing issues the industry group, which collects and assesses staffing data and makes the recommendations for staffing that nursing homes follow, actually has.

These are the people that are appointed by government to senior policy committees, as advisers and as consultants. In his book, regulation authority and investigator John Braithwaite and his coauthors described this as a 'revolving door' so that the whole regulatory system was 'captured' by the industry and worked for it. The CEO of the industry lobby group LASA was, for example, put in charge of the new government controlled Quality Agency in 2014.

Decisions are being made not only without data about care, but by people who have not had real experience. Politicians are advised by them and they are accepted as authorities or '*subject matter experts*'. They are selected from industry and appointed by government and not by those in the sector who actually provide the care. The bureaucracy is also thin on clinical expertise and insight.

Glaringly absent are gerontologists and palliative care specialists, the experts in end of life care. Nursing representation is reduced and carefully selected. This is a top/down system of management driven by the neoliberal discourse. Its patterns of thought are spread down through the system by confident and assertively trained managers - trained to achieve their goals. The system is organised and its flexibility is constrained by rigid processes so that there is little room for the exercise of our skills or the expression of our humanity. In a system built on ideological certainties anyone with alternative perspectives becomes ridiculous and can be ignored.

A CEO of a not-for-profit that provides 4.3 hours per resident per day of care worked for the health department for many years before resigning in disgust. He claims aged care "*has become a smoke and mirrors game with the regulatory bodies either unable or unwilling to rid the sector of the poor performers*"⁷⁵.

Without experience, data, and a willingness to listen to contrary messages coming up from the coalface, managers and politicians are effectively shielded from the consequences of their actions. They are free to create and be innovative without regard to anything other than the financial consequences. We should not be surprised at what has happened.

⁷⁴ The Human Costs of Managerialism: Advocating the recovery of humanity. S. Rees and G Rodley

⁷⁵ LinkedIn: <http://bit.ly/2BVYHww>

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The patterns of thought and language used in the sector have both changed. Topics and speakers at aged care conferences are dominated by business, management and legal considerations rather than problems in care, their incidence and methods for addressing them.

Example: Financial advisers StewartBrown (SB) are consultants and advisers to the industry and even government. They are highly regarded and have a stellar reputation in the business world. They collect data for the industry and this is used in marketing and in lobbying government. They collect staffing data and make staffing recommendations by setting benchmarks, which we have already referred to⁷⁶. These are well below international standards.

They have collected 'direct care' staffing data for many years and accurately charted and labelled those charts as "direct care". In their June 2016 report, the year of the senate workforce inquiry, they generated another staffing chart that included staffing for hotel and other services and was not 'direct care'. This chart was also labeled 'direct care'.

It gave the impression that residents were receiving over 25% more direct nursing care (nearly an hour of care per resident each day than they were actually getting).

Only 3 days before industry leaders were interviewed by a Senate Inquiry into Australia's Aged Care Workforce, a previous CEO of LASA, now working with SB, disseminated this wrongly labelled graph by social media to counter claims of inadequate 'direct care' - including to members of the senate. At least one other industry group also used these figures to counter the claim.

Aged Care Crisis discovered what was happening and alerted the senate committee. They must have planned to present this to the senate during the interviews but we do not know if they still did so.

A detailed description of what happened is **included as Appendix 5**. It is taken from our 2nd supplementary submission to the Aged Care Workforce Inquiry. At the time we thought that this deception revealed a cynical willingness to sacrifice the wellbeing of residents in order to support industry.

In retrospect, we think this was a reflection of the level of knowledge and experience of both SB and the two industry bodies involved. While SB, who have correctly charted direct care in the past, must have known this was not direct care we suspect that they simply had no idea of the consequences for residents and staff had the senate accepted these figures and government taken action based on them. To them, it was simply another image and branding exercise for their customers.

We simply cannot believe that the industry would knowingly stoop to something so damaging to residents. **The worry is that this is the industry body that sets the staffing benchmarks that industry uses and that this is the level of clinical knowledge and engagement on which they are based.**

⁷⁶ The true cost of providing quality aged care, LinkedIn: <http://bit.ly/2BVYHww>

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2.2.1 Accreditation and Complaints - clinical expertise

In the previous section we wrote about the lack of clinical skills among Quality Agency assessors and staff handling complaints. The board of the Quality Agency over the years has been thin on actively involved clinicians. The current executive team of the new Quality Agency is even thinner⁷⁷.

That clinical considerations are not understood or a prime concern for senior management explains why appointed assessors of performance or of complaints are not suitably skilled or focused to assess the clinical aspects of care properly. Managers from the industry who think the same way get preference. As we indicated clinical consultants and nurses have been critical of the performance of the quality agency and of the complaints system.

2.2.2 Captured regulation elsewhere

There is nothing unique in the way regulators are captured by the market, adopt their discourse and come to think like them. There are glaring examples from the USA.

The point we want to make in referring to what happened in the USA is that the gut response to the sort of criticisms we are making is that they are unbelievable and we tend to simply discard them and the data as ridiculous. But what we are describing is mild when we look at what has happened with other discourses that people believed in eg. Fascism in Germany in the 1930s, Communism in Russia and China, Apartheid in South Africa, the Samurai tradition and Kamakazi pilots in Japan and even the beliefs of radical Islam today.

What we describe in aged care in Australia is very similar to what happened quite recently when believers in free markets persuaded politicians in the USA and UK to accept free market neoliberal discourse and apply it indiscriminately to health and aged care.

We would be naïve and arrogant if we thought we were somehow superhuman and different. There are so many similarities that it cannot be discounted. Clinical considerations challenged the discourse and the system it set up in the USA. They suffered a similar fate to that we have described in aged care. There is much to suggest that it has happened in the UK too but we have not studied it in as much depth.

2.2.2.1 US Health care

Psychiatry: In the psychiatric scandal in the USA at the end of the 1980s when the neoliberal discourse was in its ascendancy untrained assessors were screened⁷⁸ to be sure that they did not have any clinical reservations that might impede their important business role in persuading those coming for free psychiatric assessments into hospital - whether they needed to be there or not. National Medical Enterprises (NME), a company that also had an aged care division led the way.

Clinicians were rewarded for being team players and handing care over to those without clinical experience. They signed off on profitable but unneeded treatment programs designed by the provider and were pushed aside if they refused. Administrators were fired for being too clinical. A senior manager was instructed *"I concur with your assessment of the current associate administrator; that he is too clinical and not a decision maker. Please proceed with his 'resignation'"*. Administrators were told to stop doctors from discharging patients when they no longer needed profitable care.

⁷⁷ Executive team Quality Agency <https://www.aacqa.gov.au/about-us/our-people>

⁷⁸ The Impact Of Financial Pressures On Clinical Care Lessons From Corporate Medicine - Corporate Medicine web site <http://corpmedinfo.com/corpmed.html>

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Government regulators, two accreditation agencies and insurance assessors all thought this way and accepted profitability as a measure of care. It was a policeman that stepped in and took action so releasing the flood of community anger that ended with inquiries and criminal convictions. NME changed its name but not its patterns of thought.

Heart surgery: In another health care scandal in 2002⁷⁹ nearly 800 patients, recruited by advertising and community screening programs, were subjected to major heart operations they did not need in probably the most profitable hospital in the USA. Critics were ignored. Regulators were captured and, as later happened with our Quality Agency, a senior industry figure was put in charge. They rubber-stamped it. It was a priest who saw what was happening and blew the whistle to the FBI.

2.2.2.2 US Aged Care

There are many examples, the most glaring in 1998⁸⁰. A nursing home company called Vencor in the USA saw nothing wrong in evicting residents already in its nursing homes. Their Medicaid insurance paid poorly and they could replace them with more profitable wealthy residents who paid their own way or were covered by Medicare, which paid much better than Medicaid. Other companies did the same thing.

The state regulators saw no problem with this and the regulator considered *“deciding not to keep residents on Medicaid was a business decision, which the facility had every right to make.”* It was whistle blowers, a public outcry, court action and a large fine that finally stopped this. Its staffing record and its care record were poor and like others with a poor record it changed its name but not its practices.

2.3 Blame it on belief - not people or the regulator

It is easy to be critical but we should understand that neoliberal discourse believed that regulation inhibited the market and advised it be removed. When the agency was established in 1997 Judy Moylan the minister made it clear that the accreditation agency was there to accredit and not to act as a policeman saying *“in place of a rigid policing style system, we will have a system that will work to assist residential aged care facilities to improve service delivery and, indeed, the social and physical environment by the process of continuous education”*.

Accreditation was never intended to be a formal regulator but by 1998 when there was a public outcry demanding regulation this was tacked onto its functions so that by 2003 it was the regulator that we all depended on. It became the rock on which this much criticised aged care market's legitimacy depended. Every concern and almost every criticism has been rejected on the basis that accreditation was so effective. For example, concern that ownership type might impact on care was discounted both on the basis that owners did not interfere in the running of the business and that the requirement to meet accreditation standards would prevent problems.

⁷⁹ Redding hospital scandal Corporate Medicine web site a) 2003. http://corpmedinfo.com/tenet_redding.html
b) 2007 update http://corpmedinfo.com/tenet_reddingupdate.html
c) 2007 administrators story http://corpmedinfo.com/tenet_admin.html
d) 2007 fallout for sector http://corpmedinfo.com/tenet_redding_fallout.html

⁸⁰ Extracts from multiple press reports at Vencor's Care, Morality And Ethics - Corporate Medicine web site http://corpmedinfo.com/vencor_care.html

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2.3.1 Conflicted

The agency was never happy about being a regulator and it did not give regulation any priority over its role of supporting industry through accreditation. It has on occasion asserted that it was only an accreditor and that the department was the actual regulator. This was in spite of the fact that the department depended on its findings and everyone else saw it as the regulator. Braithwaite considered it to be a regulator and assessed it as a regulator in his 2007 book - as did the Productivity Commission in 2010/11.

The agency asked the Productivity Commission to relieve it of this burden as the two roles are incompatible saying “*Is the accreditation body a regulator? – No*”⁸¹. It was unsuccessful in this.

The problem was that accreditation was not created as a regulator. It was based on a discourse that rejected regulation. It was developed to work with and support those it accredited and not to assess and regulate them. It was deeply conflicted by two incompatible roles but governments refused to recognise this.



Example: Carla Baron giving evidence to the senate hearing into Oakden in Adelaide in November 2017 described, as an example of the problem, the very different interaction and response she got from staff in a facility where she had worked as a supportive consultant. When she returned as an auditor for the agency it became “*Oh, Carla!—oh, you're here from the agency.*” Their whole demeanour changed. It was not open, it was fearful; it has become a punitive exercise”.

Source: *Senate Inquiry - Public Hearing, 21 Nov 2017, Adelaide* <http://bit.ly/2CQ5Ddj>

2.3.2 Resorting to tokenism

The agency’s ‘exemplary role’ as regulator was a tokenistic attribute given to it in 1998 to meet criticism. When confronted by their critics, politicians and industry rapidly turned it into the rock on which the legitimacy of the entire aged care system as world class rested.

The agency was required to show that its accreditation process and so regulatory effort was working. It was expected to demonstrate the same standard of ‘continuous improvement’ that it required from nursing homes. This was impossible to do and as we have argued elsewhere the only way out of this impossible situation is to tokenise⁸². The words become a token, substituting for something that is not there. They are used to claim that it is. The staffing data shows that care is deteriorating and not improving.

Tokenism is adopted when people are trapped in dysfunctional systems and have to meet expectations and defend their actions. There are other examples in health and aged care.

The agency’s supposed ‘rigour’ was the token used to rebuff the many criticisms when failures in care were exposed. As shown by the Austrade quote in Appendix 1 it was used to support our systems excellence when marketing our companies to Asia claiming a “*robust framework for accreditation, quality and regulation*”.

⁸¹ Submission By Aged Care Standards And Accreditation Agency in response to draft report Productivity Commission Mar 2011 <https://www.pc.gov.au/inquiries/completed/aged-care/submissions/subdr763.pdf>

⁸² see section ‘Tokens and tokenism’ on page **Theory and Research in aged care** on Inside Aged Care: <https://www.insideagedcare.com/aged-care-analysis/theory-and-research#tokens-and-tokenism>

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The philosophy behind the ‘discourse’ of accreditation is built around insights into the normal continuous way we reflect on and learn from our life experiences. They have been taken out of their normal context in the everyday world to create the concept and goal of ‘continuous improvement’ in a different context. The staffing data shows that the current levels of staffing make real improvement impossible.

Developing a process that becomes a token obviates the need to collect data about what actually happens to residents and so exposing their and government’s failures.

2.3.3 Social control reduced

We should also consider the difficulty in regulating this complex and nuanced sector from a central agency that visits at the most once a year – visits that are seldom unexpected so do not occur in the context of everyday care. Complex human situations like this are best modulated and controlled by the normal day to day social processes of interaction - the positive and negative signals that we send to one another in everyday life, from admiration and praise to open condemnation.

The process of marketization and commodification of care as a product to be bartered in the marketplace has transferred it from its social context into a market silo where this sort of social control is largely excluded.

We argue that social control and formal regulation are interdependent. To work effectively they require one another.

In 1999 one of us (MW) made this point when corresponding with the department about the removal of probity as a prerequisite for providing aged care⁸³. Abolishing probity requirements sent a clear message to providers that aged care had become a free for all and should not be treated any differently to any other product in the marketplace.

He wrote:

“While regulation in the absence of effective complementary ‘social control’ has failed, it is essential for effective social control that the values and intentions of society be given explicit form in regulatory structures”.

⁸³ Letter to Andrew Stuart, Certification and Approved Services. Dept. Health 27April 1999
http://www.corpmedinfo.com/agedcorresp_1999.html

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2.4 Financial performance has become a token for good care

Many submissions to inquiries and reviews as well as the reports they make have commented on the lack of data about care to set against the financial data. No one could see whether funds were being allocated and used effectively. There has been no financial accountability.

Because there is no data about performance, advice and decisions have been based on financial metrics and not on the standards of the services provided. Even the aged care roadmap has specified the need for data but with little impact.

Profitability has consequently become the primary measure of performance and by default come to mean good care as well. It has become a token for care. This is readily apparent when financial reports from consultants are examined. With relatively controlled income increased profitability can only come from cost reduction and the major cost is staffing.

‘Good financial performance’ has become a token for good care, when in fact the care is more likely to be poor due to the cost cutting that is required for good financial performance.

The non-profit CEO who writes a critical blog like us considers that as a financial adviser SB is simply doing its job but he is critical of its reports⁸⁴ *“which by design imply those who spend more money are inferior performers. It also undervalues the true cost of quality care”*. They *“are solely concerned with financial benchmarks and not quality”*.

We also agree that:

The fault lies with a sector who put these reports and their ridiculous averages on a pedestal so then everyone tries to emulate them in their homes without thought of diminishing quality because "we have to hit the SB mark" or we are "inefficient" or not an "industry leader".

This has been supported by a government who have encouraged private equity firms and for profit providers whose main (and very public) aim is to turn a profit.

In a Feb 2018 blog *“The True Cost of Providing Quality Aged Care”*⁸⁵ he indicates that:

“The problem I have is that the averages in the reports are wildly misleading, they compare apples with oranges and do not correlate to the provision of quality ... and it is this quality that is expected by taxpayers, the government and consumers of aged care services and the lack of quality is the cause for many of the sectors very public woes”.

These reports “present figures that can only be achieved by cutting corners and then through their publication, promote these financial achievements as the pinnacle of aged care operational performance”.

He goes on to compare his own costs with various benchmarks and the difficulty in providing the staffing levels and the sort of care he would like to with available funding.

⁸⁴ LinkedIn: <http://bit.ly/2F0tlm4>

⁸⁵ The true cost of providing quality aged care, LinkedIn: <http://bit.ly/2BVYHww>

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Later he says:

“... I can give you a service that meets the benchmarks but you will not be happy, you will scream at me, your home will smell like a public toilet and you will need new carpets in a couple of years. I can also give you a service like some 5-star groups are demanding but it will cost you more. But you can't have 5 star outcomes and pay the StewartBrown benchmark ...”

Part of the problem of course, is that all the big growth focused groups build impressive buildings and market what looks like 5 star outcomes on their web sites then deliver SB benchmarks or even less. People feel cheated and they have been.

We made the points about the different views profit on pages 27 to 30 of our 28 Nov 2016 submission to the Workforce Inquiry⁸⁶ by relabelling some of their financial charts in the way a community organisation would have evaluated them. The facilities are grouped in bands representing the funding they receive because of the residents acuity - with Band 1 getting the most money.

Figure 7 - Gap in care result between top quartile average and the average of other groups in survey

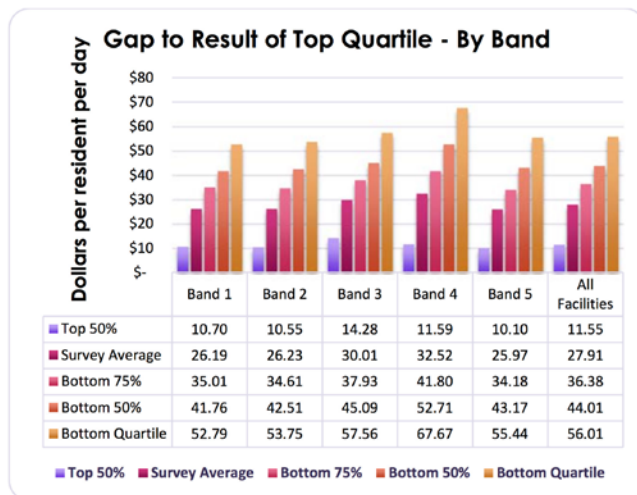
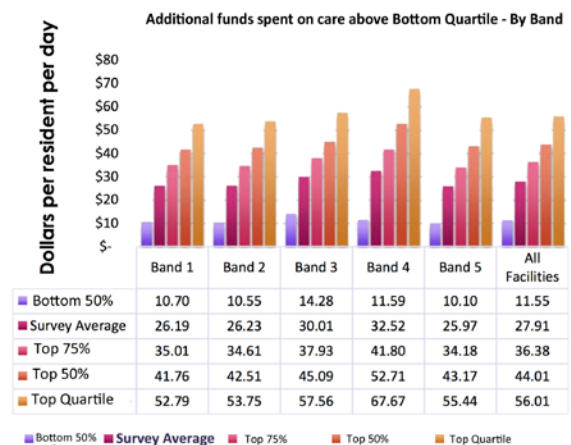


Figure 7 Additions funding provided to care between bottom quartile average and the average of other groups in survey



This SB chart represents the money that bottom quartiles are not making because their managers are not paying enough attention to cost saving. They are losing up to \$56 per person per day in potential profit. They need to improve their performance.

Were the same material to be collected and reported by a community-focused organisation they would label it differently praising the extra \$56 spent on care in the top quartile as in the chart above: Those not spending enough on care need to improve.

The issue here is that the patterns of thought (discourse) in the sector encourage and support the provision of substandard care and a past Department of Health employee considers that the department embraces the same discourse and is supporting this.

⁸⁶ Supplementary submission to Senate Workforce Inquiry 28 Nov 2016 https://www.agedcarecrisis.com/images/pdf/sub302ss2_ACC.pdf

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The impact on staffing:

Good financial performance comes at the cost of care, particularly staffing. In the early years the unions tried vainly to counter this and made many complaints about inadequate staffing and other matters. It was rare for the Complaints system or the Agency to respond and tell them what they had found or done, unless they actively pressed the issue.

They complained about falling staff numbers and particularly, reductions of expensive registered nurses (RN) after staffing ratios were removed, even to a quarter of the number of RNs on some sites. In a hearing of the Community Affairs References Committee - (27/04/2005)⁸⁷ a union representative indicated she wrote *“numerous letters to the agency in relation to concerns we had over staffing levels that would obviously lead, and were leading, to poor care”*.

They eventually *“got a letter back stating that the issue related to staffing levels was an industrial issue and not one relating to care. When I pursued that even further I was told that the Commonwealth reserved their right to set staffing levels. But they never have”*.

Staff and the union had also complained about the gaming of accreditation. The extent of the ‘capture’ of the agency by the marketplace and the resultant negative attitude of the agency to the nursing unions is reflected in the response when this was raised in person with the head of the agency. *“I was told that they had investigated all of those complaints and they were merely malicious and litigious”*.

Would they so readily have dismissed the complaints if they had come from a provider organisation? This was the same sort of response that doctors in a US hospital got when they tried to remonstrate with management about two doctors who were performing hundreds of unnecessary major heart operations.

These responses are a graphic illustration of the way the neoliberal free market discourse thinks and behaves and of the way the discourse decides who is credible and who not and 'labels' them accordingly. At that time the term 'looney left' was often applied to critics.

2.4.1 The inverse relationship between profit and care

International data indicates that in this sector, strong pressures for financial performance is associated with poor staffing and failures in care. Increased profitability reflects poor care and not good care. The stronger the focus on profits the less staff are employed and the more failures in care occur. The response in Australia is to ignore evidence and simply deny that owners who are focused on profits have any impact on care. Ownership data directly confronts and challenges industry and government policy – a powerful disincentive to the collection of data in Australia.

2.4.2 Available data about profits and care

Large volumes of data have been collected in the USA. This shows the differences in staffing and in failures in care among different types of owners. These owners have different profit priorities and unsurprisingly the studies show that increasing pressure to be profitable has a direct relationship with staffing and failures in care.

This sort of data is not collected in Australia but the data that is available indicates that a similar situation probably exists. The available US and Australian data were reviewed in our submission to the Senate Workforce Inquiry in 2016. The relevant sections are included below in **Appendix 2**.

⁸⁷ Community Affairs References Committee, - 27/04/2005 - Aged Care: <http://bit.ly/2thcCus>

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Submissions to the review after it was reconvened in the 45th parliament were not considered in preparing their report. Perhaps the data was too challenging. It needs to be examined critically in any inquiry looking at the quality of care.

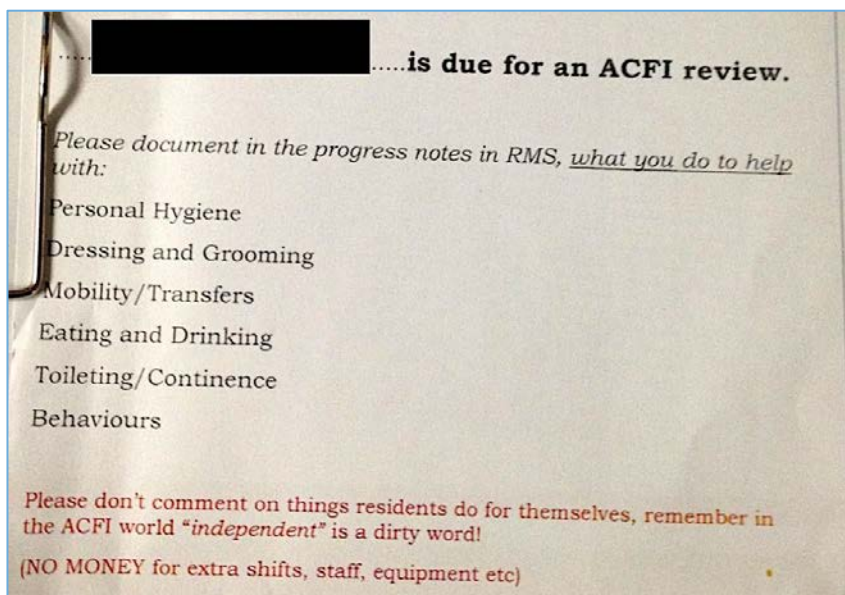
Confirmation that profit is trumping care in Australia comes from the coalface, where the consequences are seen. Many of the comments in *Appendix 1* reflect this.

Here is a typical example from a submission to the Carnell/Paterson Review.



Example 2: A personal care worker recorded the providers focus on profitability by copying the instructions that staff were given prior to an assessment of billing by the ACFI⁸⁸. They were reminded to document in the records “*what you do to help with- - - Personal Hygiene, Dressing and Grooming - - - (list) - - -*” Then prominently in **red**:

“Please don’t comment on things residents do for themselves, remember in the ACFI world “independent” is a dirty word! (NO MONEY for extra shifts, staff, equipment etc)”.



The personal care worker went on to describe the “*workload issues and safety issues*” that had been raised in the staff room “*over a month ago*”, explaining that “*workloads, safety and communication tools discussed that day remain an issue*”. This was followed by a description of what the everyday work in that facility entailed, a workload that saw some in tears. “*The resident care needs are high and yet the staffing level is unable to meet these needs. Staff aren’t getting all the work done nor are we fully completing tasks*”.

The tasks and the poor conditions described show how little interest is being taken by management in the state of the facility and the care given when compared with their interest in getting more money.

2.4.3 Maximising the funding system and then squeezing residents

Costs were not the only source of profits for some providers. Providers went looking for vulnerability in the payment system to see where they could maximise income and were successful in this causing cost blowouts for government.

⁸⁸ Submission ID 484782787 by Personal Carer to Carnell/Paterson 2017 Review: <http://bit.ly/2GA1QSU>

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There were multiple problems in 2012, 2013, 2014, 2015 and the government was forced to cut off funding initiatives designed to bring relief to problem groups needing extra care only to see it maximized and exploited.⁸⁹

The extra funding supplied during the *Living Longer Living Better* reforms supplemented by this maximizing, led to an acquisition frenzy in 2014 and 2015 with an increase in the prices of aged care businesses in the market.

Competition was to grow and increase market share. This extra income was used to raise loans to fuel growth. When the funding was cut the companies still had to pay the interest on these loans. This could only come from cost cutting. Several found ways of charging residents more than they had originally agreed to and the private equity groups who were most exposed led the way⁹⁰. The market value of nursing homes securing the loans would have decreased creating further instability and stresses.

The issue here is that most providers now enter aged care in order to make a profit and investors invest their money in these companies in the clear expectation that they will make large sums of money (private equity and market listed companies). In the marketplace we have created, this is legitimate and we cannot blame them for this. But we do not fund the system in a way that would enable them to do so. As individuals we cannot afford to do so and neither can government.

The CEO who writes a LinkedIn blog⁹¹ says that “*Aged care is full of smoke and mirrors and a lot of ‘grey areas’*”. He puts the problem this way:

The conundrum of staffing ratios is ever present and wont go away until the government has the intestinal fortitude to comprehensively cost the delivery of care and then match the funding to these real costs (or explain to the general public that what they want is not affordable).

When you invite the fox into the hen house it is going to be ugly - for profits are there to make a profit, they don't hide the fact so it should not come as a surprise to anyone ... nor should anyone criticise them for it either.

The problem is that government and industry have since 1997 been promising us something that cannot be delivered by the system they have created – one where inevitably care is rationed and compromised in order to feed the profits that providers must make to maintain any sort of service.

A highly competitive market is the most inefficient, deceptive and harmful way of rationing humanitarian services and the public should be furious at the deception. A very different sort of system is required and we need to move towards it as soon as we can.

2.5 We were warned many times

The changes that have occurred in health and aged care are the application of free market thinking to these sectors. This an error in logic, a category error and a failure to understand the necessary conditions for a market to work. It ignored two and a half thousand years of knowledge and experience in the provision of health and then later human services. Large numbers of people have warned about what would happen and have been critical at what has happening over the last 30 years.

⁸⁹ Consequences of marketplace thinking – Examples in Australia Inside Aged Care <http://bit.ly/2sITG6z>

⁹⁰ Aged care providers hike fees by thousands Australian Financial Review 9 June 2016

⁹¹ Is aged care in Australia as bad as the media would have us believe? LinkedIn: <http://bit.ly/2HZCfmK>

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Health including aged care: The errors were pointed out and there were many warnings. Eminent doctors and social scientists in the USA looked closely and argued strongly but these arguments were no match for the huge profits generated by companies in the sector - profits that delighted the market. Health and aged care became the most expensive in the world yet one of the poorer performers in the provision of health care to its citizens in the developed world.

In Australia leading doctors were very critical and warned of the consequences. Rees and Rodley coauthored a book warning about the changes and Ron Williams, who had just completed his doctorate in the USA wrote another book warning of the consequences for patients. Doctors and advocates rallied to keep the large multinational megacorps out of Australia. These groups all had tarnished histories and were unable to meet our state probity requirements. This frustrated government's efforts. Large amounts of material describing what was happening in the USA were supplied to government but as in the USA it was ignored and ideology triumphed.

Doctors in Australia rallied and refused to sign government-supported contracts with corporate interests so retaining market power. They have used it to contain and limit the damage to our health system. They did not have power to influence aged care.

Aged care in Australia: The Giles report had exposed shocking failures in care in 1985 and the 1993 Gregory report warned of the difficulty in maintaining staffing levels in the free market option that was introduced in 1997. There was intense debate in parliament where the problems were identified and we were warned about what was likely to happen and what we now know has happened. The government's popularity plummeted but, supported by the for-profit industry they rammed their program through parliament.

They repealed the federal probity requirements so removing the vetting process that advocates in health care had used to keep undesirable and criminal groups out. They threw out a welcoming mat instead. All accountability for how aged care was provided was removed and a regulatory system introduced that would protect government and industry from publicity when the system failed and poor care was provided. Nonprofits initially objected but all resistance has since evaporated. Their missions have become tokens for what they believe they are maintaining as they are forced to behave in ways that are incompatible.

These developments are explored in **greater depth in Appendix 3**

2.6 Much more than just the pressure for profit

"market models of finance have not worked well in the field of aged care"

"Economics has long ignored the phenomenon of care"

" - significant risk of exploitative, low-quality care that fails to meet their needs at best, and is abusive at worst".

" - - care needs to be reframed within a discourse of citizenship, rather than markets, for it to become a means of self-determination and social participation for both carers and cared-for".

"the richness of academic discussion on the topic of aged care stands in contrast to its limited use in policy".

Pressures for profit is only one of the problems that have developed in the provision of aged care as it has been structured within a neoliberal free market discourse. The comments come from papers written by Professor Fine and his team⁹². He has had real experience of care, has looked at the world literature about care and has written extensively about the nature of care, what it

⁹² Quotes taken from articles by Professor Fine. A brief outline of some of these papers and links to the original papers are provided at <http://bit.ly/2ASdXtZ>

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involves, dependency and interdependency, and more. He has looked at the sort of relationships between carers and those cared for that are needed for good care. His analyses repeatedly bump up against the problems for real care, for staff and those needing care in a system driven by a discourse that ignores pretty well everything we know about care.

Earlier we referred to the impact that these patterns of thinking have had on civil society, the way it has been 'hollowed out'. It no longer has the knowledge, the capacity, the social selves and sense of civic responsibility to manage its own affairs and see that its members are well cared for when they are in need. It is excluded from those activities and responsibilities that hold and bind it into a human endeavor.

2.7 Refusing to acknowledge when we get it wrong

If we continue to airbrush our past and ignore human psychology in favour of glib sloganeering, how will we ever devise policies that succeed?

--- asking serious questions about what the past can tell us about the likely effectiveness of proposed policies is rare. Even more uncommon is any deep exploration of what we know about human behaviour and how social structures are likely to influence it ⁹³.

Long-term politician Carmen Lawrence, who wrote this was reflecting on fantasy in politics and why we have gone so wrong. We hope that we have given enough of the history of aged care to remove the airbrushing that it has received and show what has happened.

To understand where we have gone wrong we need to examine human psychology, human behaviour and social structures. We find that insights from great thinkers and studies in the social sciences over a long period have been ignored rather than airbrushed. It should not be necessary to remind politicians of these but it is necessary.

Philosophers and social scientists have explored the human condition and our human society in order to understand:

- why we are so prone to develop and believe in ideas that fly in the face of evidence and logic,
- why we ignore logic, criticism and evidence of harm when applying these ideas,
- why we adopt a one size fits all approach and apply ideas that work in one sector to sectors where they don't work, and
- the strategies we use that allow us to:
 - ignore what is happening in front of us,
 - deceive ourselves when needed, and
 - neutralise critics and their criticisms.

This body of knowledge and the many criticisms of what was proposed were ignored in 1997. All of the strategies described have been employed in the years since then in order to protect the neoliberal free market ideology. This ideology is the driving force behind an aged care system that is not serving elderly Australians well and is harming many.

⁹³ Carmen Lawrence. *The denial, the infantilising babble, and the fantasies that permeate politics* - The Guardian, 30 Jan 2017
<https://www.theguardian.com/commentisfree/2016/jan/30/the-denial-the-infantilising-babble-and-the-fantasies-that-permeate-politics>

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Until we recognise this and take steps to confront and correct those aspects of marketplace belief and practice that are causing harm this market in misfortune is unlikely to work effectively.

These ideas are not always simple to understand and many will reject them because they are outside their personal experiences. We have tried to explain some of this in **Appendix 5**.

Some understanding of this is important if we are going to:

- make changes that recognise and address the underlying problems in the current system,
- develop a system that will serve communities by caring properly for their elderly members, and
- most importantly create a situation where it will not be possible to make the same or similar mistakes again.

Our proposals for change are informed by this body of work.

Part 3: Using our knowledge to find a way forward

3.1 Objectives

Examining this complexity in the real world is more than an academic exercise. We can see the merit of a system that escapes the straight jacket of the free market discourse and makes it subordinate to the discourse of care. If we place decision making close to where care is given it will be constantly confronted by real suffering and frail humanity. It will be much more difficult for it to escape into illusionary and illogical belief again.

We need changes that make the market work, reset the balance between conflicting discourses, collect and use data transparently, regulate effectively, address the problems in management, combat illusions, address the problems in staffing and make us acutely aware of consequences so that we can respond immediately. We need to carefully trial and evaluate any new policy and not repeat the errors of 1997.

If we are to find a way of making this market work for the community and their elderly members then we need to look at what has happened from multiple points of view and see what is needed to address what we see there. We have tried to do this.

The longer we take to address this the worse it will become and the more difficult to do.

3.2 A new direction

...Many problems can only be solved at the level of local communities - bringing together local understanding, leadership, expertise and resources. Many of today's problems no longer suit centralised solutions with their bureaucracy, elitism and patronage. The authors of this discussion paper argue that it is time to change our understanding of both the role and structure of local government".

It is time to move to new organisational structures that embrace local innovations and encourage local capacities.⁹⁴

If we are to get a better system we need changes that are not so immediately disruptive of what we have now that residents are harmed. They need to be carefully considered and then introduced in a carefully considered way. Our assessment suggests that the only way in which these objectives can be met is to move the overall management of aged care back into local communities and so put it into the hands of civil society. This can be done in stages and to the extent that individual communities can manage.

This is not going to be an easy task when we consider the parlous state of civil society, which will have to rebuild during this process. This is not a quick fix but we see no alternative with any prospect of success. Accepting this as an objective and describing its intention will of itself send a clear message that will impact on behaviour. It will require strong support from government.

The rebuilding of civil society around a community aged care service will have a positive impact on society as a living and dynamic entity. We have been impoverished by its absence.

In **Appendix 4** we provide an outline of our proposal. In the following table we set out the major problems that we have identified in this and other recent submissions.

⁹⁴ Comments explaining Yapp C and Howell C **Community Sourcing and Social Care** Centre for Welfare Reform 2013
<http://www.centreforwelfarereform.org/library/by-az/community-sourcing-and-social-care.html>

Part 3: Using our knowledge to find a way forward

Objectives	A new direction
<p>A. Markets: We might start with the traditional understanding of markets, one based on observation and not belief - going back over 200 years. This recognised that markets are based on self-interest and, if unchecked, will do what they can get away with. For a market to work for customers we require an informed and effective customer with the power to get what they want, an involved and effective civil society that sets the limits of acceptable behaviour, and a political system that represents and supports all of civil society and not only one sector.</p> <p>Instead we have vulnerable customers whose capacities are seriously depleted supported by isolated families who are anxious and uninformed. Civil society is a hollow shell and politicians are supporting the marketplace on whose financial support they depend to fund the marketing that gets them elected. Continued donations are likely to depend on their being given what they want⁹⁵.</p>	<p>The local service built with the community will become the local source of information, guidance and support. It will be working with and supporting the vulnerable customer before, during decision making and while a resident. This will be regular and ongoing.</p> <p>The community will be monitoring care and dealing with staff and management on a regular basis so setting out what is acceptable. It will be empowered by its role in advising prospective residents and its role in deciding who should be permitted to provide local services.</p>
<p>B. An illusory discourse: At the root of the problem is the dominance of the marketplace discourse and its illusions over the discourse of care. We will not get a system that works until that is reversed and the market discourse is required to recognise the primacy of the discourse of care and serve it in substance rather than form.</p>	<p>The community will be managing the oversight and regulation of care and be responsible for collecting data. It will be dealing directly with management which will be accountable to it so placing the centre of care and its discourse in the community. The discourse⁹⁶ of care would dominate and it would be pinned closely to the real world of suffering humanity. The many eyes of an entire community will ensure a broad understanding at all times.</p>
<p>C. The problem of accurate data: Data must be transparently and verifiably collected, properly analysed and transparently reported. It must form the basis for oversight, regulation, and policy decisions. Neither government nor industry can be trusted to do this nor is the government capable of doing it effectively when they are seldom on site.</p>	<p>Empowered visitors who will usually have clinical and aged care experience will be examining charts and working with staff to collect data so that it will be verified by all parties and transparent. It will be used locally for remediation and advising prospective residents as well as being sent centrally for data banking and use in policy development and research.</p>
<p>D. But objective data is not enough: While good data about staffing and care is essential, experience elsewhere shows that simply collecting some data and making it public has only limited impact on care. There is a data trap to be avoided. A far broader overview including subjective impressions and user opinions is required. The modulating</p>	<p>Members of the community will have roles within the facilities and communities which would provide a broad if subjective experience of the system and a broad context within which all data would be used to monitor and improve care.</p>

⁹⁵ Example: Donations by Tricare during a disputed development see "Donations under fire" and "Tricare donations made only to LNP" Westside News on 6 and 20 Sept 2017

⁹⁶ For an explanation of "discourses" see Appendix 6

Part 3: Using our knowledge to find a way forward

Objectives	A new direction
and constraining factors, the context within which it is all done and the way in which it is handled are critical.	
E. Regulation: The centralised model of regulation and complaints handling is deeply flawed and even if a less flawed model were introduced a centralised system would still be incapable of regulating the sort of service that is provided at the bedside. Primary regulation should be based on the normal processes of social control and this should be built into any solution. This should be supported but not usurped by government.	The collection of data, the monitoring of performance, the perceptions of residents and their families and the handling of complaints would be week by week activities in which there would be regular interaction with staff and management. The normal social signals of encouragement and disenchantment that control our behaviour would become the front line of regulation. This would be mentored and supported by more formal central regulation and when required sanctions.
F. Management: Current centralised management is poorly coordinated, process driven, impersonal and dehumanising. It lack empathy and the flexibility to manage complexity. Myagedcare is a representation of the managerial mind. This is about frail people and it needs a human face. An integrated bottom up management and regulatory system empowered and driven by those close to the bedside who know what is happening and work within the discourse of care is required.	Management, oversight, regulation, advocacy and more would be integrated and coordinated locally. It would be person on person, empathic and flexible.
G. Combatting illusions: As well as data we need a system where insights and knowledge comes directly from close association with the care that is given so that discourse is formed close to, constrained and tied to what is happening at the bedside, and anchored to data. There should be diverse input into this debate with involved citizens with many and wide experiences so that many eyes are focused on the problems.	Discussion and power originating from the bedside would increase knowledge and experience so that this requirement could be met. Academics would build on this and engage with the community. Professor Michael Fine who has real experience of care and its workforce has analysed the nature of care, the processes, and the conflicts between the various discourses. ⁹⁷ Politics has ignored these academic insights.
H. Staffing: Aged care is not an attractive place to work and this is partly related to the culture within facilities, the management structure, the lack of control over their work and the low staff numbers. The neoliberal discourse and its management structures are unsuited to the sector and make it extremely difficult to develop the sort of workforce that is needed.	Making the discourse of care dominant would improve the culture within nursing homes and value staff and their efforts. With a bottom/up management structure staff would gain greater control of their lives and have greater say so working would be more rewarding. Diverting funds from staffing to profits would be much more difficult and when more funding became available staff and residents would benefit.

⁹⁷ An outline of some of Fine and his group's academic papers with links are at <http://bit.ly/2ASdXtZ> Of most interest **2005:** Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency,' **2012:** Care: A Critical Review of Theory, Policy and Practice, ::: Employment and Informal Care: Sustaining Paid Work and Caregiving in Community and Home-based Care, :::: Individualising care. The transformation of personal support in old age, **2013:** Re-Thinking Care for the 21st Century, **2014:** 'Ageism, Envy and Fear. The Contradictory Politics of the Sequestration of Old Age in the 21st Century', ::::: Intergenerational Perspectives on Ageing, Economics and Globalisation, ::::: Nurturing longevity: Sociological constructions of ageing, care and the body, ::::: Economic Restructuring and the Caring Society. Changing the Face of Age Care Work, **2015 :** Cultures of Care.

Part 4: Recommendations

Long-term recommendations

Aged Care Crisis is advocating for change that is based on evidence rather than belief, carefully considered, constructively addressed, carefully introduced and closely monitored – the very antithesis of what has been happening since 1997. To ensure that this happens the process needs to be tied to what is happening at the bedside and not in the boardroom or in the corridors of parliament although the guidance and support of both are required.

Recommendation 1: That market failure be addressed by progressively creating and supporting local structures which embrace community participation in the management of aged care and in doing so create an advisory support system that enables the vulnerable to become effective customers and builds a community that has the power to insist on the sort of aged care services needed.

Such structures would aim to:

- a) Empower the customer and the community
- b) Advise and support resident and their family
- c) Give the community sufficient power to embrace and promote a discourse of care that would be the dominant force in the sector.
- d) Give them an important role in data collection and oversight so ensuring transparency. This would give them the power to control discourse, assert their position strongly and contribute to policy development. Changes in policy and practice would require their acquiescence and support.
- e) Provide nonintrusive regular and close oversight so that problems could be prevented, detected early and addressed by immediate intervention and when needed social pressure.
- f) Provide the social context where the excesses of competitive pressure and efficiency would be effectively modulated and controlled.
- g) Integrate the services locally that are currently managed by a central fragmented system.
- h) Create a context embracing staff, residents, families and community in which a dialog can be built around the actual care provided. Central policies could be evaluated and new ideas tested before being spread upwards to government and boards as well as laterally to other facilities and services. Discourse, and policy would be closely tied to the real world of care and be examined from multiple equally empowered points of view. This is the best defense against another escape into fantasy.
- i) Ensure that staff at all levels would be in close contact with the community organisation and so bring their experience and ideas to the debate. They would become part of the debate and a major contributor to decisions about staffing and care. It should be a system where those at the bedside contribute to management and their ideas are empowered by support from the community.
- j) Create a context and culture within facilities where staff are valued and can realise their social selves through the work they do and their contribution to the discourse of care so reversing the poor working conditions and the negative image that the sector has for nurses. This is the first step in addressing staffing problems.

Part 4: Recommendations

Recommendation 2: That a central representative body be created to integrate the activities of community structures, support them, represent them centrally and provide a pathway to proper representation of a knowledgeable community on policy making and other advisory bodies. This organisation would be well placed to collect data, evaluate it, integrate it and report it transparently to all parties including the community.

Recommendation 3: Central government and independent oversight, regulation, complaint, advocacy, advisory, financial and other aged care services should be restructured as support organisations which would support the devolution of services to local services by:

- a) Helping them to build local services and providing education
- b) Providing an ongoing mentoring service that local staff regularly engage with
- c) Providing oversight and when necessary stepping in to correct problems and mediate disputes that arise (such a system will not be problem free)
- d) Provide the formal structures needed to support community and give objective form to their activities (laws and regulations) and to take over when greater powers are needed eg. unresolved complaints, penalties and sanctions.

Recommendation 4: That academic medical, paramedical, nursing and social service bodies be represented and work closely with the community structures and their central organisation so that they provide support and advice in the development of research projects, evaluation of new initiatives, collection and evaluation of data. While the community structures should be aligned with and informed by data they should not fall into the data trap and be enslaved by it. Data should stimulate research, which should become a driver of progress.

Short-term recommendations

What we are asking the committee to consider is not trivial. These changes cannot be accomplished overnight and it will take time to build and empower local structures which should not be overburdened until they are ready to take on a particular role. Some may never be able to take on all of these roles fully. This is something local areas need to build themselves so that they own, identify with and are confident in what they are doing. Experience shows that services planned, initiated and managed by local communities work, whereas those that are imposed and controlled by outsiders fail.

There are acute and immediate problems that can be addressed.

Recommendation 5: Accreditation should be relieved of the burden of being a regulator. Regulation should be handed to the government, an independent body or even to states in a structure that would eventually support and work with local community based structures. Accreditation should be a support system only.

Part 4: Recommendations

Recommendation 6: Temporary improvements like regular unannounced visits might help to contain problems until local structures are able to gradually play a greater role.

Recommendation 7: While increased funding is undoubtedly needed government should be wary of doing so until financial transparency has been ensured. The track record of providers suggests that additional funds will not go to staffing. Current oversight does not ensure transparency. We recommend that additional money should be a conditional on financial transparency.

Attachment

We attach to this submission “Community managed aged care – an analysis”. This document is a critical analysis of the evidence given to the senate at its hearing in Adelaide and of the available reports released to date following the Oakden scandal.

It describes how our proposal would address the many issues identified in a prompt and practical manner. We are therefore sending it as an attachment to this submission. It is a practical explanation of what we suggested in our more theoretical submission to the senate in August 2017. It gives an outline of our proposal for a community based structure for managing aged care.


We show how our proposal would have either prevented, or detected and responded rapidly to what was described at the public hearing in Adelaide on 21st Nov 2017. We also examine the Nous and Carnell/Paterson reports. We show that our proposal would address not only the problems they identified but those they overlooked much more effectively than the recommendations they made.

We also analyse the rise and fall of advocacy groups, starting in anger at what they have experienced or seen and instinctively calling for more regulation and often getting no further. Attempts have been made to tighten regulation but this has not worked. We describe how the repeated failures of this approach have led us to reflect and so do a deeper analysis.

Our proposals now seek to identify and address the problems in the system that have made it so intractable and difficult to regulate. They would create a context where the issues can be addressed and more sensible policies can be examined, tested, re-evaluated, adjusted or changed and then tested again before being introduced. This was not done in 1997 when ideology trumped evidence and logic. Our proposals seek to minimise the risk that something like this might happen again.

Part 5: Submissions to other inquiries

Some of the issues in this report as well as additional issues have been addressed in greater depth in recent submissions we have made. These expand on what we have said here. If this review is to examine the whole rather than the fragmented parts through the prism of their impact on care then they may be of interest. We summarise some here.

 **Senate Inquiry:** Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practiced.

Submission August 2017⁹⁸ <http://bit.ly/2A4Uu6x>

Part 1- Regulation in Context: This submission argues that regulation cannot be effective if it is not suited to the context where it is applied. Even good regulation won't address the problems in a flawed system. A whole of system approach is needed. The submission uses the concept of discourses to examine the problems in the system. It argues that growing evidence shows that systems in which communities 'own' the human services provided to them work best.

Part 2: Comparing regulation in the USA and Australia: Similar material to that in this submission.

Part 3: Analysis of regulation of aged care in Australia: This explores the history of social responsibility and the influence of neoliberal discourse. It examines the potential for social control as the first line in regulation in more depth. It examines the problems in accreditation, the complaints system and the department of health quoting from and using Braithwaite's 2007 work to support our assessment. It looks at missed opportunities for more effective regulation. We look at regulation as part of a system problem and at the potential for social control as the front line in regulating in greater depth but less onerously.

Part 4: Inquiries, reviews and consultancies: This looks at the record of these processes and why they have not worked in aged care.

Part 5: Suggestions for change: We make suggestions for change describing the approach that we are suggesting in greater detail than in this submission.

Appendices: Because the senate review was focused on regulation we expanded on the system issues in Appendices. These included 1) expanding on the approach using the concept of 'discourses', 2) Exploring the reasons for system failure, 3) Describing a changing pattern of failures, 4) An examination of the recently announced Carnell/Paterson Inquiry expanding on Part 4, and 5) Evidence that the review is not expected to impact on government' policies with Carnell and Paterson both scheduled to speak at a meeting progressing and reaffirming the Aged Care Roadmap.

Note: This detailed submission and analysis includes material previously sent to the minister, and later included in a submission to the Carnell/Paterson Review.

⁹⁸ 1st submission to Senate Inquiry (Aug 2017) - *Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practiced*
<http://bit.ly/2A4Uu6x>

Part 5: Submissions to other inquiries


 **Senate Inquiry: Future of Australia's aged care sector workforce (2016)**

This review spanned the 44th and the 45th parliament but although additional submissions were accepted, they were not considered in preparing the report. The supplementary submission below was made when staffing data became available during the 45th parliament. Appendix 2 and Appendix 5 below were taken from this submission. The two bar charts of profit generation under heading 2.4 Financial performance has become a token for good care on page 50 come from this submission

2nd supplementary submission to the 2016 senate workforce inquiry 28 Nov 2016

<http://bit.ly/2rEeSqM>

Appendices 2 and 5 below are copied from this submission. In addition this submission did a detailed examination of staffing and care in the USA using 2014 sources comparing this with staffing levels in Australia. (Later submissions used a 2016 source). The submission used reported financial data to make the point that almost all assessments in Australia are based on financial and market assessments. Because most profit comes from cutting staffing an assessment of care by consumers and community would instead find that those labelled as the worst performers were actually the best providers of care.

 **Productivity Commission: A public inquiry into the increased application of competition, contestability and informed user choice to human services.**

Submission 1 - 3 Aug 2016: <http://bit.ly/2biHimm>

The submission asks the reviewers to listen to their critics. It draws attention to widespread market failure across competitive markets wherever there is any vulnerability and particularly in human services. It uses aged care as an example of a failed market. It criticises and describes the limitations of the neoliberal free-market discourse and the way innovations are restricted by it. It presses for a 21st century approach to these services that embraces the principles of participatory democracy, rebuilding community and local structures to involve and support citizens and set the limits of acceptable conduct - services built around data. It addresses the tense relationship between profit and care, the negative role played by private equity and the adverse impacts on civil society. It uses aged care as an example. Broad recommendations are made.

Submission 2 - Response to preliminary findings report - 27 Oct 2016:

<http://bit.ly/2APziQX>

This response explores the ways in which "Competition, efficiency, contestability, choice and even the handling of information can be seen differently and have different consequences in different contexts. It warns of the consequences of some of the proposals and suggests that there are better ways of doing things. It draws attention to errors in logic and fact. We have reservations about the sectors selected for more competition.

Submission 3 - 31 Oct 2016: <http://bit.ly/2FR80Oz>

A short submission attaching a report from the department of health describing the governments market based roadmap for aged care. We also attached an industry developed roadmap predicting that commercial consolidation would see the number of providers of aged care drop rapidly from 1200 to only 300 over a few years and discuss the consequences. Our final paragraph related to the difficulties in estate planning due to the total unpredictability of the need to pay crippling sums for aged care at the end of life and the hollowness of the mantra of the choices they are being offered.

Part 5: Submissions to other inquiries

It seems that under the mantra of 'choice', Australian citizens are being denied the most important choices they need to make - the ability to plan for the future of their families and the right to choose a provider who will look after them and guarantee not to sell them to someone they would have avoided at all costs.

Submission 4 - Response to draft report - 14 Jul 2017: <http://bit.ly/2CSsdkE>

We challenged the relevance of this review in light of the rapidly changing political and community context since it was appointed. We question why aboriginal communities are seen to require a measure of ownership over the services that are provided to them, but this is denied to the rest of Australia. We drew attention to the implications of the now released senate workforce review for what they planned. We give examples of situations where 'Flexible and Local' services had been successful. We argued for '*community voice and place-based approaches*'.

We use the concept of 'discourses' to examine issues using aged care as an example indicating that a community based approach would be better for some of the sectors they are targeting. We refer to research and conclude that

The neoliberal discourse and its management structure inhibits the development of a culture that builds caring relationships, empathises, embraces community values and is built on a sense of mutual responsibility. It fosters a system that is centralised, task focussed, process driven, impersonal, complex and insensitive to personal need.

The draft report relies on data for its implementation and we draw attention both to the difficulties in collecting data and pointing out that this is insufficient and has also failed elsewhere. We point out that their proposals for palliative care are impractical because of the staffing issues revealed in the workforce inquiry. We challenge the faith the proposals place in government stewardship showing how this has failed and the lack of sector knowledge within government as a consequence of managerialism.

Australian Law Reform Commission (ALRC): Inquiry into Elder Abuse

Submission 1 - 30 Aug 2016: <http://bit.ly/2AMYYho>

Our submission focusses on the role that community organisations should play in addressing elder abuse and the integration of elder abuse services into a system of local aged care services and regulation so that '*services would build on each other*'. It argues the urgent need for a new direction suggesting that rebuilding civil society will alter the context within which abuse occurs and how it can be addressed. It considers poor care and neglect to be elder abuse.

It draws attention to the 'societal factors' created by policy and recent social changes that impact elder abuse and the consequences of current policy both for abuse in aged care services and for its detection and exposure. Examples are given. It describes the contribution that community based services could make. The lack of data about abuse mirrors the lack of data about care. The victimisation of whistle blowers inhibits disclosure.

Many examples of elder abuse in nursing homes are cited. The inadequacy of the current regulatory system is described. In Appendix 3 of this ALRC submission we describe "*The essence of the 'Community Aged Care Hub'*" exploring the ideas behind our proposal as well as its relationship and congruence with other 21st century social movements.

Part 5: Submissions to other inquiries

Submission 2 - Response to Elder Abuse Discussion Paper 83 - Feb 2017:

<http://bit.ly/2Fslwr5>

We welcome the plan to create an effective aged care visitors scheme. Our concern with this is that *“all of the problems detected are to be managed within the current aged care regulatory framework”*, a framework that protects industry and government rather than the residents who are abused. We were also concerned at *“the fragmentation of the regulatory process for aged care and elder abuse between a multitude of regulatory processes”* so that people fall through the cracks. This will not work. We urged local integration of all services.

The submission looks at the global failure of the sort of regulation that has developed within neoliberalism in multiple sectors. Regulation in Australia has depended on resident and staff whistleblowers. There is a critical analysis of aged care regulatory failure.

Submissions were also made to the 2015 New South Wales inquiries into Registered Nurses and Elder Abuse.

Aged Care Legislated Review

The contributions to this review were controlled and structured within a restrictive online survey format, responding to questions the reviewers had selected. Although we were critical, it was not possible to address issues with the system that the reviewers did not want addressed. Aged Care Crisis attended meetings with Mr Tune in Melbourne, Sydney and Brisbane. We were invited to make an additional contribution and one of us (MW) did.

Letter in response to Aged Care Legislated Review - public consultation 19 Feb 2017

<http://bit.ly/2D2KgJ1>

The letter pointed out that the questions in the feedback forms all related to finances or organisation and none to care or quality of life. *“Missing are any assessment of the care provided or the quality of life – the objective outcomes that the system is intended to achieve”*. There was no opportunity to *“engage with the legislation and examine its underlying philosophy and mode of operation”*

Critical problems were:

- the primary difficulty in society is not society’s inability to change but politicians’ adherence to obsolete ideas that no longer serve society and their inability to change,
- those who want innovation are those who are least willing to be innovative,
- civil society is depleted and in disarray - as markets have structured and grown civil society has stagnated and been eroded,
- aged care is trapped in this dated 20th century thinking and civil society is powerless to do anything about it,
- selling choice as a defining market attribute is hollow indeed when the chooser rapidly becomes no more than a profit body traded on the share market, and
- the aged care roadmap is set firmly within 20th century ideas that mis-specify the nature of man. It misunderstands the human condition, society and the caring process. Its lofty objectives can only be attained in spite of and not because of it.

Our response dealt with the abolition of social responsibility as a requirement in the sector and the consequences of this. This had been raised at the meeting but not discussed. It then addressed a) regulatory capitalism, b) data collection and handling, c) Professor Fine’s work

Part 5: Submissions to other inquiries

on the nature of care and the difficulty in providing this sort of care in the system being developed, d) nepotism in the neoliberal family, e) participatory democracy and its potential in aged care and f) the reasons for a community based aged care system

 **Review of Commonwealth Aged Care Advocacy Services 2015/16**

Submission - September 2015: This review was contracted to a consultant and was restricted to the questions it was asked to address so any innovation was excluded. We were critical in our responses and indicated our preferences for local advocacy services. We were able to attach a document that looked at this possibility.

Supplement to submission: <http://bit.ly/2wtj7dl>

We highlighted advocacy's low profile, the lack of data about the effectiveness of advocacy and how seldom advocates seemed to have been involved when problems were exposed. It was missing in action. After reviewing the many problems in the aged care system it explores the literature on community engagement and participatory democracy and gives examples where community based services have worked. It looks at problems that have been experienced by advocacy groups. It goes on to show how local organisations built around and including advocacy would be better than the centralised system that was being pursued.

Part 6: Appendices

Appendix 1 - Contrasting industry with families and staff

Appendix 2 - Ownership type, staffing and care

Appendix 3 - We were warned many times

Appendix 4 - A community based solution

Appendix 5 - Ignorance about direct care

Appendix 6 - About Discourses in aged care

Appendix 7 - Understanding why we go wrong (*Belief, Ideology and Discourses*)

Appendix 1 - Contrasting industry with families and staff



Australian Government
Australian Trade Commission



“... The Australian aged care system is a global benchmark for best practice, thanks to strong government funding, a robust framework for accreditation, quality and regulation, and a long history of cooperation between government, service providers and the community ...”⁹⁹

Contrast the comments made by staff and families at various times over the last roughly 15 years with the government and industry’s idealised view as revealed above on the Austrade web site. Yet most of the leaders in the sector seem to think this way. We have seen similar inflated assessment by market and industry providers preceding major scandals in corporate hospitals and in aged care in the USA. It sets alarm bells ringing.

In another example, after experiencing the system as a family member Lynda Saltarelli made extensive inquiries and then wrote a newspaper article in 2007 describing her findings¹⁰⁰. The then chief executive of Aged and Community Care Victoria, Gerard Mansour responded:

LYNDA Saltarelli (Opinion, 19/11) has unfortunately missed the central point - Australia has one of the most robust accreditation and complaints systems anywhere in the world.

*The aged-care industry is highly regulated and accountable. The introduction of legislation to deal with elder abuse, our 44 accreditation standards, police checking and new complaints system demonstrate it isn't regulation or accreditation that is the failure in aged care*¹⁰¹.

Later in 2012 as CEO of LASA, Gerard Mansour was reported as responded to a report of assaults in aged care homes¹⁰²:

Gerard Mansour, the chief executive of the peak body representing providers, Leading Aged Services Australia, denied that quality was declining.

"Overall the industry has an outstanding quality record as measured by our independent accreditation scheme, under one of the most robust quality systems anywhere in the world," he said.

"Where there are isolated incidents, these are treated seriously and acted on promptly by providers even when it means reporting allegations or suspicions. The data reveals that many assertions may not ever be substantiated."

Those who have studied society over the last 2-300 years have recognised that the most difficult situations to deal with are those in which the perpetrators believe implicitly in what they are doing, so implicitly that they are unable to see what is happening in front of their noses. Because they believe in what they are doing they are not restrained by their consciences. This phenomenon is now well recognised and there are a number of ways of understanding the psychological strategies used and the way in which groups reinforce each other in deceiving themselves. (See Appendix 7)

"virtue is more to be feared than vice, because its excesses are not subject to conscience"
(Adam Smith 18th century)

"It's always the good men who do the most harm in the world" (Henry Adams 19th century)

⁹⁹ Aged Care: Setting the Global Standard for care - The Austrade website 2015 <https://www.austrade.gov.au/aged-care/>

¹⁰⁰ Vulnerable elderly deserve better care - Lynda Saltarelli in The Age - Opinion, 19 Nov 2007 <http://bit.ly/25tw54Q>

¹⁰¹ We must prepare for the future The Age, Letters, 20 Nov 2007 <http://bit.ly/2Gx1yMr>

¹⁰² Aged-care assaults increase - Sydney Morning Herald, 30 Nov 2012 <http://bit.ly/25xfNV>

Appendix 1 - Contrasting industry with families and staff

What staff and family members told us in 2005

The following snippets are a small collection only, of extracts of emails and letters sent to Aged Care Crisis. These short quotes were part of a submission made to the Senate Community Affairs References Committee - Inquiry into Aged Care, in June 2005.

Ten years later in 2015 there was another of the recurrent cycles of allegations of abuse and neglect in the aged care system with similar allegations. Aged Care Crisis published these 2005 comments on a web page to show that despite all the reviews and inquiries and token regulation, nothing had changed.

Feedback 1. "...As a PCA8 or Nurse's Aid, one doesn't have a voice. You are considered quite lowly and no respect is given. So I decided to go to Uni and study to become an Enrolled Nurse (Div 2). I only lasted for half the course due to my disillusionment of the industry.

The class was supposed to consist of 22 students, but had 39. You were taught some things once and then considered qualified in that area. When we were sent to placement at a Nursing Home/Hostel, they were understaffed so us, the students, were left to shower, bandage and feed with no assistance or supervision. Because I'd had some experience, the other students would come to me for help and advice.

This is what they called training... The government have a lot to answer for..."

Feedback 2. "...there seems to be an influx of untrained and unsuitable staff who, because of the unemployment rules, take on any job because Centrelink tell them they have to. Companies want to take on Division 2 Trainee to make money, then ask them to leave when their traineeship is over, causing loss of trained staff. Many of the PCA10 trainees have come into aged care because they are not able to find employment elsewhere and companies are desperate for staff take them on with very limited skills putting the residents and other staff at risk..."

Feedback 3. "... Mum is in her mid fifties, yet it is not unusual for her to work double shifts and she routinely stays back two and three hours after her shift ends to catch up on documentation. In fact, although her official working hours have been cut back recently, the hours she actually spends at work have not. She is a highly dedicated nurse and does everything she can to give the residents the best care possible under very poor conditions..."

Feedback 4. "... it is difficult to "care" for residents with the present staffing levels. I burnt out within twelve months of commencing work in a Nursing Home, because of what I saw and as a result of not having the time to spend with people who so desperately needed me to just be there for them.

As a Nursing Home employee I treasure the time when I can speak to a resident, and listen to what they have to say. That only happens when they are naked on a chair, in a shower. This is their quality, one to one time.

I have 15 minutes maximum to get that person out of bed, often with a lifter, get them to the bathroom, shower them, dress them and transfer them into another chair. I also should have the bed made in that time. If someone needs to use a pan while I am in the shower, they have to wait. I can't leave the person I am with. Then we wonder why the majority of residents are incontinent. Most aren't when they are first admitted.

I am going to university to study so I can escape the tragedy of our nursing homes. They are a huge indictment on our society. I challenge anyone, who knows the reality of life in a Nursing Home, to say that they would like to spend the last years of their life in one.

We couldn't come up with a better way to strip aged people of all their dignity and humanity..."

Feedback 5. "... I am now in my mid 40s (a baby boomer) and for most of my working life have worked as a trained nurse (now no longer). During my initial years as a nurse, I worked as an

Appendix 1 - Contrasting industry with families and staff

untrained nursing assistant in the area of aged care, and I must say I found it difficult and depressing to say the least.

I witnessed many acts of brutality and cruelty from more senior registered nursing staff and doctors alike, but due to my low rank at that time (felt) I wasn't able to do anything about it.

The thought of me having to rely on strangers to take care of my personal needs (like bathing and toileting), for me, is simply out of the question. My feelings would be the same if I were to ever need the services of a nursing home..."

Feedback 6. "As a nurse in an aged care facility, it is very frustrating to have a resident returned from a hospital visit of only a few days, return to us with pressure sores that did not exist before the hospital admission. Let me tell you - the hospital nurse/patient ratios are FAR less than what we nurses in aged care deal with. I was in hospital myself recently and the ratio was 1 nurse to 4 or 5 patients, compared with the ratios I work with at present 1 carer/nurse to a minimum of 12 residents on an afternoon shift. Sometimes it is more, if you are short staffed. Morning shift is worse because the workload is even heavier, and the night shift is 2 carers for 45 high care residents, with one RN Div 1 for almost 100 residents - this is a lot of responsibility for the RN Div 1. Not only is the RN responsible for the residents, but the care staff as well, and including the building itself.

Based on the hospital nurse ratio's one has to wonder how they cannot give adequate pressure area care required to avoid pressure sores..."

Feedback 7. "... I work in an aged care facility as a nurse/carer. It is a lovely facility but it has many problems. I specifically see problems in the delivery of quality and best practice care to residents.

I get very frustrated working along side people who call themselves carers who do not have experience, and some have no formal training/skills. Unfortunately, the government let aged care facilities employ such people. I believe the elderly deserve to be looked after respectfully and with dignity, but the delivery of care falls short by most facilities when employing staff who basically 'do not know what they are doing' and do not have the passion and dedication to perform and deliver quality care..."

Feedback 8. "... I have been a personal carer for several years now, and for the last few months working in nursing homes.

I care deeply for my residents and treat every one of them as I would my own grandparent and I am disappointed that many people believe that Personal Carers (PC's) are careless or abusive. I guess there are people like that out there, but given that where I work I am pressured to carry out the ADL's with speed... (aim for 15 minutes/ resident), I am not surprised that residents are injured at times.

I have been instructed through communications (at my work) that if we cannot fulfil our tasks in the allotted time, then maybe we should not be working here (place of employment). We are short staffed and apparently 'under funded'.. something I find very hard to believe, but that is what I am told.

On average, each employee would stay on the shift (unpaid) for up to half an hour just to complete tasks and make sure that the residents are comfortable. All my work colleagues are compassionate and caring individuals. It is the management and owners of the nursing homes that need to be accountable for the funding they receive.

My understanding is that as long as a nursing home meets the accreditation standard, they continue to get funding to be spent in whatever way they choose. We bear the brunt of abuse, a career that very few others would choose to pursue and get paid very little for a job very few of us would swap for another career. We don't work for the money.... we work for the love of our elderly citizens.

Would someone please help us, to help our elderly live out their remaining years with dignity and comfort?"

Appendix 1 - Contrasting industry with families and staff

Feedback 9. "... I have in the past had expressed concerns about the level of aged care but have not been heard. I worked in a large aged care facility for the best part of a decade many years ago and not a great deal has changed. In the industries where accreditation is implemented I see fundamental flaws. I see agencies given accreditation status in aged care and child care facilities and I often wonder how they achieved this standard. The only way accreditation will work is if spot accreditation is applied. A set schedule for the process only provides the organisation the opportunity to dress up the "facade" for the occasion. It is a farce and always has been. I could tell you many a story about accreditation!"

Feedback 10. "... have just left employment with a categorised Low Care Hostel employed as a PCA. Over the 6 months I was there, I was a silent partner in out and out deception regarding accreditation:

- I was told to complete 18 months worth of bowel assessments before (accreditation);
- the staff were hand-picked for the day the on spot review happened (the roster was changed to accommodate this);
- the residents who may of spoke of concerns where sent on a bus trip to local RSL for the day (a first I might add), unbeknown to them the accreditation team were coming in;
- the ratio of staff was upped for the day; and
- the menu changed to something very palatable the residents did not normally receive.

Of course, the home passed with flying colours. I was lucky in the respect I was not stopped and asked any questions, saving me an ethical dilemma, due to the fact 3 weeks earlier, had been rushed through my medication competency - to the extent I arrived for a shift at 6am and found I was giving medication out, and at 9.00am the R.N arrived and then signed me off for 3 previous supervised medication rounds that had not happened.

I was working that day with one other carer who had no experience in aged care and had only worked one shift the evening before. She (no buddy shift/no competency passed) walked in and had to shower 9 residents before 8.00am and burst into tears when faced with a colostomy bag. (*The poor woman had called 2 days previously on the off chance looking for domestic work and had been employed on spot as a carer.*)

I was lucky that day, as no incidents/accidents occurred. When I queried the fact I was not conversant with the medication I was giving to the cognitively impaired (as per regulations), and (asked) 'when would education happen for that', I was told 'you have a MIMS11 in the clinic, read that'.

My next shift as the Carer giving out medication was over the long weekend, no R.N is rostered on for 4 days, and unfortunately for me she also was not answering her phone or mobile so I had to make my own judgement calls re PRN medication¹². When I brought my concerns up, I found they were not addressed - leaving me no choice but to leave before they fabricated a reason to get rid of me as happened to previous staff members."

Feedback 11. "...Speaking with other relatives today, there are still ongoing issues. One resident asked to go to the toilet and was told to wait until after she had finished her breakfast. Staff did not return and she soiled the bed. It seems they are still not adequately staffed, either quantity or quality..."

Feedback 12. "... A nurse wheeled Mum into the disabled toilet and went away. The nurse then went off duty. Unable to see any buttons (blind) Mum called out until her voice was gone. She was found 3 hours later at meal time by a staff member searching for her..."

¹¹ MIMS – A handbook containing medicine information from Australian pharmaceutical companies
¹² PRN Medication - the name given to 'when required' medications. PRN medications are defined by the Australian Pharmaceutical Advisory Council (APAC) as being those which are ordered by a medical practitioner for a specific person on that person's medicine records and when the registered nurse, using clinical judgment, initiates, or delegates to an authorised enrolled nurse, when necessary. The administration of PRN medicines must be recorded on the person's medicine record (APAC

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2002). Staff should record the times and dosage for which that medication is administered on the resident's medication chart and record why the medication is given and the outcome (for example, pain relieved, resident settled) in the progress notes.

Feedback 13. "... Lack of surprise inspections: I worked in a Nursing Home, which was privately owned for nearly two years. In this time the proprietor sacked over 18 D.O.N's (Directors).

Food for residents was locked with a padlock in a fridge because the owner felt we might steal her milk or margarine or jam. So, hungry residents couldn't get a snack after 7.30pm when kitchen staff went off duty. We once had two chickens to feed to 30 residents because she wouldn't purchase more food. If we ran out of stuff, we had to buy milk or bread for the people.

Sure, we complained, and complained about so many things you could never believe. Nothing ever was done. All in a very affluent Melbourne suburb too!"

Feedback 14. "... Self regulation is a joke. Why would a proprietor, who most often is an absentee landlord with no emotional bonds with the patients, expend extra money if he does not have to? Philosophically how many people invest in aged care homes to provide good quality care as the first objective? Surely the main objective is to make a profit. The two are contradictory.

How many inspections take place at "dinner time" at 4pm when the bread and butter and cup of tea are handed out with nothing else until 7am the following morning?"

Feedback 15. "... This home has had sanctions placed since and one of the biggest flaws was that they have one qualified RN on each shift and sometimes none at night time. When my husband spoke with the RN on Sunday, the RN had no idea that MIL 13 had been sick. The report on the accreditation stated that often care assistants were in charge of residents and did not report illnesses back to the RN's (Registered Nurse). She was showing signs of flu and maybe the assistants didn't think it was bad enough - who knows.

The doctor had not been called for her. My MIL (Mother in Law) was just under the impression that that was the case as she had commented on her unwell feeling to the staff. When we brought it to the RN's attention, a Dr was arranged for the next day. Unfortunately, the infection had already hit the brain causing hallucinations and 4 days later, despite antibiotics, she had deteriorated enough to be admitted to hospital with pneumonia.

The poor RN's have way too much responsibility - medication records, changes in resident's health/appetite, etc and often don't get to actually spend time with the residents. If they had, they might have picked up her illness and acted upon it earlier."

Feedback 16. "... Due to staff shortages my mother (totally blind and with dementia) had several bad falls, one when she fell out of bed suffering bruising, cuts, and a broken collar bone and resulting in extensive hospital treatment. The relieving staff member was unaware my mother was blind and forgot to put the restraining sides up on her bed".

Feedback 17. "...Are you aware, to reach Accreditation nursing homes have to tender an application, at the cost of thousands. Nursing Homes have to be accountable for care given, we have to prove we do what we say we do. Hospitals do not have to do this..."

Feedback 18. "... My grandmother, a dementia sufferer was often put in the humiliating position of being left on a commode chair in full view of other patients and their families.

She was harnessed into the chair by a piece of cloth tied around her waist to the arms of the chair. One day she wriggled down and was trapped by the cloth around her neck. Had it not been for one of the other residents, she would have choked.

She was admitted to hospital, bruised and very ill. She was left too long without supervision..."

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Feedback 19. "... My mother was in a nightmare of a nursing home....a broken walker that no-one knows how that came about; items that go missing never to be returned; a lady that empties her bowels in my mother's room - faeces all over her things.

I complained to staff and management. I was told they don't have enough staff or money to look after them properly. If it was the RSPCA, they would have closed them up!"

Feedback 20. "... My mother in law had lots of falls and was often there for some time as the nurses rounds are only every few hours through the evening and she seemed to manage to fall between checks. One morning I found her on the floor at 8am. Never knew how long she had been there. She had a dislocated shoulder. The ambulance took hours to come as she was not an 'urgent case'.

I do really feel for the staff though the good ones are just run off their feet. and most do care it is just the insufficient funds for good care and supervision..."

Feedback 21. "... The domestic staff were doing most of the caring with only one qualified nurse for 65 patients. My mother was often left to sit for hours, on a vinyl chair, not properly clothed or covered. One day she fell off this chair and broke her hip. She was sent home from hospital 48 hours after her hip replacement and untrained domestic staff were used to bathe and move her. Within two days her hip had dislocated. This happened again - twice. Once it was dislocated for nearly a week but the doctor had not been called.

A physiotherapist was supposed to train staff, but the one nurse there told me 'she didn't have the time'."

Feedback 22. "...We actually verbally discussed our concerns regarding the medication with both the DON (Director of Nursing) in January and the Managers/Owners on several occasions during February and March. They were meant to "look into it" and get back to us and we heard nothing. After several discussions with the pharmacy, we informed the Compliance part of the Department who after investigating our comments, strongly advised us to place a formal complaint. It was only after this that something was done by the nursing home. The fact that we had not put our concerns in writing, gave the owners a chance to claim that we went straight to the department.

The home does have a written communication book to write concerns but part of the assessment found that none of these were being followed up...(we are concerned that there is no) proof that they have received the complaint..."

Feedback 23. "...I'm more concerned about their "sneakiness" in not providing information when requested and lying about what is going on in the facility (missing medication) and only supplying information and admitting the truth when the Department became involved upon our complaint. This leads me to wonder what will happen after their sanctions are lifted and the department is no longer watching..."

Feedback 24. "...Nurses in a hospital setting have little or no understanding of aged care and how to manage any person over 70 years of age.. We hate sending our folk to hospital, they return with pressure sores (very little are known in a nursing home setting) their behaviours have usually exacerbated and are out of control, they are malnourished and to put it bluntly - are worse than when they were transferred for a said 'acute illness'... It just makes me sad, angry and quite disgusted that elderly people nearing the end of a good life are enforced to go through this debilitating treatment..."

Feedback 25. "...My 88 year old mother, highly educated, has just been dumped by a hospital in Sydney into a respite facility without any further plan in place. Whilst she has minor cognitive impairment she does not have dementia - yet the private facility, operated by a religious charity, is insisting that we take out power of attorney or they apply for guardianship and insist that I am responsible for all form filling in. I contacted a legal service who told me this is incorrect and she is fully responsible as she has full legal capacity. The emotional pressure and emotional blackmail

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employed by these places and by the hospital social workers has been nothing short of immoral and they are willing to treat the elderly like children and take away their rights just to ensure their money comes in. The system is broken, completely. The aged are treated like cash cows, toddlers and nuisances instead of with respect ...”

Source: *Ten years - what's changed? Aged Care Crisis* <http://bit.ly/2rQ5wg0>

Subsequent similar comments

Aged Care Crisis ran a discussion forum for staff and families between 2008 and 2012. Here are a few snippets:

Principles? Principles? What have principles got to do with aged care? There are NO principles in aged care, it's all about money, one way or another. Saving money, cutting costs, cutting corners, cutting staff, cutting quality care, that's what aged care is about, and I doubt if you will find any principles involved in that lot!! And, as XXXX is constantly pointing out, it is actually getting worse. Over my 9 years of continuous involvement with aged care, it had declined hugely.

The current accreditation system with its emphasis on measuring against Providers' benchmarks has resulted in inconsistent and inaccurate findings; good nursing homes are punished while bad ones continue to be allowed to operate.

Care is much more than glossy posters stating that they respect the dignity of the Elderly. A ridiculous statement when they allow this kind of neglect to go on with absolute disrespect of an Elder person's dignity. I am tired of the excuse - not enough staff. If they don't have enough staff then they shouldn't be accredited.

The Nursing homes in Australia dispense some mind boggling disgraceful care.

And the onus is not on the staff, the DON and the RN and all the others in the mix. The onus is on the owners to stop treating the elderly like cash cows. And the onus is on the government to enforce much better compliance to proper standards. And the onus is on the Accreditation people to make more spot checks and open their eyes to the horror that exists in these homes and the misery inflicted on so many vulnerable old people. It is a disgraceful situations. And I am sick of the false rhetoric that passes off as caring words but is just window dressing, spin and PR speak. Not good enough.

I can go on and on, years of frustration and angst against a system of systems that are so different and uncaring, and the only reason I stay is because I look at my clients and KNOW they deserve better than what they are getting.

Well, thanks for 'listening". I am sorry it is a long post. I am in tears as I write this as I just feel I have let the poor residents down with the shocking non existent care that they receive at night because we just cannot possibly get through the workload. The powers that be just don't give a stuff. Shocking to the core.

I don't blame you in the least for resigning. I've done the rounds of Aged Care Complaints and it wasn't worth the 20 cent phone call for all the good it did. Absolutely useless. Accreditation is a joke.

Source: *snippets from discussions on the Aged Care Crisis Forum between 2008 and 2012*

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Inquiry by Senate Community Affairs References Committee 2016

To see what has happened and is currently happening in aged care today we need only look at submissions to the 2016 Senate Community Affairs References Committee Workforce Inquiry. Of the 315 submissions there are approximately 73 (25%) from staff or family members with direct experience of what is actually happening in aged care. Many of them are nurses with many years of experience.

While the inquiry was about workforce the impact of what these people are saying on the lives of residents is glaringly apparent. As the Centre for Sustainable Organisations and Work indicated in their submission *“job quality is a necessary precondition to the provision of good quality aged care services”* also expressed as *“the conditions of work are the conditions of care”*.

Job quality is largely determined by the context within which the work is carried out. These submissions describe the context within which aged care workers carry out their work and it is a dreadful indictment not only of our aged care system but of the society that has stood by while this happened.

The following submissions many of them quite short show exactly what is happening in our aged care system.

Submission Numbers: 3, 6, 8, 9, 10, 18, 21, 23, 25, 29, 34, 40, 42, 55, 69, 74, 79, 80, 81, 82, 88, 93, 98, 111, 113, 115, 117, 123, 124, 126, 129, 130, 132, 141, 156, 157, 159, 161, 164, 166, 167, 173, 176, 177, 181, 182, 186, 192, 196, 198, 207, 216, 218, 224, 231, 234, 252, 257, 258, 259, 260, 261, 262, 264, 265, 266, 267, 271, 274, 286, 287, 288

We have selected short illustrative quotes from some but there is much more in these submissions. The submission number precedes the quote:

129: If there was anything that I could say to the senate. Something that I hope they would listen too. Is please, please open your eyes, your hearts, your minds and really look at aged care in Australia.

132: We are now an industry that has been hijacked by big business. Care of our residents and staff come a very distant second. It is all about the bottom line not the care of our residents or our staff. - - - In services that talk about “person centred care”, the organisation talks the talk but does not walk the walk.

156: Please, please change things. At the risk of sounding melodramatic, the aged care system is truly a hidden humanitarian crisis.

198: I have been a nurse for 48 years and have seen nursing care for the elderly decline to an abhorrent level - - .

216: I do not want to ever be put in to a nursing home!! - - - due to the low staffing levels I was concerned and regularly dismayed at the treatment endured by the residents of these high level care facilities.

218: - - - the litany of distress and needless suffering might make any of us wonder if we really want to get old.

231: I hope you will also hear the voices of many individual aged care workers, aged care clients and

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their families because statistics and data rarely shed light on the real impact of policy decisions.

233 (family member): The aged care sector needs a massive overhaul.

234: I have been in number of meetings with General and care managers at these homes to inform them that this was the wrong skill set for safe practice in nursing homes but are repeatedly shot down by the corporate bureaucrats at these large aged care providers and training organisations.

257: I do not believe that the residents receive adequate care, and more staff are required in order to make sure that the care is given properly The employers always say that they cannot afford to hire more staff, but at the end of the financial year, they have millions of dollars in profit (even if they are a not-for-profit business).

---- The accreditation process is useless. Management usually puts on more staff (or ensures staffing is covered) when a visit is scheduled.

—— Legislation needs to be tightened to stop facility managers cutting corners and using loopholes to save money

258: What I have found is that no matter where you work in aged care the staffing per client ratio is really bad.

---- The food in these places is really really bad. - - Most of these clients have dentures and are unable to eat the rubbery toast and that goes for a lot of the meat in roast etc as well

---- Some staff in these facilities should not be there. There is no care what so ever and I include management in that statement. In fact management is the worst.

259: The workforce in aged care is ill prepared to deal with the issues around dementia, and aged care facilities are not appropriately designed to meet the specific needs of people with dementia.

260: Aged care is a dangerous field to begin your nursing career. You are provided with little supplies, bare minimum knowledge of the elderly and completely unrealistic expectations. - - - I feel stressed at work. I feel unappreciated by my managers - - - .Our elderly are being neglected.

261: I have also worked with people that should have left the industry years ago. The one constant in the time I have been in the industry is staff shortages and the constant cutting of corners due to time and financial constraints.

271: Speaking from experience working in aged care facilities I am disappointed with the quality of care provided to this sector. - - - residents left in wet/dirty continence aids for far too long, - - - left sitting in day rooms or bedrooms with little or no stimulation.- - - - - malnourished because they are unable to feed themselves and there is insufficient staffing to assist all residents who require help with meals.- - - going from resident to resident with little or no hand hygiene

273: The system is in disrepute. I do not blame the nurses. They are overworked and underpaid.- - - - Some staff simply “do not know what they don’t know”.

279: I am a retired Professor of Aged Care Nursing. - - - - it must be blindingly obvious from all reports that Aged Care is in crisis. - - - - What concerns me is that people die after years of criminal neglect, without adequate nursing care.

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280: Aged care is like a monster that devours vast resources & finances, but with our population ageing, it must be addressed.

286: WAS EXCITED TO BE AT THE FORE FRONT OF PIONEERING 'A BETTER WAY'!! Now, 30+ years later, I am very disappointed with how I see aged care going in our society. I always thought that integral to care provision, was to demonstrate to our frail elderly, that they were VALUABLE individuals, worthy of quality care and respect. Sadly, we are failing miserably in achieving this! ---- we have a system which DEVALUES residents, tricks their families and loved one's by selling them poor staffing ratios and access to professionals in caring for their loved ones. ---- It is horrendous the deceit that prevails and anyone who is prepared to speak up to uncover it, is quickly 'short shrifted' out of the home, something that has happened to me personally a couple of times during my journey. IT DOESN'T PAY TO ROCK THE BOAT - - - - most are constantly looking for ways of reducing their costs. ---- most organisations, be they for profit or not, have hugely 'top heavy' hierarchies which consist of many very well paid executives who are 'once removed' from the realities occurring at the coal face. ---- I am - - - just someone who sees gross injustices occurring every day.

287: I am baffled by 'aged care palaces' that I worked in; facilities with magnificent interior design and no staff! - - - -Please can we focus on humanity for residents, rather than 'glamour'

288: Over the years I have watched the industry move from a care industry where christian agencies were trying to care for their community to a business whereby private operators are concerned about share profits rather than provision of care. ---- Everyone talks about a person centred approach to care but these are words only as our research demonstrates that the work is task focused
The system is broken and needs a complete overhaul

Source: *Future of Australia's aged care sector workforce. Inquiry by Senate Community Affairs References Committee 2016:* <http://bit.ly/1U3wvM0>

The extracts above are taken from a web page "Those who know". There is a large amount of additional information from other enquiries as well as other sources illustrating the way staff and families see and experience the aged care sector.

Those who know Inside Aged Care 2016 <http://bit.ly/2H1ryPp>

Comments on articles

Australian Ageing Agenda is a digital publication where those involved can add comment. Much of that is very critical not only of some industry articles but about what is happening and the direction the government is taking the sector. For example:

I worked as an agency worker for many years and the things I saw in nursing homes will haunt me forever

Source: *Comment on Frontline workers can help clients achieve adequate food intake Australian Ageing Agenda Aug 29, 2015* <http://bit.ly/2rXpeq9>

A 2015 article "Aged care staffing requirements 'too vague' NSW inquiry finds" in Australian Ageing Agenda described the heated parliamentary review in NSW into the requirement to have registered staff on duty at all times. The comments about the article made by staff and residents are revealing

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In regard to the Quality Agency the article indicated

The report noted there was “deep division” over the effectiveness of the Commonwealth’s aged care regulatory framework among the inquiry participants, which included providers and their peaks, GPs, nurses, unions, seniors advocates and researchers.

The accreditation standards did not prescribe the type of staff, qualifications required by staff or the number of staff who work in an aged care facility, the report noted. The way residential facilities were described by inquiry participants as being monitored and assessed against the accreditation standards was “troublesome,” it concluded.

Comments on this article :

By an AIN: In that 30 year period I have seen the ratio of six residents to one nurse (AIN) deteriorate to ten residents per AIN. The problem in aged care has always been the ratio of AIN’s to residents. The professionalism in aged care has also disappeared with the down grading of training. Aged care ‘on the floor’ work has always been unfortunately production line work and it has got worse, where there is often no time to even ensure your resident’s get a drink of water regularly through the day. In the 1980’s we had time to ensure people got a drink and exercise. The large turn over of staff and difficulty of getting staff would be due to the very nature of the pressure to move increasingly heavier people get their basic needs met and poor wages. In fact the pay is so poor there really should be more AIN’s on the floor.

The ‘hidden’ world of aged care is rife to elderly abuse and that can be as mild as pretending to shower someone to physical harm etc. Now that RN’s no longer ‘run’ their wards/wings there is no continuity of care, with AINs/PCA/s making up the care and changing it at will.

Basically it’s the old bottom line about money. No such thing as not-for-profit organisations, it’s an oxymoron and insulting. It’s about slight of hand, a hidden world away from the public eye.

Another AIN: Incidents occur regularly. It is literally impossible to keep on top of our workload and prevent incidents with our usual ratio of just under 1:10 which apparently we aren’t entitled to, we are just lucky to get it. When we brought up the fact that the impending shift had unsafe ratios we were basically told to suck it up. Despite the fact that the policy ratio for afternoons is an unsafe, but apparently “carefully researched” ratio of 1:12.

So I find myself apologising to the next shift (whose ratio is worse) and to families and residents when things aren’t done, or an incident happens. And I feel guilty for not providing the care these people deserve. And I go home exhausted and guilty and sore from trying to complete everything. Then the next day I get talked to about paperwork I have left undone because I was too exhausted to remember all the parts of paperwork needed for so-and-so’s ACFI.

So many of my workmates are considering quitting aged care. There’s better pay in the home care sector. One’s thinking of studying to be an accountant. I’ve seen at least 4 people who’ve been there for a couple of years quit, and 2 more are working their notice. Aged care is in crisis. It shouldn’t be for profit. It should be for best possible care.

An Aged Care staff critic: How else could one explain their (*provider representatives at the inquiry*) unwaivering conviction that the AACQA is diligently monitoring the care standards of residential facilities?

The public have been treated to yet another example of our peak bodies sabotaging their own credibility. What they say just doesn’t match the way it is. Aren’t they even just a little embarrassed by their suggestion that residents don’t need RNs 24/7 ? Or do they really believe emergency situations

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only occur during office hours?

Your track record indicates that you can't be trusted to do the right thing. Unskilled care staff, dangerously high resident to staff ratios and rosters that schedule one RN to oversee up to 180 residents are proof that we need more legislative intervention and less self-congratulatory backslapping from representatives with no understanding of what it's really like on the floor.

And another: It makes me feel sick to think that people believe in accreditation ... people who swoop in once in, tell you all is good with your nursing home, while your heart breaks as you know that the elderly deserve far better than they get. Its even more sad that we are so time poor, that we are like robots, injuries occur daily for staff and residents and you get please explain. This is not how our elderly should be treated.

And again: I have been in aged care for 10 years, starting as carer and moving on to nursing also in aged care. I now teach cert 111 and 4 and facilitate students on their placement. With all the students who go on placement the main feed back is always time, or lack of. Having been through the surprise visits by the accreditation teams at both levels, carer and nurse its amazing that the company always know a couple of weeks before they turn up;;; and surprise surprise we have more staff on the floor. My fellow teachers and I are doing the utmost to train good carers but its hard to beat the system that is currently out there. - - - - as most of us in the industry say I hope I do not have to go into a nursing home when I am old, how sad.

And from an anonymous resident in a nursing home: Thank you for a very thought provoking read. I am the a resident in an Aged care facility. I was looking for proof to back the conclusions I have formed while just sitting and watching. I intend to take my thoughts to the next residents meeting, not that they will listen to me and they will talk loudly over the top of me but I want to be sure that what I have to say is minuted. What I am looking for is to establish a paper trail. The staff here is over worked and in danger of burn out. I just hope I can help in some small way to get them the support they need.

Source: *Aged care staffing requirements 'too vague' NSW inquiry finds* Australian Ageing Agenda 4 November 2015 <http://bit.ly/2nuYCau>

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Lawyers who deal with family members are aware of the problems. Eg, in staffing

"Often there are too many patients to staff. The patients need constant attention and if they are neglected they can put staff at risk," he said.

"We're finding the staff are undertrained for this sort of thing and you'll find a 60-year-old slightly built woman looking after big and sometimes disruptive men.

"I'm hearing about injuries every day."

Source: Lawyer speaks out on 'unspoken crisis' in rest homes - Lawyers Weekly:
<https://www.lawyersweekly.com.au/sme-law/22514-lawyer-speaks-out-on-unspoken-crisis-in-rest-homes>

Comments by nurses to the 2017 Carnell/Paterson Review

Comment about the care of a nurse's parent in a chosen nursing home:

Anyway, 2 weeks after going into my last choice (of nursing home) and not a very good one, I attended on a Saturday morning and the RN asked would I like to check out the wound as she was going to dress it. She knew I was an RN too.

She took the dressing down and out dropped maggots and they kept coming, he was transferred back to a private hospital and once ok back to palliative care where they could not believe how much he had gone down hill in such a short time.

A clinical consultant described breeches in infection control:

- High rates of wound infections
- No special identification or specific care systems in place for infectious residents (MRSA, C Difficile, VRE, ESBL, etc)
- High percentages of residents (up to 90%) with fungal infections, dermatitis and eczema. (A quick look in the medication trolley would reveal appalling rates of skin infections at many facilities)
- These are often the result of poor infection control practices from care staff. (Communal showers and shared equipment not being correctly sanitised between use)
- Untrained/unsupervised care staff using gloves instead of washing their hands. It is common to see staff using the same gloves as they attend multiple residents. Infection control knowledge and education is universally poor.
- Several new facilities in Sydney have dispensed with fundamental infection control strategies because it doesn't fit their 5 star hotel image. Hand washing stations are hidden or non-existent.
- I have recently seen wash stations that use air blow-dryers instead of paper towels! (apart from being noisy and ineffective, it's also time consuming to dry your hands this way so staff just use alcohol rub instead...or nothing at all)
- One new facility's wash stations have the waste bin mounted next to the sink...staff have to manually remove the lid to dispose the hand towels and then replace the lid. The 'bin' is only 20cm deep so it is always overflowing with used paper towels.
- A cursory check of any medication trolley or clinical fridge will identify a range of creams, eye drops and other preparations that are either past their 'use by' date or have not been marked

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with a 'date of opening'.

- Last month I attended a large provider's facility that was accredited in May. Every needle and syringe in their clinical room had an expiry date of 2012. The main store room contained equipment with expiry dates as far back as 2001.
- It is common practice in many residential facilities that 'care rounds' are done by staff that go from room to room without adhering to any accepted infection control procedures. Contenance pads are simply changed without washing or moisturising the incontinent resident when the soiled pad is removed. (There's no special skill required to assess this practice...all you need to do is smell the poor residents...but then I suppose you actually have to get close to them to do this)

and in Nutrition and Hydration:

- The majority of frail residents are chronically dehydrated. A cursory check of the Urinary tract infection rates will confirm this. Surely the assessors should notice when water jugs are placed out of reach of frail residents or that there are no fresh snacks available at all times. And surely they should notice when residents are all put into bed by 4pm each afternoon...this means that instead of at least having everyone that requires assistance in the one place, the two or three care staff available to assist with feeding twenty residents have to rush from room to room, usually only having a cursory attempt at feeding a resistive resident their cold food.
- There are facilities that have over 80% of their residents on nutritional supplements. The agency will check they are prescribed and signed for but they don't ask why so many residents need them (Poor food, not enough staff to assist with feeds, etc.) And the list goes on...and on

A personal carer describes the result of impossible work loads:

What you are not seeing is the tasks not being done. Showers are left to residents to do - people who really require supervision. There are residents who will report they have showered when they haven't or have just washed their faces. Residents who don't buzz don't get assistance. They simply fly under the radar. Dirty clothes are worn again. Rooms are not cleaned properly. Rooms are filled with hazards.

No one checks jobs are being done or done properly. Important information is not handed over. The PCs are mostly trying hard to juggle tasks and provide care. We have residents listed as HHH ACFI who get almost no time or assistance from staff as they don't make a fuss and there is not time to get back to address their needs.

We need more resources to perform the tasks required and provide the care XXX is paid to deliver for residents and to keep staff safe.

The frustrating thing is the lack of linen, the poor cleaning, the poor maintenance, the phones not working, the hearing aids left with batteries in them, the fallout mats, and room hazards - have all been brought to the attention of various managers over many months. Repeatedly.

Eventually you don't bother reporting things anymore as it seems to fall on deaf ears. Instead we chastise PCs for asking for a brief prayer during Handover when the YYYY was going on or tell PCs to "get a job at Coles if you're unhappy". Hardly inspiring management practices and not what you expect when XXX push the Code of Conduct down our throats all the time. It is time for managers to start living the core values and earning the respect from the staff rather than demanding it.

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Additional sources with multiple links

- **19 years of care** Inside Aged Care 2016 < <http://bit.ly/2a4hiXE> >
This page provides an overview of what is happening and links to a web page “**Scandal after Scandal**” < <http://bit.ly/2aFe4dg> > which examines the recurrent failures in the aged care system in more detail with links to the sources.
- **Further reading** Aged Care Crisis 2015 < <http://bit.ly/2FmANwm> > contains links to more material about various aspects and problems in aged care
- **Corporate Medicine web site** A site with over 500 pages dealing with the corporatisation of health and aged care in the USA from the late 1980s and Australia from the early years after the changes in 1997. The problems that developed are documented, examined and analysed. A short note on the Australian < <http://bit.ly/2oDbWeo> > and US site maps < <http://bit.ly/2FcDoFM> > indicates the content of each web page.

There are 100 pages on Australian Aged Care. They can be accessed from the “*Wrinkle ranching - the aged care bonanza*” section of the main Australian web page.

< <http://bit.ly/2F96Alo> > or from “*Markets and the Aging Bonanza*” < <http://bit.ly/2H1WlpU> >

There are 66 pages on the US aged care system during the 1990s. These can be accessed from the “AGED CARE AND SUBACUTE CARE” section of the main US page.

< <http://bit.ly/2FfaRzm> >. An update page “Nursing Homes Update June 2001 to August 2003” < <http://bit.ly/2l3ZjkC> > could be describing Australia today.

Partial extract from submission to ALRC Issues Paper (2016)

(ALRC Inquiry into Elder Abuse) <http://bit.ly/2AMYyho>

5. Elder abuse: speak out ... if you dare

For most of the 18 years (since 1997) of the reformed aged care system, the victimisation of whistleblowers and the fear of retribution against family members in care have served to hide what has been happening.

This is a problem in almost every sector where people are vulnerable¹⁰³. Under the new 'Consumer Directed Care' (CDC) model, much of the care currently provided in nursing homes will be provided in the resident's own homes. Will providing care at home when the person receiving care will be alone with the person the family have complained about be any different?

Elder abuse and market forces: Under the new regime, where aged care will be exposed to much greater market forces, elder abuse may not be immediately obvious to uninitiated and inexperienced family members. Many are unaware of the real human costs involved for frail residents and the impact on their lives.

Feb 2016: Report - 'Who will keep me safe? Elder Abuse in Residential Aged Care' In October 2015, the NSW Nurses and Midwives' Association (NSWNMA) invited members to complete a survey regarding elder abuse¹⁰⁴. The report raised major concerns about the prevalence and management of elder abuse in residential aged care settings. When survey respondents were asked what they thought increased the risk of elder abuse in their workplace, almost 76% of respondents cited inadequate staffing as a precursor for elder abuse. In addition, 61% of staff feared repercussions if they reported elder abuse¹⁰⁵. Information we receive is congruent with this report.

In a competitive, corporate marketplace the vulnerable too often become simply 'beds' - in effect, depersonalised profit vehicles being managed for profit and when market forces dictate, traded on an impersonal corporate market¹⁰⁶. Businesses are sold to the highest bidder, the one who feels they can extract the most profit from these vehicles who, despite all the rhetoric about choice, still have no say in this.

These frail, older people need stability and do not shop around. This impersonal exploitation can in itself be a form of inadvertent elder abuse - integral to the market system. The instability inherent in a competitive market system places stresses on the services provided, creating a context where abuse more readily occurs but is less easily exposed.

A revolving door between providers, government, accreditation agencies, complaints schemes and the various programs implemented ensures that alternate views are marginalised and deficiencies consequently overlooked. Despite multiple changes, it is clear that problems in aged care persist and these regulatory structures have been singularly ineffective¹⁰⁷.

¹⁰³ 'Voiceless' disabled 'raped, bitten, burned' while in care (The Australian, 11 Apr 2015): <http://bit.ly/24dtvQO>

¹⁰⁴ (a) <http://www.abc.net.au/news/2015-02-16/bundaberg-nursing-home-assaults-prompt-aged-care-review-call/6119456>

(b) <http://www.brisbanetimes.com.au/queensland/woman-89-dies-after-nursing-home-assault-20130603-2nmpq.html>

(c) <http://www.adelaidenow.com.au/news/south-australia/south-australian-nursing-home-death-85-year-old-quizzed/story-e6frea83-1226376970258>

¹⁰⁵ <http://www.agedcarecrisis.com/opinion/your-say/211-i-am-sorry-mary-i-could-not-help-you>

¹⁰⁶ <http://www.smh.com.au/national/officials-asleep-on-nursing-care-20130212-2eb6d.html>

¹⁰⁷ <https://www.ombudsman.vic.gov.au/News/Media-Releases/Media-Alerts/Media-Release-Ombudsman-finds-a-%E2%80%98itany-of-failing>

Appendix 1 - Contrasting industry with families and staff

6.1 Aged care failures

Over the years, aged care residents in nursing homes have been raped¹⁰⁸, robbed¹⁰⁹, bathed in kerosene¹¹⁰, attacked by rodents¹¹¹, suffered injuries or death from other residents¹¹², burnt to death¹¹³, strangled¹¹⁴, cooked¹¹⁵, melted¹¹⁶, sedated to death¹¹⁷, overmedicated^{118 119}, endured horrific infected pressure sores¹²⁰ or choked to death¹²¹.

Some staff have amused themselves by taunting, teasing¹²² or mocking residents and playing demeaning games on them like 'spot the body part' (photos)¹²³, or rolled in tomato sauce¹²⁴. Some have endured DIY staffing (*no staff rostered on for over 10 hours at night*) in a fully accredited nursing home, resulting in recurring incidents of patients absconding, wandering and falling¹²⁵.

Family members have been kept in the dark^{126 127}, banned from visiting loved ones^{128 129} or bullied by facility staff after complaining about care¹³⁰. Some Coroner's reports are particularly revealing^{131 132}.

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- ¹⁰⁸ Shocking numbers of elderly women being abused in aged care homes (7 Jul 2014)
<http://www.theage.com.au/victoria/shocking-numbers-of-elderly-women-being-abused-in-aged-care-homes-20140706-3bg9w.html>
- ¹⁰⁹ (a) <http://www.9news.com.au/national/2015/07/02/18/45/victorian-retiree-sets-up-hidden-camera-to-catch-thieving-aged-care-worker#h0h6hxxa5RbKU3Zo.99>
(b) <http://www.news.com.au/national/breaking-news/former-nurse-avoids-jail-over-fraud/news-story/fb5bbeacb36b8b99e314d99208f151de>
(c) <http://www.perthnow.com.au/news/national/carer-stole-wedding-rings-from-elderly/story-fndo6axq-1226513639985>
- ¹¹⁰ Parliament hears kerosene bath led to death (ABC-PM) (8 Mar 2000) <http://www.abc.net.au/pm/stories/s108761.htm>
- ¹¹¹ Nursing home mouse infestation was present for months (CPSA):
<http://cpsa.org.au/aged-care/aged-care-media-releases/130-nursing-home-mouse-infestation-was-present-for-months>
- ¹¹² Residential aged care report says people are being shackled, assaulted and turned into 'zombies' (12 Nov 2013): <http://bit.ly/1QxtlsO> <http://www.theage.com.au/articles/2002/10/31/1036026978735.html>
- ¹¹³ Elderly nursing home resident died of burns in 'horrific circumstances', coroner to investigate (ABC - 8 May 2015)
<http://www.abc.net.au/news/2015-05-08/coroner-to-investigate-horrific-death-nursing-home-resident/6455368>
<http://www.smh.com.au/nsw/strangled-by-a-shower-cord-20110402-1csd2.html>
- ¹¹⁴ <http://www.smh.com.au/nsw/strangled-by-a-shower-cord-20110402-1csd2.html>
- ¹¹⁵ Nursing home blamed for patient's death (ABC - 1 Aug 2012)
<http://www.abc.net.au/news/2012-08-01/nursing-home-blamed-for-patient27s-death/4169466>
Coroner's written findings: <http://www.coronerscourt.vic.gov.au/home/coroners+written+findings/findings+-+071109+joan+ambrose>
- ¹¹⁶ Nursing home probe after woman 'melted to death' by a heater (Herald Sun - 8 May 2015)
<http://www.heraldsun.com.au/news/law-order/nursing-home-probe-after-woman-melted-to-death-by-a-heater/news-story/886f4c20f7fa2828189eb824c4af22e3>
- ¹¹⁷ Premature deaths linked to drugs in nursing homes:
<http://www.abc.net.au/news/2012-08-17/dementia-patients-dying-as-anti-psychotic-drugs-over-prescribed/4204536>
- ¹¹⁸ Death by medicine:
<http://www.smh.com.au/news/national/death-by-medicine/2007/08/17/1186857771586.html?page=fullpage#contentSwap1>
- ¹¹⁹ Aged care drug abuse that points to scandal - Amanda Vanstone
<http://www.theage.com.au/comment/aged-care-drug-abuse-that-points-to-scandal-20140105-30bni.html>
- ¹²⁰ Vaucluse Gardens Aged Care facility 'understaffed' on night 85yo Barbara Westcott died, inquest told (ABC - 15 Dec 2015):
<http://www.abc.net.au/news/2015-12-15/barbara-westcott-vaucluse-gardens-aged-care-inquest/7029220>
- ¹²¹ Vaucluse Gardens Aged Care facility 'understaffed' on night 85yo Barbara Westcott died, inquest told (ABC - 15 Dec 2015):
<http://www.abc.net.au/news/2015-12-15/barbara-westcott-vaucluse-gardens-aged-care-inquest/7029220>
- ¹²² Nurse made aged patients 'beg and suck his thumb' (SMH - 27 Sep 2013):
<http://www.smh.com.au/national/health/nurse-made-aged-patients-beg-and-suck-his-thumb-20130926-2ugz8.html>
- ¹²³ Body parts used in sickening 'game' at nursing home (Herald Sun - 13 Dec 2007)
<http://www.heraldsun.com.au/news/victoria/body-parts-used-in-sickening-game-at-nursing-home/story-e6frf7kx-1111115218203>
- ¹²⁴ Sacked nurse back at aged care home (The Advertiser, 17 Sep 2007):
<http://www.adelaidenow.com.au/news/sacked-nurse-back-at-aged-care-home/story-e6freo8c-1111114440870>
- ¹²⁵ (a) <http://bit.ly/1KtuS6J>
(b) <http://www.agedcarecrisis.com/opinion/articles/213-no-staff-for-10-5-hours-per-day>
- ¹²⁶ Aged Care complaints kept secret (The Age, 27 Sep 2014):
<http://www.smh.com.au/national/aged-care-complaints-kept-secret-20140927-10myjn.html>
- ¹²⁷ John Curtin Aged Care investigated after 89yo receives serious burns during sponge bath (ABC, 2 Aug 2016):
<http://www.abc.net.au/news/2016-08-02/john-curtin-aged-care-investigated-89-year-old-receives-burns/7683616>
- ¹²⁸ Loved ones 'locked out' of nursing homes (ABC Lateline, 21 May 2013): <https://www.youtube.com/watch?v=rV76MKCxEaQ>
- ¹²⁹ Woman denied access to dying mother condemns 'monstrous display of evil' by nursing homes (ABC, 9 Oct 2015): <http://www.abc.net.au/news/2015-10-08/woman-says-nursing-homes-denied-her-access-to-dying-mum/6838448>
- ¹³⁰ Aged care residents and families 'bullied by facility staff' after complaining about treatment, advocacy group says problem widespread (ABC, 28 Sep 2015) <http://www.abc.net.au/news/2015-09-28/aged-care-bullying-a-widespread-problem-says-advocate-group/6808234>

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Some family members (out of desperation) have taken their concerns to media¹³³, setup websites (or blogs)¹³⁴, established social media^{135 136} presences, published diaries of care online¹³⁷ or setup online petitions to have their concerns heard^{138 139 140 141}. Other family members have published detailed reviews, one commenting on the difficulties in obtaining records from an aged care home regarding the care of their father, who died after 4 weeks in respite:

“ ... I, as a relative, cannot get a hard copy of (my father’s notes) but an independent body is able to, read them on my behalf and decide whether my father was treated with respect and dignity. There is no legislation, which can make a care home give this information to a family. I will be advocating for this and feel that Aged Care Facilities need to be more transparent and accountable ...”

Source: *Why can't I get the records regarding my father's care? (Patient Opinion Australia):*
<https://www.patientopinion.org.au/opinions/62204>

Some have been threatened with letters of legal action¹⁴² and a few of these have refused to buckle. One health care worker who says she was sacked after blowing the whistle on severe understaffing and appalling patient conditions at a nursing home is suing her former employer for unfair dismissal:

Ms xxxxx told of shocking incidents she saw, including patients not being given -adequate pain relief and going days without showers.

“I’d come home from work distraught about the care the residents hadn’t received,” she said.

“Someone needs to stand up and say, ‘That’s enough’.”

Source: *Health care worker says she was sacked for blowing whistle on nursing home launches legal action, Gold Coast Bulletin, 3 Aug 2016*
<http://www.goldcoastbulletin.com.au/news/crime-court/health-care-worker-says-she-was-sacked-for-blowing-whistle-on-nursing-home-launches-legal-action/news-story/c2e25294d4909b9f093c1efa946b8fb8>

At one public meeting, family members recanted allegations that frail residents were mistreated at a nursing home already connected to claims a lady (twice) had to have maggots removed from a wound¹⁴³.

¹³¹ <http://www.theage.com.au/victoria/aged-care-home-covered-up-death-of-resident-20131218-2zl0p.html>

¹³² <http://www.heraldsun.com.au/leader/east/coroner-seeks-more-evidence-on-death-of-elderly-woman-cared-for-at-templestowe-nursing-home/news-story/80d1aa9cc1c888f72b1e8a78f96f41db>

¹³³ Anger at quality of Canberra nursing home food, hygiene (13 Sep 2014)

<http://www.canberratimes.com.au/act-news/anger-at-quality-of-canberra-nursing-home-food-hygiene-20140912-10g5ir.html>

¹³⁴ Stand Up 4 Better Aged Care - Abuse and neglect in Australian nursing homes: <http://www.standup4betteragedcare.com>

¹³⁵ **facebook:** Nursing Homes in Australia - Time For Change:

<https://www.facebook.com/pages/Nursing-Homes-in-Australia-Time-For-Change/409772765798275>

¹³⁶ **YouTube:** Story following four families who try to discover what happened to their loved ones in nursing homes in Australia:

<https://www.youtube.com/watch?v=8t03loPwSLk>

¹³⁷ Online diary relates the experience of 82yo “Jean” as she attempted to ensure that her husband received adequate aged care during the last years of his life: <http://www.agedcarecrisis.com/opinion/your-say/318-a-fly-on-the-wall-in-hell>

¹³⁸ **change.org** petition by family members concerned about employment process of hiring staff in aged care: <https://www.change.org/p/health-minister-stop-ignoring-aged-care-safety-don-t-let-opal-s-negligence-kill-more-victims>

¹³⁹ **change.org** petition by family member concerned about accreditation of aged care homes:

<https://www.change.org/p/prime-minister-malcolm-turnbull-pm-turnbull-the-life-of-a-nursing-home-resident-is-often-one-of-misery-will-you-help>

¹⁴⁰ **change.org** petition by staff member concerned about staffing

<https://www.change.org/p/bupa-aged-care-encourage-bupa-aged-care-worldwide-to-focus-on-residents-not-154-profits>

¹⁴¹ **change.org** petition by devastated family member whose mother died in a nursing home

<https://www.change.org/p/health-minister-stop-ignoring-aged-care-safety-don-t-let-opal-s-negligence-kill-more-victims>

¹⁴² Care crusade: <http://www.smh.com.au/national/care-crusade-20130824-2sij.html>

¹⁴³ Nursing home in the spotlight over abuse claims: <http://www.abc.net.au/local/stories/2013/10/09/3865387.htm>

YouTube: <https://www.youtube.com/watch?v=TQiqbN1flec>

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In another home, staff complained of “*maggots crawling over the floor and a lack of basic infection control equipment such as gloves and liquid soap*”¹⁴⁴. We have also seen stories of overgrown nails, untreated infections, medication mix-ups, and research showing up to 80% of aged care residents are malnourished and reports of dehydration¹⁴⁵.

There are cases of residents dying prematurely because of over-prescription of anti-psychotic medication¹⁴⁶. Many are suffering needlessly from untreated infections, urinary tract conditions¹⁴⁷ and pressure injuries, lying in soaked pads brimming with urine and faeces (compromising skin condition) for hours¹⁴⁸ on end because there are not enough care staff to clean or turn them regularly. Then there are the cases of rationing of incontinence pads¹⁴⁹ with a daily ‘limit’, to save on costs.

The majority of correspondence we receive is due to a critical lack of trained staff, leaving many to die unnecessarily, in great pain¹⁵⁰, or without proper palliative care¹⁵¹. One partly blind frail patient admitted to a NSW hospital from her aged care home after a serious fall, was forced out of the hospital with an eviction notice (which was read out loud to her in a crowded ward, which must have been quite humiliating). This was despite protestations from her low-care home that she needed acute care¹⁵².

Research has indicated that many resident transfers might be avoidable with better primary care in place including staff skill mix, primary care services¹⁵³ and that inadequate documentation negatively impacts on the resident’s journey through emergency departments¹⁵⁴.

It is also of considerable concern that the sector now relies, to a large extent, on the employment of inexperienced carers; some have poor English language skills and are unable to communicate effectively with residents. One recent case in this instance included the death of an older woman who had difficulty communicating with her carers¹⁵⁵. Her son at the inquest contended that as his mother did not speak fluent English, the language barrier might have seemed like she was being uncooperative with carers. This illustrates the potentially dangerous consequences of communication barriers and the need for multilingual staff working in the sector.

Other family members have appealed to their local or state-based politicians around Australia for support or help. Although rare, some politicians have recorded the concerns of their constituents in parliament¹⁵⁶.

¹⁴⁴ Scabies found in nursing home: <http://www.smh.com.au/articles/2003/05/21/1053196640611.html>

¹⁴⁵ Shining the light on nutrition in aged care facilities: (Alzheimer’s Australia, 9 May 2014) <https://fightdementia.org.au/news/shining-the-light-on-nutrition-in-aged-care-facilities>

¹⁴⁶ Doctors could face prison over drug prescriptions (ABC Lateline, 29 Aug 2012): <http://www.abc.net.au/lateline/content/2012/s3579035.htm>

¹⁴⁷ <http://www.smh.com.au/nsw/elite-nursing-home-under-investigation-20121110-294u4.html>

¹⁴⁸ Nursing home care in crisis <http://www.couriermail.com.au/news/nursing-home-care-in-crisis/story-e6freow6-1111115005107>

¹⁴⁹ This open letter was written by a person with a family member in a nursing home (9 Nov 2015): <http://www.agedcarecrisis.com/opinion/your-say/360-the-oleander-project>

¹⁵⁰ <http://www.news.com.au/lifestyle/health/hospital-complaint-about-wwii-veteran-posted-to-youtube/story-fneuzlbd-1226657953493>
Australian War Veteran dies in pain: https://www.youtube.com/watch?v=xn_KOlFK0Rc

¹⁵¹ Aged care crisis (ABC Lateline, 15 Jul 2013): <http://www.abc.net.au/lateline/content/2013/s3803710.htm>

¹⁵² <http://www.smh.com.au/comment/agedcare-response-a-true-test-of-societys-caring-20150824-gj6a8b.html>

¹⁵³ Resident transfers from aged care facilities to emergency departments: can they be avoided? *Faculty of Medicine, Nursing and Health Sciences, Monash University*: <http://www.ncbi.nlm.nih.gov/pubmed/26095333>

¹⁵⁴ Shortfalls in residents' transfer documentation: challenges for emergency department staff *School of Nursing & Midwifery, Monash University*: <http://www.ncbi.nlm.nih.gov/pubmed/25113312>

¹⁵⁵ ABC News: Home care examined after 75yo Perth woman died with infected pressure wounds(4 Jul 2016) <http://www.abc.net.au/news/2016-07-04/inquest-into-death-of-perth-woman-maria-niceforo-kincare/7567784>

¹⁵⁶ The Need to Improve the Accreditation Standards for Aged Care Facilities Speech (Anthony Byrne MP – 5 Jun 2014: <http://anthonybyrnemp.com/category/speeches/page/6>

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ABC Lateline has exposed widespread human rights abuses in Australia's aged-care industry. The series found many vulnerable people are suffering abuse and neglect in Commonwealth-accredited facilities with little accountability¹⁵⁷.

There is an abundance of information for those who want to look^{158 159 160}.

Residents acting themselves

Residents and their families are at an even greater disadvantage. If they are unhappy about anything or make allegations, they are considered to have dementia and discounted. If they or their families do speak out publicly, then staff and management see them as troublemakers and treat them accordingly. The lady in the quote below knew she was being robbed and had contacts in the surveillance industry. With a hidden "grannycam", video footage was soon in the hands of police. She is leading the way by doing this in Australia.

In countries with market systems like ours (UK and the USA) CCTV is increasingly being seen as the answer to the problems of elder abuse we are having in nursing homes. The regulator in the UK, the Care Quality Commission, publishes guidelines on how to do so¹⁶¹.

“... When the disabled 75-year-old attempted to report the incident to retirement village company (xxxxx), they dismissed her claims. "They thought I had dementia - and for that reason I was a trouble-maker and I would have been making it up," Ms (xyz) said.

Source: Victorian retiree sets up hidden camera to catch thieving aged care worker - Channel 9 News, 2 Jul 2015 <http://bit.ly/1CcHCdV>

Family members ignored

When family members reported their father was being abused to management, their concerns were dismissed. Distraught for their father's safety, they installed a video camera in his private room and caught the suspect abusing their father in broad daylight when a video camera was recording for 48 hours. The perpetrator was charged with several criminal assault charges ranging from recurrent torment, physical abuse and attempted suffocation.

If that is what is revealed in 48 hours, what would we find if everyone had this option?

As a result of their experience, the family are petitioning for video surveillance cameras in residents rooms in aged care¹⁶². The change.org petition has accumulated nearly 43,000 signatures, with thousands of comments by concerned supporters. This has been an ongoing concern¹⁶³.

¹⁵⁷ Aged care crisis (excerpt) - Human Rights Awards 2013: <https://www.youtube.com/watch?v=w1DVpMPxno0>

¹⁵⁸ 19 Years of care: <https://www.insideagedcare.com/aged-care-analysis/19-years-of-care>

¹⁵⁹ Scandal after scandal: <https://www.insideagedcare.com/aged-care-analysis/19-years-of-care/scandal-after-scandal>

¹⁶⁰ Those who know: <https://www.insideagedcare.com/aged-care-analysis/19-years-of-care/those-who-know>

¹⁶¹ Care Quality Commission - Using hidden cameras to monitor care: <http://www.cqc.org.uk/content/using-hidden-cameras-monitor-care>

¹⁶² <https://www.change.org/p/australian-human-rights-commissioner-advocate-rights-video-surveillance-cameras-vulnerable-peoples-safety>

¹⁶³ Santoro admits flawed response to nursing home abuse: <http://www.abc.net.au/am/content/2006/s1575471.htm>

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change.org petition:

Without a voice and evidence elderly people have **no ability to protect themselves from abhorrent abuse, assault and neglect.**

My father (89y.o. with dementia, bedridden, non verbal and frail) was physically/mentally abused and tormented in Residential High Care facility by a male staff carer over many months.

I became suspicious of my father being abused. My **concerns were dismissed** by Management. Frustrated and distraught for the safety of my father I installed a video camera in his private room and caught the suspect abusing my father in broad daylight while he was feeding him lunch.

Source: <http://chn.ge/2cpOP3H>

The daughter when interviewed, commented that she felt she had no option to protect her father and was prepared to go to jail:

(nursing home's) response when South Australian Police detectives showed the secret footage to management was to forbid Ms Hxxx from any further recordings.

"Instead of offering Ms Hxxx empathy, they instead sent her a letter to cease and desist from filming, as if she was the problem," Mr Dxxx, lawyer for the (family), told 7.30.

"[nursing home] said that I had breached [the] Privacy Act, the Aged Care Act and Video Surveillance Act," Ms Hxxx said.

Mr Dxxx said Ms Hxxx was fortunate the evidence she collected was found admissible and that it led to the successful conviction of Lxxx.

"I was prepared to go to jail for whatever I did and if I'd breached whatever [nursing home] said I'd breached, I would be responsible for all that," Ms Hxxx said.

"But to me I had no option but to do what I did to protect my father."

Source: <http://ab.co/2a9PNeg>

Despite both the complaints system and accreditation of aged care homes being updated, renamed, claims of 'independence' or 'strengthened' in response to pressures from the community or after recurrent scandals in the sector, **at no stage have the underlying problems or the disenfranchisement of the community been addressed.**

As a consequence, the system of oversight has become ever more onerous for nursing home staff and the community ever more disenchanted with the information provided and the way complaints are addressed.

The importance of whistleblowers: The vast majority of reports are based on or consequent of tip-offs by whistleblowers - either nurses in the system, or the relatives of residents. Staff who tried to complain to their superiors have been ignored^{164 165} or fired¹⁶⁶. Others were fired after speaking out or going to the media. They are seen as troublemakers and struggle to find another job in the sector.

¹⁶⁴ Care allegedly turned to crime (The Age, 15 Jul 2006) <http://bit.ly/21196YE>

¹⁶⁵ I am sorry Mary, I could not help you: <http://www.agedcarecrisis.com/opinion/your-say/211-i-am-sorry-mary-i-could-not-help-you>

¹⁶⁶ Death in a five star nursing home (ABC Radio National, 21 Sep 2014): <http://ab.co/Z3RSCH>

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Speaking out about failures and institutional elder abuse is always stressful and confronting. Because the only oversight system, "accreditation" is failing so badly, we have no choice but to depend on whistleblowers for the information we get.

The Aged Care Complaints system has not been productive in resolving these types of issues, leaving many family members and staff traumatised. Sadly, the system frustrates the exposure of deficiencies instead of supporting it.

The stories below, are further examples of situations where vulnerable people experience elder abuse and neglect, family or staff were not listened to, were disregarded and discredited, or blatantly bullied:

- **18 Mar 2016: Disabled people experience violence, elder abuse and neglect in 'epidemic proportions', says rights group:** *"... Other case studies outlined in the submission include allegations of staff at an aged care group home stuffing tissues into the mouth of a resident to prevent them from calling out and multiple claims of boarding house proprietors sedating and drugging disabled residents ..."*
<http://www.abc.net.au/news/2016-03-18/disabled-people-experience-violence-abuse-and-neglect/7256198>
- **7 Mar 2016 : Newcastle nursing home accused of failing to deliver care, resulting in elderly resident's death:** *"... The Newcastle nursing home at the centre of a year-long police investigation, where a staff member was charged with poisoning three elderly residents in late 2013, has now been accused of failing to deliver the proper standard of care in another elderly resident's unrelated death earlier that year ... I think the failures in care that we believe have occurred in this facility broadly reflect the failures in care that we have seen up and down the state and across the country ..."* <http://ab.co/1p1JnEz>
- **7 Mar 2016: Former aged carer speaks out at parliament meeting:** *The carer said she witnessed failures of duty of care "on a daily basis and when I lodged formal complaints to supervisors I was told leave it with them, but they only went through the motions". The carer resigned in 2015 in heartbreak and frustration after just under 12 months. "If some of the staff took a set against a client, they would neglect them, for example deliberately make them miss out on a bath or a shower, or not perform other care tasks," "People like me who were prepared to stand up got bullied and ostracised," she said.*
<http://www.ulladullatimes.com.au/story/3767475/resigned-in-heartbreak-and-frustration/>
- **6 Mar 2016: My Dad was given drugs 'like potato chips': how the elderly are being restrained:** *A palliative care clinical nurse consultant and lecturer in nursing, said her dad was given a lot of olanzapine, a lot of risperidone. "He just kept getting it like potato chips," she said. She said it took 10 days to detox her father when he was moved to another health facility that took a different approach to the use of drugs.* <http://bit.ly/1Qzum7M>

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Further examples below, are from disability care where a similar situation exists. In one, it is only coming to light 20 years later:

“...People with disabilities have been found severely neglected, repeatedly raped, with broken bones and left humiliated in their own faeces for hours at a time, a Senate inquiry has been told.

Ms Richards said people with disabilities often did not report abuse because they feared retribution from people within the facility they lived in.

"They are very vulnerable and unable, more often than not, to speak up for themselves," she said.

"They are worried about retribution ..."

Source: *People with disabilities raped, beaten, neglected while in care, hearing told ABC News 10 April 2015* <http://www.abc.net.au/news/2015-04-10/disability-hearings-in-perth-report-rape-neglect/6384308>

Illustrative of the way in which these things are swept under the carpet and ignored is something that happened 20 years ago, which those involved, are only now speaking out about. There are many more examples.

“... The wheels of the self-protecting Victorian bureaucracy were turning, making sure that the complete story of the shameful treatment of the Mornington Peninsula residents would stay hidden ...”

Source: *Disabled were abused in house of horrors and governments covered it up The Age, 11 April 2015* <http://bit.ly/2FnA7qH>

Speaking out about failures and institutional elder abuse is always stressful and confronting. Because the only oversight system, "accreditation" is failing so badly we have no choice but to depend on whistleblowers for the information we get.

Despite the criticism and evidence of failures, government and industry continue to describe accreditation and the equally criticised complaints system as "robust". They use it to discredit critics. This is intolerable and both need to be replaced by fully transparent systems where civil society itself has control and oversight.

November 2015: A Senate Committee Inquiry (below) found a royal commission is needed into the abuse of people with disabilities in care, including aged care^{167 168}, after the inquiry called the evidence "shocking" and "cruel" examples of violence and neglect around Australia¹⁶⁹.

¹⁶⁷ Senate Community Affairs References Committee: 11 Feb 2015
Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability
http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report

¹⁶⁸ Senate calls for royal commission into assaults in care (1 Dec 2015);
<https://www.thesenior.com.au/news/senate-calls-for-royal-commission-into-assaults-in-care/>

¹⁶⁹ Inquiry calls for royal commission into widespread institutional abuse of people with disability in institutional and residential settings: (ABC, 26 Nov 2015), <http://ab.co/1KLKhz8>
<http://www.abc.net.au/news/2015-11-26/widespread-violence-of-people-with-disability-in-institutions/6974798>

Appendix 1 - Contrasting industry with families and staff

The Inquiry report¹⁷⁰ found existing abuse reporting mechanisms did not provide adequate protection, and in some cases could cause abuse¹⁷¹.

Senator Siewert presented the report of the *Community Affairs References Committee on the treatment of people with disability in institutional and residential settings*, together with the Hansard record of the proceedings and documents presented to the committee:

Senator Siewart: We heard accounts of violence, abuse and neglect in institutional settings, in residential conglomerate settings, in schools, in aged care – across the board. **Nobody at all in this country can say that this is not happening. This report clearly articulates that...**

... The other issue that came up really strongly and repeatedly was the need for national workforce and workplace regulation to address some of the systemic workforce and workplace issues that increase the prevalence of violence, abuse and neglect. There is a need for ongoing training, so we are calling on the government to consider the implementation of such a process.

One of the key things here was access to justice and the denial of justice for people with disability.

Not only were people scared to report assault, abuse and violence, but when they had the strength to and could report it **they were not believed** by the police, by the service provider, by the judicial system.

People were told: 'No, this would never stand up in court. People wouldn't believe you as a witness because you've got a disability,' and this was particularly so for those people with a cognitive impairment.

So, even when people could report it, they were not believed.

... We need to be working at a national level, and our states and territories also need to be working on this issue. **I will come back to the issue of data because it came up again and again.** I am sure Senator Moore will also address the issue around data, because it comes up for us again and again...

Source: Community Affairs References Committee - (25 Nov 2015) <http://bit.ly/2tcpLoQ>

Nurse academics speak out: Nurse academics from university departments have written theses and articles on their findings. They have accepted their responsibility as academics and spoken out about what they have seen and found. Instead of addressing their findings and criticisms, like Gillian Triggs¹⁷², they have been attacked, their research criticised and their universities asked to discipline them.

This is one example - there are others:

¹⁷⁰ **Report:** Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability:
http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report

¹⁷¹ Senate to hold inquiry into abuse of disabled people following Yooralla case: <http://bit.ly/21cfGyJ>

¹⁷² <http://www.abc.net.au/news/2015-06-12/gillian-triggs-says-she-has-not-considered-resigning/6540862>

Appendix 1 - Contrasting industry with families and staff

“... The other thing that I wanted to talk to you about was the issue of research in aged care and the issue of researching in residential aged care. When Prof ... published her PhD in the mid 90s she was banned from residential aged care facilities on the mid north coast because her findings were adverse to those wanted by the industry.

“... I have been subjected to threats of violence, verbal abuse, constructive dismissal. I've had contracts terminated and we sold our home and moved to another town because of the professional bullying that I was undergoing because I was revealing the outcomes of that PhD research ...”

Source: *Productivity Commission Inquiry - Caring for Older Australians: - evidence of Dr Bernoth: Transcript of Proceedings - see pages (39) 1371 (Canberra, 5 Apr 2011)*
<http://www.pc.gov.au/inquiries/completed/aged-care/public-hearings/20110405-canberra.pdf>

Appendix 2 - Ownership type, staffing and care

This is an extract from our supplementary submission to the senate workforce committee on 28 Nov 2016 (pages 23 to 27). Because it was submitted to the 45th parliament and not the 44th it was published but not considered for the final report.

Staffing of nursing homes and ownership type

One of the most heavily studied parameters in the USA has been the ownership structure of the facilities. This has been shown to have a major impact both on staffing levels and on the objectively collected data of performance, particularly failures in care.

Little effort has been directed to assessing the important parameters of corporate culture, facility culture, staff motivation and morale or the patterns of relationship between staff and residents/families – the quality of life. Because corporate objectives in profit-focused entities are often so different from those of staff, this is more likely to become an issue. It is something we need to measure to understand the impact.

Since 1997 in Australia when the probity requirements were replaced by the approved provider process, politicians and bureaucrats have strongly asserted that it was the managers of the provider and not the owners who were important for care. All the regulatory effort has focused on the local facilities and on managers. This belief flies in the face of evidence.

The second pillar of their arguments has been the alleged strengths and effectiveness of the “rigorous” Accreditation process. While the industry and the Quality Agency continue to support these claims, politicians have gone silent. None of these claims stands up to any sort of evidence based or logical arguments.

Analysis of structure and staffing in the USA

There have been multiple studies in the USA since 1994 that have documented the lower levels of staffing and the increased number of deficiencies in care in nursing homes by the large for-profit chains including those owned by private equity^{173 174 175 176 177 178 179}. This has also been found in Canada¹⁸⁰.

Further studies have shown that the performance of private equity owned nursing homes on both of these measures is worse than the market listed chains and continue to deteriorate the longer the facilities are owned by private equity.

¹⁷³ Harrington C, Schnelle J F, McGregor M, Simmons S F. The Need for Higher Minimum Staffing Standards in U.S. Nursing Homes Harrington C et al Health Serv Insights. 2016; 9: 13–19 <http://bit.ly/2fHPvhB>

¹⁷⁴ Non-Profit vs. For-Profit Nursing Homes: Is there a Difference in Care? Center for Medicare Advocacy accessed Nov 2016 <http://bit.ly/1SJcMLJ>

¹⁷⁵ “Money or Mercy” multiple reports of a 6 month study Tampa Tribune 15 November 1998

¹⁷⁶ Fernandez E Low Staffing and Poor Quality of Care at Nation's For-Profit Nursing Homes University of California San Francisco 29 Nov 2011 <https://www.ucsf.edu/news/2011/11/11037/low-staffing-and-poor-quality-care-nations-profit-nursing-homes>

¹⁷⁷ Harrington H, Olney B, Carrillo H, and Kang T Nurse Staffing and Deficiencies in the Largest For-Profit Nursing Home Chains and Chains Owned by Private Equity Companies Health Research and Education Trust 2011 DOI: 10.1111/j.1475-6773.2011.01311. <https://www.ncbi.nlm.nih.gov/pubmed/22091627>

¹⁷⁸ Nursing home data compendium 2015 edition Centre for Medicare & Medicaid Services <http://go.cms.gov/2f5STGH>

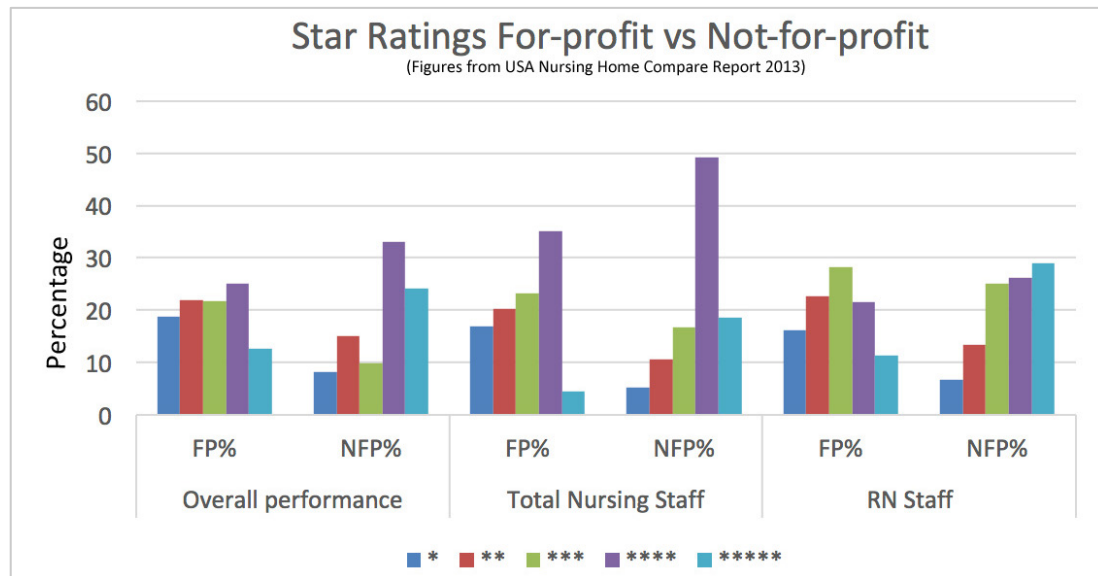
¹⁷⁹ Nursing Home Compare Five-Star Quality Rating System: Year Three Report Center for Medicare & Medicaid Services 7 June 2013 <http://go.cms.gov/2gKgyxs>

¹⁸⁰ McGregor M J, Cohen M, McGrail K, Broemeling A M, ., Adler R N, Schulzer M, Ronald L, Cvitkovich Y, and Beck M Staffing levels in not-for-profit and for-profit long-term care facilities: Does type of ownership matter? CMAJ. 2005 Mar 1; 172(5): 645–649. <http://bit.ly/2f9UP0P>

Appendix 2 - Ownership type, staffing and care

The Nursing Home Compare web site uses a five star rating system to inform potential clients. It is based on staffing and on overall performance including health inspections and quality measures. Its report (*Footnote: 179*) gives a comparison of for-profit and not for profit facilities. The not-for-profits outperform for-profits in overall performance in total staffing and in registered nurses (*see Figure 3*).

Figure 3: Analysis of performance when comparing for-profit vs not-for-profit



The charts show the percentage of each group that were awarded star ratings. Note that in every comparison, the for-profits have larger numbers in the poor one and two star columns. The not-for-profits outperform the for-profits in every four and five star column, the best performers.

The CMS Nursing Home Data Compendium 2015 Edition¹⁸¹ documented the findings between 2010 and 2014. The supplementary tables show that Not-for-profits had consistently lower failure rates overall including for: Actual Harm or Immediate Jeopardy, substandard quality of care, citations for use of restraints and Pressure ulcers.

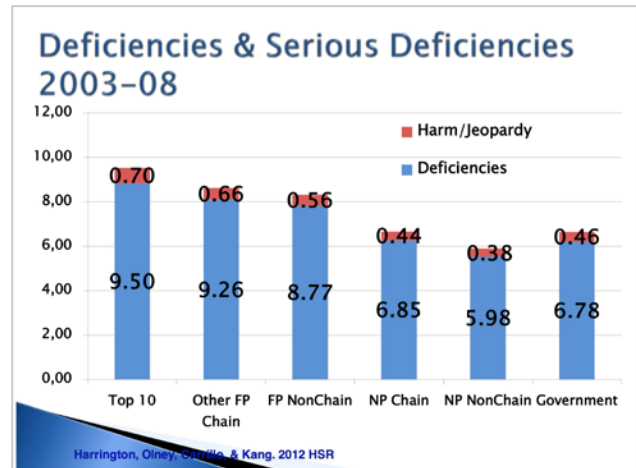
An article¹⁸² to a Normacare organised seminar “*Marketisation in Nordic eldercare*” in Stockholm in 2013, and charts¹⁸³ from a presentation to that seminar by Professor Charlene Harrington UCSF School of Nursing, bring it all together. She has been involved in many of the major analyses of the USA data and written about it extensively.

¹⁸¹ Nursing home data compendium 2015 edition Centre for Medicare & Medicaid Services <http://go.cms.gov/2f5STGH>

¹⁸² Harrington C - Understanding the relationship of nursing home ownership and quality in the United States - Marketisation in Nordic eldercare: A research report on legislation, oversight, extent and consequences Stockholm Studies in Social Work 30 2013 Chapter 8 page 229 <http://bit.ly/2fEBPUv> (Poor care persists and visits easily gamed FP and NFP differences. FPs able to market in spite of poor quality and more lawyers to fight regulators and politicians, (weak, decentralized regulatory system)

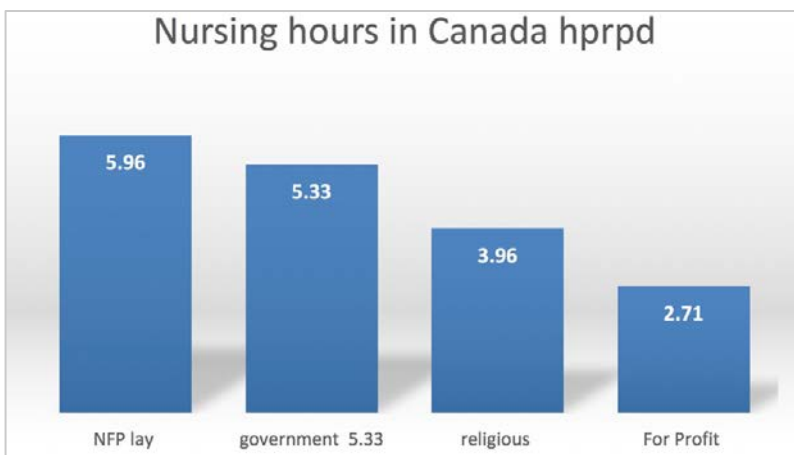
¹⁸³ Harrington C. USA Quality differences in For-profit and Not-for-profit Nursing Homes Presentation to Normacare conference - Marketisation in Nordic eldercare 2013 <http://bit.ly/2gjlxku>

Appendix 2 - Ownership type, staffing and care



The charts from Harrington’s presentation compare the most aggressive top 10 market for-profit chains with other for-profit chains, and with non-chain (private) for-profits and then the more profit focused non-profit chains, non-chain non-profits and government facilities.

The graphs show how the increasing pressures for profitability impact staffing and care in the far more regulated USA system. Private equity is not separated out. Canadian figures also show the for-profit owned facilities staffing poorly.



Canada: Figures show a different pattern but staffing in for-profits facilities are also by far the lowest at 2.71 hprpd

(Figures from Banerjee A. An Overview of Long-Term Care in Canada and Selected Provinces and Territories¹⁸⁴)

Studies of private equity in the USA

The Australian Senate Standing Committee on Economics Inquiry investigating Private Equity investment in 2006/7 rejected arguments^{185 186} that Private Equity posed a threat to our health and aged care systems in its final report¹⁸⁷.

On 20 August 2007, exactly one month later the *New York Times* wrote the first major analysis¹⁸⁸ of the impact of private equity in aged care.

¹⁸⁴ Banerjee A. An Overview of Long-Term Care in Canada and Selected Provinces and Territories Women and Health Care Reform October 2007 <http://bit.ly/2fRhone>
¹⁸⁵ Wynne J M. Submission 3 The Senate Standing Committee on Economics Inquiry 2007 <http://bit.ly/2gjCCO4>
¹⁸⁶ dela Rama M. Submission 5 The Senate Standing Committee on Economics Inquiry 2007 <http://bit.ly/2gowIOR>
¹⁸⁷ Private equity investment in Australia The Senate Standing Committee on Economics Inquiry 2007 <http://bit.ly/2gDfRW6>
¹⁸⁸ More Profit and Less Nursing at Many Homes The New York Times, 23 Sep 2007 <http://nyti.ms/2gow6DA>

Appendix 2 - Ownership type, staffing and care

USA studies have since shown that private equity owned facilities perform more poorly^{189 190} than all other for-profit facilities in regard to both staffing and care and one found that both continued to deteriorate^{191 192} the longer the facilities were owned by private equity.

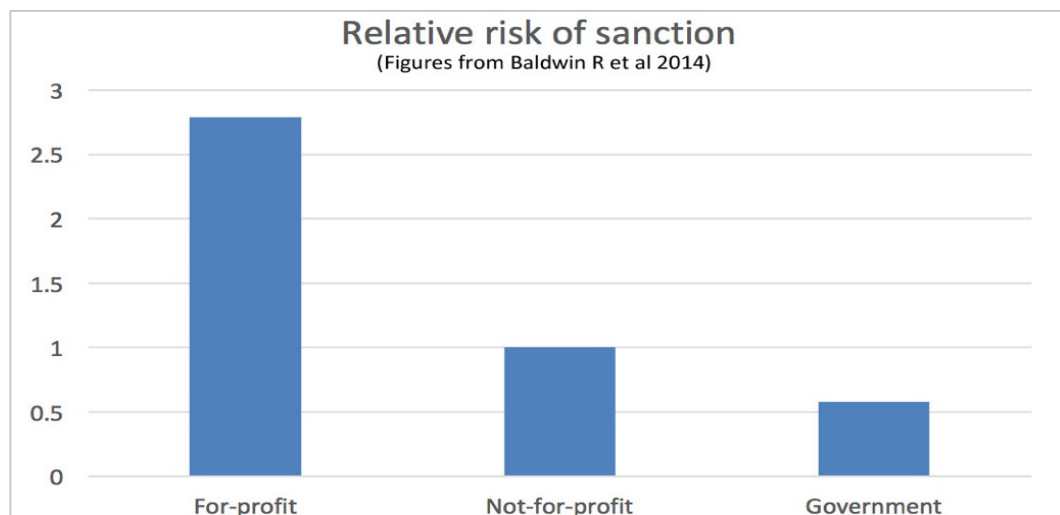
Private Equity has been a major problem in the UK¹⁹³ and is blamed for much of the disastrous state of their aged care system. Problems have recently developed in Private Equity owned facilities in Australia (*Footnote: 193*).

Analysis of structure and staffing in Australia

The 2014 Kaiser commission report¹⁹⁴ of which Harrington was a co-author and its supplemental tables¹⁹⁵ was able to provide detailed data on 175 types of deficiency over the years 2009 to 2014. Australia does not collect this sort of data and similar analysis is not possible. Available evidence suggests that if it did the findings in Australia would be similar. We do not have the data to compare staffing in Australia but the likelihood that a similar situation exists must be high.

Sanctions: Baldwin et al in 2014¹⁹⁶ compared the incidence of sanctions in Australia. They showed that the relative risk that for-profit facilities would be sanctioned for failures in care was 4.8 times that of government facilities and 2.79 times that of not-for-profit facilities (**Figure 4**). In a subsequent article and several opinion pieces, the direction current Australian policy is taking us is questioned.

Figure 4: Study comparing incidence of sanctioned nursing homes in Australia by ownership type



¹⁸⁹ Fernandez E Low Staffing and Poor Quality of Care at Nation's For-Profit Nursing Homes University of California San Francisco 29 Nov 2011 <http://bit.ly/2fTWG9q>

¹⁹⁰ Harrington H, Olney B, Carrillo H, and Kang T Nurse Staffing and Deficiencies in the Largest For-Profit Nursing Home Chains and Chains Owned by Private Equity Companies Health Research and Education Trust 2011 DOI: 10.1111/j.1475-6773.2011.01311. <https://www.ncbi.nlm.nih.gov/pubmed/22091627> (Private equity)

¹⁹¹ Nursing Facilities Owned by Private Equity Firms: Fewer Nurses, More Deficiencies Center for Medicare Advocacy Accessed November 2016 <http://www.medicareadvocacy.org/nursing-facilities-owned-by-private-equity-firms-fewer-nurses-more-deficiencies/>

¹⁹² Pradhan R, Weech-Maldonado R, Harman J S, Al-Amin M, Hyer K Private Equity Ownership of Nursing Homes: Implications for Quality Journal of Health Care Finance Vol 42 no 2 June/July 2014 pages 1-14 <http://healthfinancejournal.com/index.php/johcf/article/view/12/15>

¹⁹³ Private Equity - Inside Aged Care: <https://www.insideagedcare.com/aged-care-analysis/aged-care-marketplace/private-equity>

¹⁹⁴ Harrington C and Carrillo H. Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2009 Through 2014 The Kaiser Commission on Medicaid and the Uninsured <http://bit.ly/2gACZEe>

¹⁹⁵ Harrington C, Carrillo H. Nursing Facilities, Staffing, August 2015 Residents and Facility Deficiencies, 2009 Through 2014 Kaiser Supplemental tables Commission on Medicaid and the uninsured <http://bit.ly/2ggIYPy>

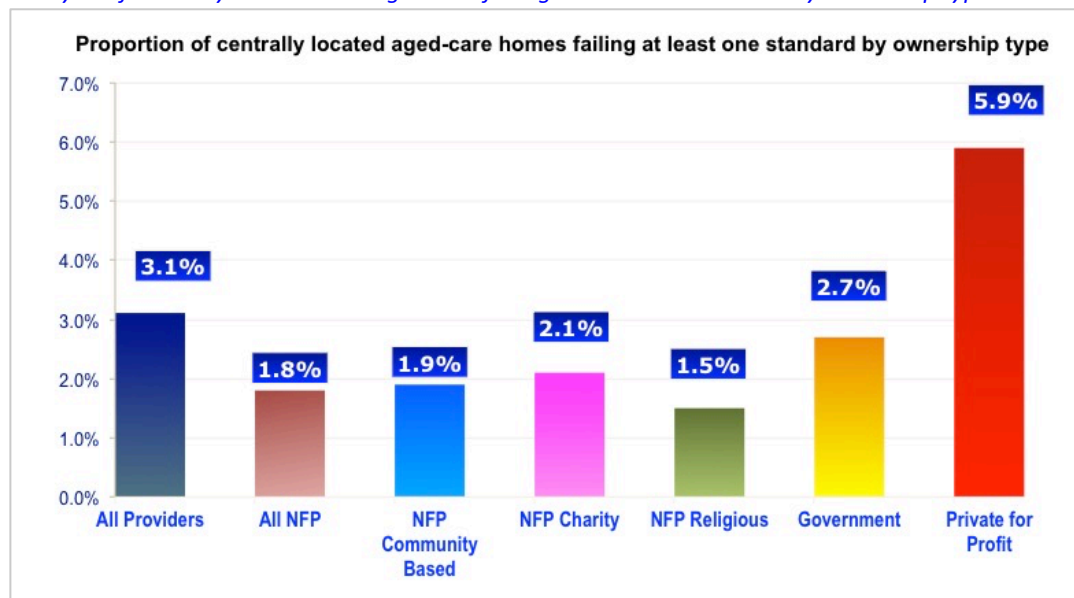
¹⁹⁶ Quality failures in residential aged care in Australia: The relationship between structural factors and regulation imposed sanctions Baldwin R et al Australasian Journal on Ageing 22 May 2014 <http://onlinelibrary.wiley.com/doi/10.1111/ajag.12165/abstract>

Appendix 2 - Ownership type, staffing and care

Accreditation: We consider that the accreditation process yields only low quality data because it is primarily based on surveys of processes after weeks (sometimes months) of pre-planned visits. The majority are prepared for well in advance. On the basis of its crude figures, the Quality Agency claims that the performance of for-profit and not-for-profit nursing homes is equal¹⁹⁷. It documents wide differences between metropolitan and regional facilities. As there are almost no for-profit facilities in regional (or remote) areas (4% in 2008), not-for-profits must be performing several times better than for profits.

Aged Care Crisis confirmed this¹⁹⁸ in an analysis examining only centrally located facilities performed in 2008. For profits failed an accreditation standard 3.3 times as often as not-for-profit facilities and 3.9 times as often as religious facilities. We think it likely that this difference would have narrowed since 2008 because of the increased pressure put on not-for-profits to compete with for-profits in the marketplace and their adoption of similar policies and practices.

Figure 5: Analysis of centrally located nursing homes failing at least one standard by ownership type



¹⁹⁷ Quality Agency rejects ownership factor on accreditation Australian Ageing Agenda, 25 Mar 2015 <http://bit.ly/2fvux4v>

¹⁹⁸ Aged care report card Aged Care Crisis 2008 <http://www.agedcarecrisis.com/news/research/108-aged-care-report-card>

Appendix 3 - We were warned many times

The changes that have occurred in health and aged care are the application of a belief in and the application of free market thinking to these sectors. Large numbers of people have looked critically at what has happening over the last 30 years.

Initially the focus was on health care and at that time it still included aged care. In the USA Arnold Relman, editor of the eminent New England Medical Journal spent much of the 1980s and 1990s arguing against what was being done to medicine¹⁹⁹. Robert Kuttner editor of 'The American Prospect' wrote of the "Limits of markets"²⁰⁰ mentioning health care specifically. He wrote several critical articles examining the conduct of some of the biggest and most fraud prone health care companies.

In 1996 in Australia Professor Stephen Leeder, writing about health care talked of transfusing what he called 'mad cow thinking' into *"every possible vein, compatible or not"*²⁰¹.

Dr Peter Arnold chairman of the federal council of the AMA warned of the consequences indicating that what was proposed *"is lethal for standards"* and *"With the price of services as the sole determinant of health care, ethics will fail and standards will fall"*²⁰².

In 1995 Stuart Rees and Gordon Rodley edited a collection of essays warning that the new managerialism was destroying our humanity.²⁰³ They indicated that managers trained in market practices were being put in charge of sectors where they had no training or experience. Aged care is a good example of that.

In 1992 Ron Williams who had been studying health care in the USA returned to Australia and wrote a book *'Remission Impossible'* 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"*²⁰⁴

During the 1990s and early 2000s one of us (MW) sent multiple packages of articles from the USA describing what was happening in health and aged care (with summaries of each set) to both major political parties, and to government bodies like the FIRB. On 26 June 1999, Prue Karmel from the aged care section of the health department was, for example, sent 400 pages of selected articles describing what was happening in the profit driven US aged care system.

The Corporate Medicine website documenting and analyzing what was happening in health and aged care in the USA and then later in Australia was commenced in 1996.²⁰⁵ Politicians and bureaucrats cannot pretend that they were not given every opportunity to become well informed about what they were doing. They simply ignored the warnings.

The medical profession understood the risks and won an acrimonious battle with the Health Minister, Michael Wooldridge to preserve their independence.

¹⁹⁹ Arnold Relman Wikipedia https://en.wikipedia.org/wiki/Arnold_S._Relman

Relman A **What Market Values Are Doing to Medicine** - The Atlantic Monthly, Mar 1992
<http://www.theatlantic.com/past/docs/politics/healthca/relman.htm>

²⁰⁰ Kuttner R **The Limits of Markets** The American Prospect No 31 Mar-Apr 1997 <http://prospect.org/article/limits-markets>

²⁰¹ Leeder S **"Mad-cow thinking - how far has it spread"** Professor Stephen Leeder Australian Medicine 20 May 1996 p 6

²⁰² **Price competition, professional cooperation and standards** Dr. Peter C Arnold, Chairman, Federal Council, AMA (MJA 2 Sept 1996 page 272)

²⁰³ **The Human Costs of Managerialism: Advocating the recovery of humanity.** S. Rees and G Rodley
<http://www.plutoaustralia.com/p1/default.asp?pagelid=314>

²⁰⁴ Extracts from **Remission Impossible** Corporate Medicine web site <http://www.corpmedinfo.com/williams.html>

²⁰⁵ **Corporate Medicine website** <http://bit.ly/2oFXdPA>

The Impact Of Financial Pressures On Clinical Care - Lessons From Corporate Medicine <http://www.corpmedinfo.com/corpmed.html>

Appendix 3 - We were warned many times

From the outset Wooldridge's policies had been opposed by the profession.²⁰⁶ The profession used the independence they had fought for and the market power it gave them to frustrate government and industry, to force a large Australian company that had supported the minister's policies out of the market when it resorted to practices they considered unethical and a threat to care. They were able to limit the harm to health care and prevent us from following the USA. The medical profession had no market power in aged care and if we look at aged care in 2017 we can see what might have happened to the rest of health care.

Specific Aged care warnings: To understand the many warnings and the disputes in Australia over the years we need to go back to the 1970s and 1980s, and the Giles report. Private ownership of hospitals and nursing homes had grown in the 1960s and 1970s. By 1981 there was growing concern in the community about the ownership and operation of private hospitals and nursing homes. These included allegations about the standards of care received in nursing homes.

The reports *'painted a bleak and depressing picture of life in a nursing home and some articles raised serious allegations of ill treatment or lack of care. In addition, allegations that private nursing home proprietors were making excessive profits at the expense of patients had become common.'*²⁰⁷

As in 2017, there were claims that private nursing home proprietors were making excessive profits at the expense of patients well-being.

A champion of human rights and social responsibility, Senator Patricia Giles²⁰⁸, was chair of the Select Committee on Private Hospitals and Nursing Homes (1983–87). Trained as a nurse herself she understood the issues surrounding care.

Senator Giles was responsible for a 3-year review. It produced two reports²⁰⁹, which made significant recommendations on the ownership, administration and quality of care in nursing homes and private hospitals. These reports were critical of the failures in care in some private facilities as well as of the fragmented regulatory system. They made several recommendations for increasing regulatory oversight. Large numbers of distressing photos showing what was happening were published.

During the 1980s neoliberal free market ideas were entering Australia and several large corporate groups went to court in an attempt to challenge the stricter regulations that had been imposed but were unsuccessful. Led by Doug Moran their ideas became influential and gradually dominated.

Several reviews were conducted including the 1989 Ronald's aged care report whose desire to empower visitors and advocates to have a regulatory role were according to Braithwaite blocked by the industry.

The important 1993 Gregory report commented on the neoliberal free market proposals warning that *"neither the current standards monitoring system, nor any alternatives considered, would be able to prevent the diversion of funding from nursing and personal care to profit"*.

²⁰⁶ Wooldridge M, *What Are The Government's Broad Objectives For Competition Policy In Health?* Speech to the AMA, May 1996: http://www.corpmedinfo.com/wooldridge_1996.html

Criticism during Welcome By DR David Weedon, President, AMA, May 1996 <http://www.corpmedinfo.com/weedon.html>

²⁰⁷ Select Committee on Private Hospitals and Nursing Homes - Report (22 Feb 1985): <http://bit.ly/2rThtRd>

²⁰⁸ Giles, Patricia Jessie (1928–) Australian Senate Biographies <http://biography.senate.gov.au/giles-patricia-jessie/>

²⁰⁹ Select Committee On Private Hospitals And Nursing Homes 22 February 1985 Hansard p 61 <http://bit.ly/2qCFGL8>

Appendix 3 - We were warned many times

The steadily declining figures for trained staff in the face of increasing acuity show how right Gregory was. Poor funding might have played a part but it is significant that when more funding was made available it did not go to staffing.

Example:

Additional funding was provided under what was marketed to the public as the 'Living Longer Living Better (LLLB)' reforms in 2014/15. The increase in funding created a profit stream that enabled companies to fund loans so that they could compete in a buying spree to consolidate, grow, list on the share market and expand their empires to increase market share and so their power and influence. High risk Private Equity groups were attracted to the sector pushing up the costs of nursing homes and so growth.

The extra LLLB funds were absorbed by the market with little evidence of any impact on staffing or care. Australians were promised that the LLLB 'reforms' would improve care but this did not happen.

Some of the income on which this growth was based came from 'maximising' loopholes in funding. When government closed these loopholes in 2016 corporate income was reduced but the loan repayments had to continue so putting more pressure on staffing and care. This may have contributed to the unhappiness about care and staffing throughout 2017.

There is little to suggest that anyone except the providers would live longer or better as a result of these 'reforms', - rather the contrary.

The for-profit sector helped the Howard government gain power in 1996 and were given everything they wanted in the 1997 legislation. They have been in close partnership with government and there has been a revolving door ever since.

Senator Brenda Gibbs²¹⁰ had a particular interest in protecting the vulnerable. These groups were stigmatised and abandoned by the neoliberal discourse that now dominated policy. During this period Gibbs was one of the governments strongest critics drawing on the horrors of the Giles reports to warn of what was likely to happen.

Gibbs gave a telling and prophetic speech in parliament in June 1997.²¹¹

She predicted the future when she warned of '*managers with no nursing experience. No longer do nursing homes have to employ a qualified director of nursing who will ensure that professional standards are met*'.

She referred to '*dramatically decreased guarantees of the level of care that residents will receive*' in a system where there would '*no longer be the checks and balances*'.

She asked '*who is going to ensure that the taxpayers' money that the government allocates to these nursing homes is properly spent on nursing care?*'. She challenged the minister who was '*going around claiming that accreditation will take care of everything*'.

In referring to the 1997 Aged Care Bill she said that there was '*a deliberate budget driven omission which fails to appreciate the health risk to residents in reducing or removing nurses*'.

Gibbs concluded her speech saying '*I believe this legislation will start a move which will work to the disadvantage of many of our most vulnerable senior citizens*'.

²¹⁰ Gibbs, Brenda (1947–) Australian Senate Biographies <http://biography.senate.gov.au/gibbs-brenda/>

²¹¹ Aged Care Bill 1997 Hansard Senator Gibbs 24 June 1997 page 5042 <http://bit.ly/2rfThau>

Appendix 3 - We were warned many times

Twenty years later we can see how prophetic her speech was. But her warnings were a double-edged sword because they must have alerted the government and the industry to the risks for them of the sort of publicity that accompanied the Giles report. They created a system that did not collect data and which protected the system and the industry from disclosures. That is why it has taken 20 years to reveal what is happening and why industry and governments have cooperated so closely to maintain the illusion that we have a “world class system”.

Nonprofits tried to object: During the early years the nonprofits tried to protest. In 2004 Catholic Health²¹² accused “the Howard Government of squeezing church and charitable groups out of aged care in favour of commercial operators driven by profit”. An internal memo said “While most for-profit providers may have good intentions in delivering aged care, their prime focus will always be making a profit,- -”.

The director of Catholic Health, “Mr Sullivan said yesterday the not-for-profit sector would resist any policy shift that encouraged the privatisation of aged care and a focus on the bottom line over quality of care. “There seems to be a very worrying policy direction aimed at getting investor-owned companies to run the aged care program, with the Government throwing its weight behind the for-profit sector and capital equity markets to solve the problem,’ Mr Sullivan said”.

Director of Aged and Community Services Australia Greg Mundy “echoed these concerns, saying the private sector ran leaner staffing models, which meant fewer hours per resident and this inevitably diluted the quality of care”. For data showing the relationship between profit, staffing and care see Appendix 2

But ideas like this were not part of the ‘discourse’²¹³ and survival ultimately depended on being part of the system and not fighting it. These lofty goals have been eroded as a revolving door developed between nonprofit organisations and both for-profits and government²¹⁴. To a far larger extent they now share the same discourse (are on the same page) and large nonprofits are copying the for-profits in reducing staffing and so providing suboptimal care²¹⁵.

²¹² Churches ‘squeezed out of’ aged care The Australian 18 Feb 2004
see also The Not-for Profit Dilemma Corporate Medicine web site 2006 <http://www.corpmedinfo.com/notforprof.html>

²¹³ See Appendix 6 for a discussion of ‘discourses’, as well as their relationship with and control by the powerful.

²¹⁴ Dilemma for not-for-profits Inside aged care <http://bit.ly/2F9UM25>

Views among not-for-profits Inside aged care <http://bit.ly/2FeFtkU>

²¹⁵ Southern Cross Care defends nursing home cuts, families hit back Chinchilla News 13 Jul 2017 <http://bit.ly/2und9av>
Now it’s Blue Care cutting nursing hours for elderly residents Media Release 1 Aug 2017 <http://bit.ly/2Fbdlin>

Appendix 4 - A community based solution

(The section below is copied from the document we have attached to this submission. It summarises and puts a slightly different slant on a longer and more detailed description in our earlier submission to the senate in August 2017.)

The solution we offer

Aged Care Crisis is challenging what has been done, the policies that are believed in and the structure of the system we have. We have suggested changes that will really address the problems identified and allow us to move ahead. We cannot go back to the past. That door is closed. We don't want another revolution or a new belief system. We don't want more hollow reforms.

We want change. Change that is based on evidence rather than belief, carefully considered, constructively addressed, carefully introduced and closely monitored – the very antithesis of what has been happening since 1997.

We must have changes that create a context that fosters and encourages the type of people and the sort of organisations that care. We must foster and support the sort of people who empathise with others and care about them and who build the sort of interpersonal relationships on which care depends. In our submission to the senate we called this a discourse of care leading to a culture of care.

Oakden graphically illustrates our failure to do so and the sort of people the neoliberal managerialist discourse fosters and supports. Those who really care feel uncomfortable and go elsewhere. By making the discourse of care the dominant discourse in the sector, we hope to reverse this process and so discourage those who are unable to care. The Aged Care Roadmap²¹⁶ fails to do this. We should scrap it and build another road instead.

The response has been to ignore our suggestion, deny it or claim it is impractical – anything to avoid confronting the enormity of what we argue has happened, the money wasted, and the needless harm.

This is a very human response but until we confront and reject it we cannot move forward because this denial is what binds us to the system we have. Until we break those bonds we will not be free to deliver the changes that are really needed.

Our proposal

We argue that caring is something that we as a community do for one another when we are vulnerable and need help. We are all vulnerable and depend on others at many points throughout our life. The community is the repository of our humanity - the relationships we form, the empathy we feel for others, the values we build and share and the motivations that drive the creation of our social selves.

Aged Care Crisis is pressing for a system that puts community in the driving seat for aged care, and in which the government's role is to support them - a system in which the industry is directly and immediately accountable to the communities they serve.

²¹⁶ Aged Care Roadmap (InsideAgedCare): <https://www.insideagedcare.com/introduction/aged-care-roadmap>

Appendix 4 - A community based solution

We propose changes that will put the heart of care, its management and its regulation into empowered local communities. Here, each caring person is responsible for their fellows and ultimately for their own future. We are bound together and build our communities through our joint responsibility.

Our suggestion is built on and embraces a discourse of care, community and social responsibility. In doing so it draws on the long-standing traditions of caring communities and caring professions. These have suffered under the present system and we are a poorer society as a result. This is not a return to the past but it builds on and learns from the knowledge of our heritage and a close examination of our recent failures.

An approach and not a model

What we are pressing for can be structured and organised in different ways. The lesson coming from successful community services is that it is citizens themselves who should try out different options, develop and innovate, learn, modify and finally work towards the best ways of achieving their objectives.

While it may not be efficient, this involvement binds the community and the system they manage to the real world of human suffering and protects us all from escaping into fantasy as happened in 1997. In doing so we stimulate interest, gain knowledge and build experience. We develop social selves and so identities that embrace social responsibility as a core value. We come to 'own' what we do and it becomes a part of our psychological DNA. As a community we build social capital. Community services built in this way work.

It would be a mistake to be prescriptive or to impose or market a solution at our citizens. We have had more than enough of that. We are seeking to engage the community and create a context within which they can develop and so own and embrace the system they introduce – be a part of it.

One practical way

If we are to show how something might work then we do need to offer some sort of model to illustrate the possibilities. It is not prescriptive.

We suggest that central government negotiate with local government to form steering committees and that seniors organisations, local charitable organisations and professional bodies be asked to nominate people to be on that committee. The first step might be to establish empowered and mentored community visitors and advocates who would be able to go on site regularly to support residents, monitor services and work with providers to do so. It should be trialed and done in small steps starting in a limited number of places and then developed and expanded.

This would be followed soon after by a service supporting and advising potential recipients of aged care. At an early stage nominations would be made to a central country wide representative body. While much would be voluntary some permanent staff would be required.

These local groups would then gradually build local aged care services in their region and assume most of the management, oversight, data collection and regulatory functions. Government would mentor and support. The service would be accountable to the community and to government and would support local providers by assisting them in collecting data and addressing issues. The providers would be accountable to the local community for the care provided to their members.

Note 1: The short account above is taken from the attached document 'Community managed aged care'. It explains how such a system would work in practice. This is an analysis and an explanation of how our proposal would address the many issues identified at the Oakden Senate

Appendix 4 - A community based solution

hearing in Adelaide, the issues identified in the Nous and Carnell/Paterson inquiries as well as those they overlooked.

We do not want to be prescriptive as the form this proposal might take would depend on trial and innovation within communities. More ideas about how it might work can be found below:

- Page 85 to 94 of **Aged care Crisis Submission** to the August 2017 Senate Standing Committees on Community Affairs “Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practiced” August 2017 <http://bit.ly/2A4Uu6x>
- A earlier 2015 proposal for how it might develop is on Aged Care Crisis web site: **Solving Aged Care : Part 2: A big change to aged care** <http://bit.ly/2HeE3YG>

Appendix 5 - Ignorance about direct care

This is an extract from our submission to the senate workforce committee on 28 Nov 2016 (pages 7 to 10)

Muddied waters

Since the aged care workforce inquiry has been announced, the waters have been muddied.

StewartBrown (SB) has recently started using the same term '*direct care*' for two quite separate sets of data, one of which includes '*non-direct care*'. They have included: hotel services, maintenance, administration, and quality and education under chartered staffing data labelled '*direct care*'.

We are not aware of this ever being done before.

The inflated figures for staffing data that include '*non-direct care*' have been published using the words '*direct care*' on social media²¹⁷. These were copied to senators only 48 hours before the workforce inquiry interviewed industry representatives. The industry has used these figures to respond to discussion on social media and in response to an article where National Seniors was critical of deficiencies in '*direct care*'²¹⁸.

The issue here is that a reputable organisation has used the same words for two very different sets of data without clearly labelling on the graph and in any text, exactly what the difference was. If we did that at an academic meeting or in a research paper without clearly specifying the difference on the graphs and explaining this fully in the text, we might be accused of fraud and investigated by our universities.

This is especially pertinent as the information contained in the reports are clearly used by industry bodies to lobby Government and in the formulation of policy. SB's registration form²¹⁹ states "*The results of the survey may also be used for other purposes. It is likely that summary data will be used by industry bodies to lobby Government and in the formulation of policy.*"

Critics and family members of loved ones in aged care are primarily concerned about deficiencies in nursing care staffing. The response has been to use data that includes much more without disclosing this. The Committee must draw its own conclusions as to whether this was self-serving or socially responsible.

One of those responding to criticism using these inflated figures was interviewed by the Inquiry. We do not know if this data was presented to the inquiry but to put any confusion about the data to bed we will clarify this issue before looking at data in the USA.

Use of the term '*direct care*'

By adding nearly an hour of extra time that others^{220 221 222} in Australia and specifically the MyAgedCare website²²³ call '*non-direct care*' this, we believe, seeks to undermine the accuracy of criticisms about staffing.

²¹⁷ Social media post re RACF Average direct care hours per resident per day: <http://bit.ly/2fmloAd>

²¹⁸ Comment on "Peaks raise aged care staffing levels and skill mix with Senate inquiry" - Australian Ageing Agenda, 9 Nov 2016 <http://bit.ly/2fnKDwT>

²¹⁹ Aged Care Financial Performance Survey - Registration Kit 2016, pg2: Background & Purpose of Survey <http://bit.ly/2gomLhx>

²²⁰ Nurses in residential aged care - Access Economics for ANMF, November 2009 - <http://bit.ly/2gxLmki>

Appendix 5 - Ignorance about direct care

The term '*direct care*' in Australia usually includes allied health services but what is included under that term varies, as for example between MyAgedCare and Access Economics. It would be more consistent and helpful to separate allied health and examine it separately, as they are very different services.

Figure 6: MyAgedCare website - <http://www.myagedcare.gov.au/about-us/aged-care-workforce>



The screenshot shows the top of the MyAgedCare website. It features the Australian Government logo on the left and the MyAgedCare logo on the right. The main heading is 'Aged care workforce'. Below this, there is a paragraph of text, followed by a bulleted list of worker types. The text and list items are highlighted in yellow. At the bottom of the screenshot, there is another highlighted sentence about non-direct care roles.

Aged care workforce

Aged care workers make a valuable contribution to the daily lives of many thousands of older people across Australia. Creating an appropriately skilled and well-qualified workforce is fundamental to delivering high-quality aged care services that meet the needs of older Australians. In 2012, there were over 352,100 (estimated) employees in the aged care sector working in residential and community settings, and in a variety of direct-care and non-direct care occupations.

Of these, 240,445 were **direct-care workers including:**

- **nurses**
- **personal care or community care workers**
- **allied health professionals such as physiotherapists and occupational therapists.**

Australia's aged care workforce is expected to grow to around 827,100 in 2050. There will be opportunities for people to become involved in this expanding industry. There are a range of aged care qualifications, career development opportunities and skills training available.

Direct-care workers may provide care in a person's home or in an aged care home. All aged care homes are required under the [Accreditation Standards](#) to employ appropriately skilled and qualified staff to care for residents. For example, all residents with high-level care must have any nursing services carried out by a registered nurse or other appropriate professional.

Workers in non-direct care roles might be managers who work in administration or ancillary workers who provide catering, cleaning, laundry, maintenance and gardening.

Analysis of staff data

SB breaks down its data into 5 bands based on the income generated from care. It consequently reflects resident acuity. The highest payment in band 1 indicates the greatest resident acuity and band 5 the lowest. Each band represents groups who have very similar amounts of money to spend on care so making them comparable.

²²¹ The Aged Care Workforce in Australia White Paper (draft) July 2013 ACSA - <http://bit.ly/2fleu9a>

²²² A snapshot of residential aged care Australian Nursing & Midwifery Federation August 2016 Page 2 - <http://bit.ly/2fNMg15>

²²³ Aged care workforce - Myagedcare web site Nov 2016: <http://www.myagedcare.gov.au/about-us/aged-care-workforce>

Appendix 5 - Ignorance about direct care

Figure 7: Data supplied by a Director of SB

Total care staff hours and Total staff hours June 2016 hours per resident per day						
	SURVEY ALL FACILITIES Average (817 Facilities)	BAND 1 Average (320 Facilities)	BAND 2 Average (228 Facilities)	BAND 3 Average (149 Facilities)	BAND 4 Average (68 Facilities)	BAND 5 Average (52 Facilities)
Staff Hours Analysis						
Hours worked per resident per day						
Care management	0.10	0.09	0.09	0.11	0.10	0.12
Registered nurses	0.36	0.41	0.37	0.34	0.29	0.15
Enrolled and certified nurses	0.32	0.35	0.32	0.32	0.20	0.17
Other care staff	2.02	2.19	2.00	1.82	1.92	1.50
Therapy	0.11	0.12	0.10	0.11	0.11	0.11
Total Care Hours	2.90	3.16	2.88	2.68	2.62	2.05
Hotel services	0.66	0.68	0.66	0.64	0.69	0.59
Maintenance	0.07	0.07	0.07	0.08	0.09	0.07
Administration	0.16	0.15	0.15	0.17	0.17	0.13
Quality and Education	0.02	0.02	0.02	0.02	0.02	0.02
Total Staff Hours	3.81	4.08	3.79	3.58	3.59	2.86

Figure 8: Note 'actual' nursing hours (Registered nurses, Enrolled and certified nurses, Other care staff)

	SURVEY ALL FACILITIES Average (817 Facilities)	BAND 1 Average (320 Facilities)	BAND 2 Average (228 Facilities)	BAND 3 Average (149 Facilities)	BAND 4 Average (68 Facilities)	BAND 5 Average (52 Facilities)
Total Nursing Hours	2.70	2.95	2.69	2.48	2.41	1.82

Note: Both versions of *direct care* figures charted are derived from the data in the 2016 report²²⁴. The figures fall from band 1 to band 5 reflecting the difference in resident acuity. The figures used for the 2016 charts are arrowed. **Total Staff Hours** adds 0.91 hours (55 min) of *non-direct care* to **Total Care Hours** and over 1 hour to actual “*direct care nursing hours*”.

²²⁴ Aged Care Financial Performance Survey Residential Care Report – June 2016, SB

Appendix 5 - Ignorance about direct care

Figure 9: Total Care staff hours (SB²²⁵, Chart 7)

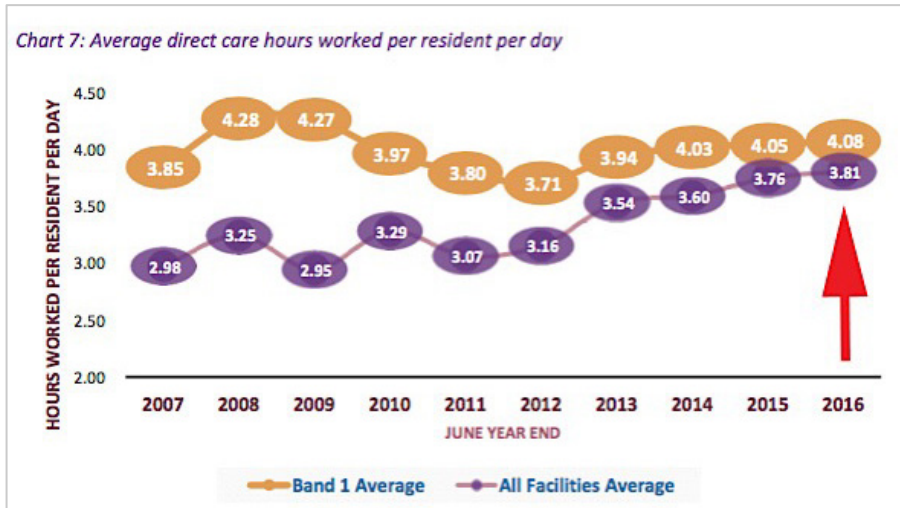


Chart 7: (left) from the June 2016 report shows the *Total staff hours* that were posted on social media as direct care and used to refute claims of poor staffing.

The arrow points to the 2016 average and band 1 figures which are identical to the total hours in the staff report above (also arrowed). These include 0.91 hours non-direct care items.

Figure 10: Total Care staff hours (SB²²⁶, Chart 28)

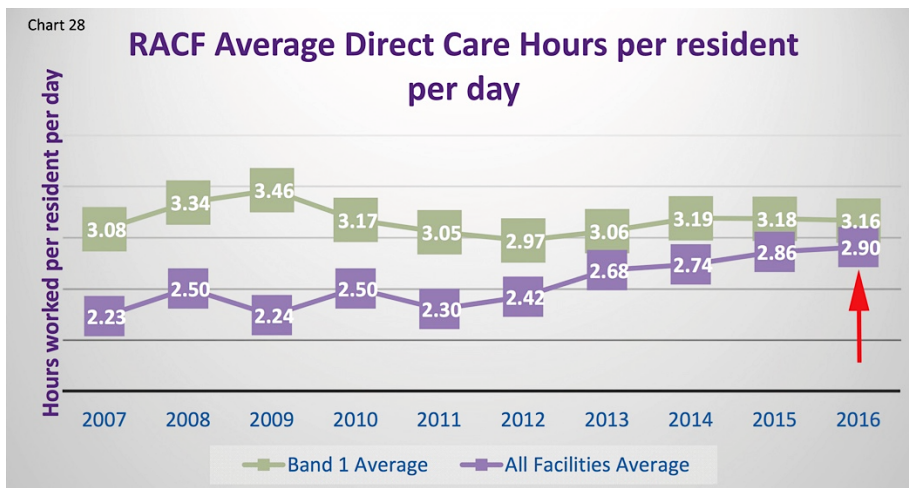


Chart 28: (left) approximates what others in Australia call *direct care* - although few would include "care management". The arrowed band 1 and average are also arrowed on the table above under *Total Care Hours*.

Others in Australia vary in what they include under therapy depending on which allied health professionals²²⁷²²⁸ are providing it.

²²⁵ Aged Care Financial Performance Survey Residential Care Report – June 2016 - SB, pg 15

²²⁶ Aged Care Financial Performance Survey Residential Care Report – June 2016 - SB, pg 38

²²⁷ Nurses in residential aged care - Access Economics for ANMF, November 2009 - <http://bit.ly/2gxLmki>

²²⁸ Aged care workforce - Myagedcare web site Nov 2016: <http://www.myagedcare.gov.au/about-us/aged-care-workforce>

Appendix 6 - About Discourses in aged care

(This material is taken from Aged Care Crisis August 2017 submission to the senate inquiry into Oakden)

In our analysis of aged care we approach these issues, in particular the failure of regulation, by examining the patterns of thought and the frames of analysis on which decisions and action are based.

The work of Philosopher Michel Foucault²²⁹ has focused on the importance of what in the past have been described as 'frames of reference', 'patterns of thought' or 'narratives'. *He includes them in what he calls 'discourses'*. He shows how the discourses we use influence our thinking, the way we understand things, the way we behave, the things we do and ultimately the sort of people we become. It impacts our psychological DNA and so what we do, who we become and our identity.

Cultures: Discourses are particularly important within cultures and subcultures and play a key role in the different ways they understand the situations they confront and their approach to the things they do.

The power of discourse: Those with the power to control the discourse in any sector are able to influence and control the thinking of participants and so their actions and behaviour. Foucault calls this process of controlling the thinking of others and getting them to identify with your ideas, 'governmentality'.

Dominant discourses put strong pressure on us to adapt and conform, sometimes when this is not in our interests or the interests of society.

We have developed strategies that allow us to avoid confronting our principles and escape the discomfort of doing so when the pressures in the discourse are strong enough. Doctors have been under this sort of pressure for years²³⁰ and some, particularly in the USA, have succumbed.

It is particularly important for those in power to control what is credible or not credible, and what is excluded or unacceptable in the discourse. They do this by controlling the way information is collected, analysed, presented and understood.

This influence is so deep and profound that we will often ignore evidence and logic in order to cling to a discourse that has become a part of who we are.

Conflicted discourses: As individuals we have difficulty in managing and working with multiple discourses particularly when they conceptualise things differently and require us to behave differently. We can find it stressful and get defensive when our discourses are challenged.

Public information can expose problems in the discourse and challenge its legitimacy. This is threatening not only for those in power but for those citizens who have identified with the discourse and built their lives using it. All ideologies are built around discourses.

They seek to censor, attack or discredit challenging information often by shooting the messenger.

²²⁹ Michel Foucault Wikipedia https://en.wikipedia.org/wiki/Michel_Foucault

²³⁰ Wynne JM Belief versus Reality in Reforming Health Care Health Issues 2005, Number 83, pp. 9-13. <http://bit.ly/2lRijsl>

Appendix 6 - About Discourses in aged care

Research: Increasingly those doing social research into human services including health and aged care are using Foucault's ideas to explain and understand what they are observing when discourses collide. We have found this to be a useful way of understanding²³¹ what has been happening in aged care in Australia and elsewhere, particularly why regulation is failing.

Two broad discourses in aged care

Two major conflicting discourses are readily distinguished and they are not restricted to aged care.

The discourse of care

History: This traditional discourse dates back at least to Hippocrates about 2500 years ago and recognises the social responsibility we have when dealing with the vulnerable. In the 19th century churches and their morality exerted a powerful influence on the way people thought. Their discourses built values and norms that protected the vulnerable and brought them care. The more modern version forms the ethical base of health care professionalism. It remains important within the larger community. While sometimes eroded and subverted over the centuries the ethic of care has stood the test of time.

Language and concepts: This discourse uses phrases like vulnerability, responsibility, empathy, relationships, responsible citizenship, trust and trustworthiness, probity, responsible capitalism etc. Its values are the core values of the community.

In this discourse, vulnerability and interdependence are set against an acknowledgement of the essentially predatory nature of markets and the need to restrain and control their behaviour.

This discourse resides in the community, and in the professionals and empathic employees who provide the hands on care. Traditionally these services have been the responsibility of the community and were provided by the community to its needy members.

Professor Fine and his associated have closely examined and teased out the nature of care and described the changing cultures of care²³². In doing so they have refined the discourse of care. This important work is largely ignored by politicians.

The free-market/neoliberal discourse

History: This is a discourse that originated in the 1970s and was underpinned by the strong assertion that social responsibility was socialist and therefore evil²³³. It impeded the operation of markets. The only responsibility was to investors.

In this it directly challenged the discourse of care, which depended on an ethic of social responsibility. The discourse claimed that markets were self-correcting and interference by government and other regulators impeded this.

²³¹ Theory and Research in aged care Inside Aged Care <https://www.insideagedcare.com/aged-care-analysis/theory-and-research#regulation>

²³² "Articles associated with - - "on web page Theory and Research in aged care Inside Aged Care

<https://www.insideagedcare.com/aged-care-analysis/theory-and-research#care>

The Nature of Care Inside Aged Care <https://www.insideagedcare.com/aged-care-analysis/theory-and-research/nature-of-care>

²³³ The Social Responsibility of Business is to Increase its Profits by Milton Friedman The New York Times Magazine, September 13, 1970.

<http://www.colorado.edu/studentgroups/libertarians/issues/friedman-soc-resp-business.html>

The Origin Of 'The World's Dumbest Idea': Milton Friedman by Steve Denning Forbes Leadership 26 Jun 2013

<http://www.forbes.com/sites/stevedenning/2013/06/26/the-origin-of-the-worlds-dumbest-idea-milton-friedman/#41f8ea8f214c>

Appendix 6 - About Discourses in aged care

This discourse was embraced by politicians in the USA, the UK and then in Australia in the 1980s and 1990s. One of the first things done in 1997 in Australia when marketising aged care was to abolish the federal probity legislation.

This was the legal embodiment of the social responsibility required within the community's discourse of care. The probity regulations had specifically barred those whose track record displayed a lack of social responsibility (described as not being 'fit and proper') from providing aged care services.

Liberalisation: In the neoliberal discourse the process where the market was freed of regulation and social restraint was called 'liberalisation'. Sectors like aged care were 'liberalised' and the repeal of the probity legislation was the first step.

The second step was liberalization from accountability by abolishing state oversight and hiding staffing and financial data, which became commercial in confidence. The third step was liberalization from regulation by replacing it with accreditation.

It is interesting that US President Reagan who (with the UK's Thatcher) embraced the neoliberal discourse in the 1980s had tried twice to replace government regulation with accreditation in aged care. Both were followed by a savage community backlash and blocked by congress²³⁴. In the USA accreditation is voluntary and unlike healthcare only about 10% of nursing homes are accredited. It is not used for regulation in aged care

Language and concepts: The words used in the neoliberal discourse include free markets, competition, efficiency, choice, microeconomic reform, incentivisation and management - a top down controlling managerialism. Its values are the values of the free market system.

Neoliberalism has become particularly successful because its discourse has been driven and controlled by its managerial structure. This managerial structure and its thinking have been introduced into almost every sector, including governments at all levels and not-profit humanitarian endeavours.

Managerialism has been a powerful vehicle for controlling the content of discourse. It was imposed on health and aged care where the words and concepts of the neoliberal discourse replaced those of the discourse of care.

Warnings: Academics and professionals from the discourses of responsible capitalism and civil society as well as the discourse of care in the USA and Australia were very critical and warned of the consequences. Their arguments and warnings were ignored

Impact of conflicting discourses on culture

(The section below is copied from the attached document)

When talking about culture we are talking about a group of people who share a pattern of ideas – a discourse – within which they understand the world they are in and what they are doing there. They build their lives using these ideas, claim an identity within them and come to own and control what they do using them. Their success in doing all this depends on the pattern of ideas being appropriate and fit for purpose.

If they are unable to do this the culture will break down and become dysfunctional. When a conflicting discourse, which does not allow all this, is imposed on the situation then the culture

²³⁴ Braithwaite J et al Regulating Aged Care' Edward Elgar Publishing Limited 2007 page 32

Appendix 6 - About Discourses in aged care

breaks down. When market discourses driven by profits or a managerial discourse that impacts on care are imposed then this has social and psychological consequences.

Every time there is a scandal or major failure in care we see from what is said that there is a significant cultural component. The isolated offender is unusual and in many instances those who abuse have previously been of good character. A classic example of this was the Winterbourne View care home in the UK²³⁵ where the abuse of residents was more extreme than at Oakden and the offenders who abused the residents operated in groups. It was exposed by a whistleblower.

The judge condemned Castlebeck for the way Winterbourne View was run. *"It is common ground in this case that the hospital was run with a view to profit and with a scandalous lack of regard to the interests of its residents and staff,"* he said. *"A culture of ill-treatment developed and as is often the case, cruelty bred cruelty. This culture corrupted and debased, to varying degrees, these defendants, **all of whom are of previous good character,**"* he added.

The Hausler case in Australia, where the carer was captured on video, was similar²³⁶. When the culture is good then those who don't fit go elsewhere or are pushed out. When it is bad those who care go elsewhere if they can. You don't see instances where 90 year old women are raped and nobody does anything about it or where nurses warnings are ignored and deranged misfits burn down nursing homes. The owner of that nursing home had a history of multiple failures in other homes and it has been in the news again recently but with a new name.

Too often the culture in a nursing home comes from the top and it can start with only one or two unsuitable people with power. At the root of these and similar scandals in other sectors is a conflict between incompatible discourses when the dominant discourse is inappropriate for the sector but where those who deliver the care are expected to identify with and meet the objectives of that discourse. In writing about the way discourses impacted on doctors in health care in 2005²³⁷ one of us (MW) indicated that *"This analysis stresses the importance of a synergy between the patterns of thought used to justify actions and the concrete situation where these actions take place"*.

²³⁵ Winterbourne View care home staff jailed for abusing residents The Guardian 26 October 2012 <http://bit.ly/2Db5d13>

²³⁶ Corey Lucas stressed about work when he abused Clarence Hausler at nursing home, court documents show Adelaide Now 27 Jul 2016

²³⁷ Wynne JM Belief versus Reality in Reforming Health Care Health Issues 2005, Number 83, pp. 9-13 <http://bit.ly/2IRijsl>

Appendix 7 - Understanding why we go wrong

(*Belief, Ideology and Discourses*)

Note: *Many tend to disengage from a theoretical analysis, so we have therefore put this into this appendix as only some will want to explore the problem in this depth. In thinking about a solution we have considered the insights provided by looking in this way to be sure that we are addressing underlying causes and designing something that will prevent a similar occurrence. It supports our arguments and our proposal but our proposal does not depend on it.*

People can get things very wrong and if we look at the 20th century we can see how whole nations became trapped in ideologies that saw millions die. We are all vulnerable to crazy ideas but our peers usually pull us into line and when they don't the consequences are usually less devastating but nevertheless harmful. As the world gets more complex we are more inclined to grab hold of simplified ideas that seem to make sense. We are bombarded by these in the media where there is less chance of our peers challenging the ideas.

Media

The development of media as a medium for spreading discourses or ideologies and controlling criticism has grown during the 20th century and with digital media into the 21st.

Albert Speer the industrialist who managed the production of arms in Germany before and during the 2nd world war later described the rise of fascism in Nazi Germany in the 1930s:

"Hitler's dictatorship...made the complete use of all technical means for domination of its own country. Through technical devices like the radio and loudspeaker, 80 million people were deprived of independent thought"

Source: [Albert Speer](#) Wikiquote

The media and the power of imagery became a vehicle for spreading the fascist discourse and so contributed to the ascendancy of the terrible ideologies of the 20th century.

The media have taken giant steps since then. Our senses are now flooded with images and words. We have an army of public relations experts as well as specialized marketing and branding experts richly rewarded for their success in influencing us. There is no more powerful means of spreading the discourses into the psychological DNA of every one of our psychological cells in order to bolster belief and silence dissent in others. We need only go to the websites of providers or listen to politicians. Only bitter experience and close contact with the real world of human suffering can immunize us.

Digital media has a great potential for building and binding civil society, for increasing knowledge and informed debate but it is too often not used in that way.

Developing a discourse: A 'discourse' develops as people reinforce one another's ideas. When this escapes into fantasy our peers and even society at large can be swept up and lose their way - and also ignore data and logic. They become resistant and discount those who question, look at data and think logically – even turn on them. The ideas in the discourse become real for believers and we 'believe' in them.

Australians have been bombarded with rhetoric about free markets, trade, competition policy and efficiency through our media and are unwilling to question their utility in every sector. We have seen similar behavior with colonialism, fascism, communism and apartheid.

Appendix 7 - Understanding why we go wrong (*Belief, Ideology and Discourses*)

In the latter large numbers of those who were disempowered accepted their status and relative disadvantage as normal. They resisted change. Much the same seems to be happening with free markets, particularly in the USA and now in Australia. People cannot imagine the discourse they believe in as responsible for the problems and anyone who challenges the discourse is not seen to be credible. They shrink from the complexity that challenge reveals.

In aged care: If we look at what has and is happening in aged care in this context we can understand why it has been so difficult for believers who experience problems or see what is happening to accept the nature of the problem and then do anything about it. We can appreciate why many simply refuse to look critically and when things go badly wrong blame individuals or particular organisations instead. We can see why it is so difficult to get others to consider this. They may have already built successful lives in aged care using these ideas, or in other sectors where this discourse have been more appropriate.

There can be little doubt that those who have developed our aged care system and who manage it believe in what they are doing. The problems created by beliefs that fly in the face of logic and evidence have been extensively studied. Few in Australia had previously needed to study them. In this Appendix we look at some other modern examples and then briefly examine some of this body of work.

Examples of how we get it so wrong

The neoliberal free market discourse originated in the school of economics in Chicago in the USA. The expectation that the market behave responsibly and serve the community inhibited financial entrepreneurialism and one of the first insightful 'truths' of the new developing discourse in 1970 was that social responsibility was socialist and should be rejected²³⁸. The only responsibility of business was to make money for shareholders. But that was only the first illogical step. Every belief system that starts by grabbing at something that lacks validity is forced to create more illusions in order to support the first one. We end up with a complex tree of strongly asserted 'self-evident' truths to support. Strategies are developed to neutralize evidence and discount critics.

Health and aged care are two sectors whose entire focus and mode of operation are based on the social responsibility that we as a community feel for our fellows who are in need. That a discourse that started out by denying social responsibility has not worked is hardly surprising. While providers may now claim to be responsible citizens, the marketplace within which they operate was built on the assumption that this was to be avoided. Social responsibility is not competitive, nor is it praised. The response to this to tokenise it. The words become a substitute for what they claim is there

As happened with the Jews in Germany, in the 1980s and 1990s believers in the business sector in the USA (and later in Australia) saw doctors as the problem in health care²³⁹. They insisted on taking over the admission and care of patients, keeping the doctors in bondage and directing the way they provided care. They were a little kinder than Hitler and softened the pill by making those doctors who conformed leaders in the industry and very rich, while leaving those who refused destitute on the scrap heap! Australian doctors saw what has happening and successfully resisted this in 1998.

²³⁸ The Social Responsibility of Business is to Increase its Profits by Milton Friedman The New York Times Magazine, September 13, 1970. <http://www.colorado.edu/studentgroups/libertarians/issues/friedman-soc-resp-business.html>

²³⁹ Joseph Califano and the Market Revolution Corporate Medicine web site <http://www.corpmedinfo.com/califano.html>

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In section “**2.2.2 Captured regulation elsewhere**” of this submission we described examples where this discourse and their control of doctors resulted in the US market exploiting vulnerable patients and residents in psychiatry at the beginning of the 1990s, aged care a few years later and then surgical patients in the early 2000s. All were exploited for profit and harmed. The senior businessmen, their nonmedical managers and even most staff believed these were legitimate business practices and the care good. All were enormously profitable and this drowned any doubts they might have had.

Internal documents and conversations with whistleblowers revealed the enthusiastic way in which staff persuaded patients to have treatment they did not need and came to believe in what they were doing. Complex and to the outsider bizarre explanations built around marketplace thinking were offered to explain how good the care was and the merits of what they were doing.

Senior managers were more surprised than anyone when the scandalous conduct was exposed in the press. As has happened in aged care in Australia, they considered this a beat up and not a reflection of what they were doing.

These beliefs were so strong in one company that even after criminal convictions, the forced sale of their psychiatric and substance abuse hospitals, and a massive fine they continued to believe in their formula for success and a few years later did it all over again. Their most profitable hospital did nearly 800 major open heart operations on people who did not need them. There have been many similar if less confronting scandals in health and aged care in the USA.

During the 1990s more effort by the FBI was directed to investigating health care fraud than drug trafficking and more money was paid by health care companies to settle actions for fraud than in any other sector.

Health care examples in Australia

In Australia we had the Chelmsford Deep Sleep scandal in NSW²⁴⁰ and the Ward 10 B scandal in Townsville General Hospital²⁴¹ both in the 1970s and 1980s. Those involved believed in treatment that was actually harmful but in doing so ignored evidence. Other doctors were sufficiently persuaded that they allowed it to go on for years in spite of evidence. None of us are immune.

Similarities to aged care

There are a number of similarities between the behaviour of those involved in these health and aged care scandals, and aged care in Australia today. Similar claims to excellence were made in the USA and criticisms by those who saw what was happening were responded to in similar ways. The political and regulatory responses in the psychiatric and other US scandals were also uncannily similar. In the absence of data widely differing views existed and those who believed in the system dominated. When data was collected it was ignored or discounted.

The US market for instance was ecstatic in its praise of these companies' successes. Market analysts attributed it to good care. In a situation similar to that revealed in aged care in Appendix 1, those who were unhappy complained but were disregarded. It took years to expose problems and then it was often done by outsiders who were able to look in more objectively.

These situations all have one thing in common. This is the development of often bizarre beliefs in treatments or societal objectives that were not based on logic and evidence and which were not

²⁴⁰ Nightmare on Chelmsford, Sydney New Scientist 5 January 1991 <http://bit.ly/2oF9sfc>

²⁴¹ The care and treatment of patients in the psychiatric unit of the Townsville General Hospital Report <http://bit.ly/2tcAqjl>

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successfully confronted and addressed by data and logic at an early stage. Those that were appealing to the powerful or to large numbers of citizens were quickly embraced and became national or global. They were able to make their beliefs and the discourse that promoted them dominant. They became powerful and then intractable and harmful.

The neoliberal free market

Problems in the neoliberal free market are not limited to health and aged care. Without an intrinsic (ie not tokenistic) commitment to social responsibility, and with a top/down management structure, closed off silos develop in which people reinforce one another and critics are excluded. Aberrant beliefs are protected from challenge.

Without close interaction with civil society and a bottom/up component in management structure, the normal processes of person on person social control are lost. In this sort of marketplace explanations and justifications are developed that allow almost any vulnerability to be exploited - whether this be customers, employees or the funding system. The manifestations differ but all of these scandals are associated with some vulnerability in the system and commercial pressures to exploit it. The discourse refuses to acknowledge that vulnerable sectors need to be structured differently.

This has happened extensively²⁴² in financial advice, insurance, the banks, the jobs market, with employees including visa holders, as well as the system for funding aged care. Aged care is not unique. While the human suffering is much greater than in other sectors it is probably easier to prevent and respond to.

In depth understanding how this happens

Social scientists have explored our individual and social nature, the societies we form and how we respond to our world.

Mankind and its relationship to the world

Over the last few hundred years we have come to realise that, while the physical world is real, it is also complex. We experience it as well as our fellow humans as electrical signals coming through our 5 senses. It is our brains that reconstitute that world by creating 'abstractions' from these signals - mental images, patterns and ideas that link and make sense of them. We construct a representation of the world and what we think are the relationships between the things we experience in our heads.

We do this by interacting with others, starting with parents and so learning from them, and later by contributing ideas and teaching others in an ongoing and developing process. Building the ideas and the knowledge we need to live in the world is a social process.

Language is critically important to this and if our language does not contain the words then that part of the world is lost to us. If we change the words we use we understand differently. We come to recognize and understand what our senses experience using the ideas and patterns of thought we have developed as if they are lenses in a camera. Only the light that passes through the

²⁴² Failed markets and culturoopathy Inside Aged Care <http://bit.ly/2ryheHr>
Contracting government services to the market Inside Aged Care <http://bit.ly/2byL9ld>
Consequences of marketplace thinking Inside Aged Care <http://bit.ly/2abLnGz>

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lenses is registered. If we do not have the words and a conceptual framework to help us understand it then it does not exist for us.

Because we speak different languages, live in different places and do different things, different groups of people and individuals will develop different understandings (cultures) of what they are experiencing. They will think differently. We are all unique. There are consequently many different and often conflicting ways of seeing the world and understanding it and most of us see the one we develop for ourselves as real. It is rather like looking through different coloured glasses, each casting a different hue.

But the more different ways we can see and experience our world, the more people with different points of view contribute, and the more we interact with one another, the more complete can our understanding of what we are seeing or experiencing ultimately become. Because we interact with others and incorporate their perspectives to build our understanding of our world we talk about the “social construction of reality”.

Becoming someone

We are all ‘existential beings’, which means that we start life as an ‘empty vessel’ and we need to find ways of filling it in order to understand and manage in the world. We develop patterns of thinking that allow us to understand our world and make sense of it. We create meanings that we can use to build lives and identities, and motivate us to become successful. We do this together. We are social animals and we depend on interactions with others to grant us the identity we want and acknowledge our achievements. None of this is necessarily easy and it can be very painful as we are molded by our lives.

In claiming identity we may claim it on the grounds of personal achievement as in sport or in making money or political success. We talk of ‘selfish selves’ particularly if our identity and success comes at the expense of others or of society. When our efforts are directed towards the welfare of others or of society and we are being responsible citizens by serving the ‘public good’ then we are building and claiming ‘social selves’.

We are driven on a trajectory through life experiencing discomfort or angst when our world is not well ordered and understood, when we are faced with conflicting ideas and meanings, when our identity is challenged and when, in order to succeed and develop an identity in a new situation we have to do things that conflict with the ideas and meanings that have become a part of who we have been and think we are.

We have developed many different ways of handling conflict and so relieving the discomfort and giving us a purpose in life that we can pursue to build our selves.

So when we talk about the patterns of thought that rule our lives we use words like ‘belief’, ‘paradigm’, ‘metaphor’ or when we believe deeply and have no doubts ‘ideology’. We tend to use ‘ideology’ derogatively to refer to others when implying that their beliefs are illusionary. We seldom if ever apply that term to ourselves however bizarre our beliefs might be. When we talk to each other within a particular pattern of ideas we can call this ‘discourse’. We all engage in discourse so this is less challenging than the word ideology.

Why it goes wrong so often

Our need for a meaningful system is so great and the struggle to order our life can be so confusing that we are prone to create coherent patterns of thinking that are based on illusions and are not logical, but which are appealing and allow us to build a successful life. We have understood this for a long time with 18th century market analyst and philosopher Adam Smith commenting “*The*

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learned ignore the evidence of their senses to preserve the coherence of the ideas of their imagination”.

These enticing illusionary ideas catch the imagination of others and are spread through discourse. They provide the meaning, the stability and the purpose we all need. The power of belief is that it creates ‘truth’ and so removes doubt. It has instant appeal and is music to our ears.

Belief too often balloons out of control and dominates thinking in a country or even the global community. People identify with it, become its disciples and incorporate it into their psychological DNA. They become inseparable from their beliefs and some become evangelists.

Often beliefs are developed within a particular sphere of activity and can be very successful there. They soon become universal truths for those involved and when believers gain political power they impose their beliefs on the whole of life and it is “transfused into every vein” of society compatible or not.

While our beliefs may be illusionary their consequences are real and often these are devastating. Millions have died in the 20th century as a consequence. Even with less bloodthirsty outcomes we look back with incredulity at earlier beliefs without realizing that others will later see what is obviously true to us as equally ridiculous. People hold on to their beliefs in the face of evidence of dysfunction and harm to others.

We suffer from an addictive weakness for large illusions, a weakness for ideology. Power in our civilization is repeatedly tied to the pursuit of all inclusive truths and utopias. p 19

In a society of ideological believers, nothing is more ridiculous than the individual who doubts and does not conform. p 20

For the ideologue, language itself becomes the message because there is no doubt. In a more sensible society, language is just the tool of communication. p 42

Source: John Ralston Saul "The Unconscious Civilization"-The Massey lectures Penguin books 1997

Saul has studied this issue and written books about it. The final quote refers to the way we substitute words for the real thing. They become tokens for something that is not there. If we are far enough away from the real world and what is happening there we can believe anything we like by using words.

He argues that our western civilization has escaped into illusionary beliefs to the extent that it is no longer in touch with the real world. We are no longer conscious of it and that is harmful.

Hollowing out civil society

Saul is one of many who are worried about the way ideology has driven the decline of civil society – often described as ‘hollowing out’ - so that it has become little more than a shell. Saul argues that loyalty is to corporate employers rather than society. People are locked into corporate organisations through employment contracts, loyalties and social pressures often compounded by legal restraints.

The corporations come to own our intellectual contributions. Most of this vast resource of knowledge, skill, intelligence and humanity is no longer available to civil society leaving it deprived and weak. Civil society’s role in managing its own affairs and protecting the “public good” including its vulnerable members is deprived of the skills, knowledge and motivation of the best of its citizens.

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In introducing a discussion paper The Centre for Welfare Reform in the UK said:

The current model of privatisation, procurement and tendering only serves to hollow out the capacities of local government and local communities. Profit, expertise and leadership are all exported outside the community and into organisations that neither know nor care about the local community ...²⁴³

Writing an article for Probono about nonprofits based on his doctoral theses Doug Hynd commented on the consequences of this 'hollowing out' for nonprofits who traditionally have been part of the community.

Hynd identifies the greatest threat of Government contracting for Not For Profits, is the potential 'hollowing out' of one's mission and the risk of becoming 'funder determined' resulting in a loss of identity.

The great loss in this process for the Australian community is the role Not For Profits have traditionally played in advocacy, identifying emerging community needs and addressing them with new initiatives that mobilise community resources²⁴⁴.

But more recently nonprofits have also been 'captured' by the market discourse as they are forced to compete to survive. Many have 'crossed over' so losing their ties to the community.

Managing challenges to belief in the free market

Challenges to belief

When our ideas are congruent with what is required in the situations where they are used and, when they accurately reflect the world we live in, then they work and there is little need to protect them.

When beliefs are based on illusionary ideas then they don't work. Problems develop, doubts appear and challenges emerge. These directly challenge who believers have become and what they do in life.

This causes true believers to harness their resources and direct their efforts to defend themselves and their belief system. There is a rich psychological and social armamentarium that enables them to keep the faith themselves as well as persuade others. They use the power they now hold to do that. This enables them to maintain the security of their beliefs and their identities in the face of evidence of serious problems, logic and strong criticism. Assertiveness and attack can be the best defense.

Managerialism

The closer people are to the problems that emerge or when they actually experience harm themselves the more likely are they to break ranks and challenge a discourse. In contrast true believers seek to distance themselves from what they do not want to know and create top down systems of control that are unreceptive to information they don't want to acknowledge. Typically this leads to an expanding gap between perceptions at the top and bottom of a system so that views are polarized. One of us (MW) wrote about this Great Divide in Perceptions in health and aged care in 2004²⁴⁵. This is readily apparent in Australia's aged care system²⁴⁶.

²⁴³ Introductory comment on Yapp C and Howell C **Community Sourcing and Social Care** Centre for Welfare Reform 2013 <http://www.centreforwelfarereform.org/library/by-az/community-sourcing-and-social-care.html>

²⁴⁴ BLOG: Strategies to Stop NFPs Being 'Hollowed Out' by Government Probono Australia, 11 Jun 2015 <http://bit.ly/2ErnSXm>

²⁴⁵ **The Great Divide In Perceptions About The Corporate Marketplace** - Corporate Medicine web site <http://bit.ly/2H0BMQ2>

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Neoliberal belief has been particularly adept at putting barriers between believers and the actual world. An integral part of its implementation was to turn management into a separate independent discipline in its own right and to make management (criticized as managerialism) a key component and driver of the neoliberal discourse – managing its implementation across society and assuming control of civil society and its structures – managing them all within the confines of the discourse.

Writing in the 1995 book “The Human Costs of Managerialism: Advocating the recovery of humanity” that he coedited, Stuart Rees wrote about a *“tendency is to control decisions from the centre, to set managers apart, to develop their own cultures, language, symbols and networks.”*

He spoke about *“numerous examples of assumptions about the universal value of management”* and that there was a *“preoccupation with management as the panacea for governments and organisations.”* The discourse was spread and imposed through *“‘culture management’ with its emphasis on changing the culture of an organisation by paying attention to language, symbolism and ritual”*.

They explained how managers were trained and *“waiting in the wings for the call to demonstrate their toughness and efficiency, their willingness to disparage old professional practices and traditions in the interests of a new corporatism.”*

Example:

The changes that have occurred were described in 2015 by the CEO ²⁴⁷ of a smaller faith based nonprofit that has maintained its mission and still has a close relationship with a community who make a large voluntary contribution to the care and support of residents.

*“The subtle introduction of these higher charges only being applicable to new Resident admissions, combined with **the total changes to the technical language used in all areas of aged care, the introduction of the ‘Myagedcare Portal’, the ‘means-testing’ by Centrelink, Government technology failures, a complete change to the familiar aged care terminology**, as well as the complete failure of the Government’s promised ‘public education programme’, all helped to add to the confusion and misinformation within the community. The cynic in me says that all of these issues, when combined, have suited the Government’s purpose, in being able to keep **the public focus off of the momentous and questionable changes that have taken place**”.*

Even though this organisation’s *“expenditure on staff pay and on-costs represents almost 75% of our total expenditure”* its response to government funding cuts for dementia care and to competitive pressure was to *“unanimously agreed to maintain the same level of services for those affected by dementia and has since further reaffirmed that commitment for the current 2015/16 year. Obviously this decision has, and will, impact on LHI’s financial results for both of the years”*.

The thrust of government policy and the discourse is revealed in the CEO’s comment about the allocation of new beds by government in that *“most of the government’s allocations being given to very large community and for-profit providers”*. International data shows that these groups staff poorly and provide inferior care. Limited Australian data suggests that this is happening here. When it comes to care the neoliberal discourse has created a race to the bottom. Good companies like this that provide good care make less money and ultimately struggle and become targets for growth companies.

²⁴⁶ Widely contrasting views Inside Aged Care <http://bit.ly/2H1MKow>

²⁴⁷ Chief Executive Officer’s Annual Report 2015/4 Dec 2015 <http://bit.ly/2FQFdtr>

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The big nonprofits the government still supports have been reducing staff²⁴⁸ in order to remain competitive and so failing even our poor accreditation requirements²⁴⁹.

Experience and knowledge: The organisation of society is managed by a hierarchy of trained managers, who often have little if any experience of the particular service they may be managing although they are very good at making it profitable and understand that well. When people who do have experience are promoted this is usually because of their willingness to embrace the discourse and work within it. The managers permeate down through the layers of the system reinforcing belief and weeding out dissenters. Little information trickles back up the system.

We need only look at the leaders in the aged care industry and at the number of industry representatives on government bodies who are used as advisers and consultants in the sector, to see what has happened. The lack of data is compounded by the lack of actual experience, knowledge and understanding of aged care that these people have. They are giving advice about management and market but not advice about care.

We have already referred to the lack of knowledge of outcomes in the health department and among the minister's advisers.

In section "**2.2 Who makes decisions and where do they come from?**" (page 43) and in Appendix 5 we described a glaring example where SB sent out incorrect staffing data on social media including the senate during the workforce inquiry.

It is difficult to conceive that SB fully understood what it was doing and then deliberately set out to deceive. This could not have been total ignorance because they had correctly charted direct care in their reports for years and included another correctly labelled chart in their 2016 report.

We think that what we saw here was an illustration of the extent to which managers and advisers had become detached from what was happening in aged care and instead become part of an out of touch marketing and branding world. The manipulation of data to create positive images had become legitimate and part of the way branding and so business was conducted. We think it likely that executives at SB and ACSA were so lost in their illusionary world that they were unconscious of the consequences of their actions.

StewartBrown (SB) is a financial adviser to the industry and a consultant. It collects data including staffing data from the industry and this data is used by SB and industry to lobby government. It also sets staffing benchmarks that the industry uses as a guide when deciding on staffing policy. When these benchmarks were used in defense of staffing in a coroners court their adequacy was questioned²⁵⁰.

The CEO of the aged care industry-lobbying group, LASA, joined the aged care division of SB and was involved in its 2016 reports. One might have expected him to be knowledgeable about care but his background was in pharmacy and in business. As CEO of LASA he had been appointed to several government advisory bodies.

²⁴⁸ Southern Cross Care defends nursing home cuts, families hit back Chinchilla News 13 Jul 2017 <http://bit.ly/2und9av>
Illoura staff run ragged as residents wait for basic assistance Chinchilla News 20 Jul 2017 <http://bit.ly/2noiVqG>
Now it's Blue Care cutting nursing hours for elderly residents Media Release 1 Aug 2017
<http://anmf.org.au/news/entry/now-its-blue-care-cutting-nursing-hours-for-elderly-residents>

²⁴⁹ Funding cuts mean nursing home residents receiving minimal care, Brisbane Times, 31 Jul 2017 <http://bit.ly/2DO0wK1>
Man recharged with assault after grandmother Elizabeth Hannaford was found bashed at Myrtle Bank nursing home - Adelaide Now, 2 Aug 2017 <http://bit.ly/2DQiUWT>
Blue care admit serious aged care breaches, My Sunshine Coast, 22 Dec 2017: <http://bit.ly/2rRx7gJ>

²⁵⁰ Record of Investigation into Death, Coroners Court Tasmania, 2016: <http://bit.ly/2unfrdR>

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Control of data

Probably the most important and revealing feature of belief systems based on illusions is the way they control data either by direct censoring or by taking control of its collection, interpretation and dissemination and in effect manipulating and massaging it to support the discourse. In aged care the limited data that is collected is processed, interpreted and then published by either industry or government departments who support them.

Pointers to problems in aged care

Pointers to a dysfunctional system built on illusions include:

- the strong promotion of idealised images supporting the discourse through media,
- a wide gap in perceptions between an insulated leadership and those at the coalface,
- a denial or minimisation of problems,
- a top-down centralised system of control,
- ignorance in the managerial class, and
- control of data

Psychological and social coping strategies

We humans are the ultimate evolutionary survivors. We are well equipped to succeed in any situation we find ourselves and we often find ourselves in situations where being successful requires us to do things which are incompatible with maintaining an unblemished identity among our fellows – maintaining our social selves.

As in aged care we may be required to serve the discourse of one ideological master that is dysfunctional while paying tokenistic service publicly to another conflicting discourse – in this instance we must serve the free market neoliberal discourse while paying tokenistic service to the discourse of care.

Strategies

Social scientists have recognized this and have studied the strategies we use in order to do this. Well recognized concepts used to understand this include

- **compartmentalising** - keeping conflicting discourses in separate mental compartments so that the conflicts are not confronted but the one needed in each context is selected and used. (eg. one for talking to the public and another when reporting to shareholders.),
- **rationalising** - justifying or explaining it away,
- **willful blindness**²⁵¹ - not seeing and not acknowledging what is under our noses, and
- **labeling** or “destroying the messenger” - a very common way of meeting criticism. By attacking and destroying the critic we make what they say illegitimate so that we don’t have to consider their evidence or arguments as valid. We avoid the difficult problem of facing the criticisms.

We do these things defensively and instinctively. There are two other less well recognised explanations – perhaps because they are more difficult to understand.

²⁵¹ Margaret Heffernan *Willful Blindness: Why We Ignore the Obvious at Our Peril* Bloomsbury 2012

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Lying to ourselves

Philosophers have looked at this more deeply. In the early and mid 20th century existentialist Jean Paul Sartre explored the nature of man and the way we develop identity by physically or mentally acting out who we are in front of real or imaginary others. He wrote an interesting paper exploring the difficulties we have in being authentic in the identity we develop and in not claiming an inauthentic identity that we want or need to have but which is not true.

He described how we attempt “*to flee from freedom, responsibility and anguish*” by an “*ultimately schizophrenic attempt at self-deception*” and need to “*continually be aware of the tendency to slip into bad faith*” by deceiving ourselves. He describes it as a “*permanent threat to every project of the human being*”. It can even be “*the normal aspect of life for a very great number of people*”.²⁵²

He argued that we escape into inauthenticity by lying to ourselves at a deep level of our being. We know that what we are claiming or doing is false but we do not acknowledge it to ourselves. We do become the person that we are pretending to be even when we are not doing the things that that sort of person would do. The example Sartre gives is trite and so hides the true significance of his insight.

To be believable, managers in nursing homes and their staff must be seen as genuine when boasting about the good care given. It is not easy to lie to others about providing good care when you know that staff are too few and untrained. But by lying to yourself that the facility is well staffed you can do it.

This lie creates a deep tension within people. As Sartre indicates the lie is often not continuous and the tension is often acknowledged in some wry way. Doctors in the psychiatric scandal we described earlier dryly joked about the ‘howdy rounds’ and the ‘wave therapy’ they did in order to collect their daily fee when they handed their patients over to their corporate masters. Weekly meetings to massage the patients records and so hide the fraud were ‘charting parties’.

Controlling others thoughts

Another French philosopher in the late 20th century, Michel Foucault, provides a different insight into this. He showed how social processes are harnessed to spread ‘discourses’ and so control disbelievers. He writes about the close relationship between discourse and power and the way those with power decide what is included as legitimate and what is excluded as not credible within discourse.

He describes the way this enables those with power to govern (ie control) the thinking and so the actions of others, whether in nursing homes or an entire country. In everyday language we call the things that we don’t talk about because they are not part of the discourse ‘elephants in the room’.

If we examine the discourse in aged care and at the many inquiries it is clear that there are often elephants in the room – matters that it is not legitimate or credible to raise. Academics are now using this ‘discourse theory’ when studying staffing behaviour including in health care.

PhD students are using it as a framework for their research. The impact of the discourse in the new management style on the way nurses understand their work and do it has been explored. This conflicts with the discourse of care that motivated them to become nurses and that was reinforced during their training.

²⁵² Bad Faith: An Essay by Jean-Paul Sartre. Philosophy magazine http://www.philosophymagazine.com/others/MO_Sartre_BadFaith.html

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Our worry is that this inquiry will behave similarly - that our submission will not be evaluated on the evidence provided or its logic but instead on the credibility and acceptability of the challenge it poses within the discourse that dominates and controls the committee.

Making it all easier to do

We have just looked at the mechanisms which we use to help us do what we have to do to conform with what we are expected to do – what we have to do to succeed. This means doing things even when we know deep down that we should not be doing that.

But there are other processes at work that encourage us not to reflect on what is wrong and so make it easier for us to do the things we know we should not be doing.

Incentives, reflective thinking and conscience

We have examined the role of intrinsic incentives and disincentives within different discourses as well as the deliberate incentivisation that is used within the neoliberal management process. This is essentially the application of behaviourist theory to markets. This has been very successful in driving profitability.

Behaviourism, the carrot and stick theory of behaviour, was based on experiments in rats. It was widely adopted in education in the 1960s. By the 1970s we realised that incentives and disincentives focused student's minds on gaining the reward and everything else was ignored. It inhibited reflective thinking and so conscience. Understanding was inhibited and behaviour was more likely to become antisocial. In essence it turned people into 'rats'. It was largely abandoned.

When events are closely examined we can see that this is exactly what happened in some of the big corporate health care scandals in the USA. Managers indulged in unconscionable conduct in order to earn their large bonuses of up to 50% of salary linked to financial performance, a massive incentive for behaving like rats!

In aged care many have entered the sector because of its potential profitability and this has remained the primary incentive within the market discourse. Financial failure and bankruptcy are the main disincentive to responsible behaviour.. Competition is competition for profitability and for empire building – growth. Profit has become the driving incentive and it confronts humanitarian values and motives

With so much pressure the consequences for staffing, and so care have been excluded from the discourse. Data that would attract attention to it and challenge the competition has not been collected. That the system we have could be failing and people suffering as a consequence has not been a credible consideration in the discourse. With such strong incentivisation focusing on profits, reflectivity, sensitivity and conscience are blunted. We more readily employ the psychological strategies described above.

When profitable but unsavory practices are developed by any operator the financial carrot is strong and the stick of failure too threatening. These practices become infectious and go viral. Soon almost everyone is doing it. In the psychiatry scandal in the USA other companies poached NME, the company that started the practices and made so much money. Soon the entire sector was doing the same things.

Because private equity is the most profit driven and the least restrained by community values they often lead the way. Others must follow to survive. Reflection and conscience, two attributes critically important in aged care, are no match for this and those who are afflicted by either cannot prosper. The system selects for the sort of people least suited to care for us and rejects the most suitable.

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Once someone gains an advantage by doing something unacceptable others must follow and it soon becomes 'acceptable' within the discourse.

Example

We need only look at one of the things that has been increasing steadily in the USA and the UK since about 2007 and the role that private equity, the most profit driven group of providers, has had in this.

USA: A December 2017 US article *Care Suffers As More Nursing Homes Feed Money Into Corporate Webs* in Kaiser Health News is typical. It states that *"In what has become an increasingly common business arrangement, owners of nursing homes outsource a wide variety of goods and services to companies in which they have a financial interest or that they control."* Kaiser's research has shown that companies that do this *"tend to have significant shortcomings: They have fewer nurses and aides per patient, they have higher rates of patient injuries and unsafe practices, and they are the subject of complaints almost twice as often as independent homes"*. The article claims that *"nearly three-quarters of nursing homes in the United States - - have such business dealings"*²⁵³.

By overpaying these related companies for the services they provide the subsidiaries providing the care are left with insufficient funding to employ staff. Care suffers. The owners gain massive incomes from their subsidiaries possibly siphoning money into off-shore havens. When creditors come calling, governments impose fines or injured residents and families seek damages, there are no funds in the company that is legally responsible for the failures. Pursuing the owners through the web of companies is almost impossible.

The UK is already well down this path. A recent article describes a private equity plan that involved *"setting up subsidiaries to create a complex layered structure, often across several countries, and then transferring cash, shareholdings, borrowings and other assets such as property or intellectual rights between them"*.²⁵⁴ Others follow the leaders. Another article claims that *"Not-for-profit Bupa has a complex corporate structure, with two-thirds of its care homes registered in Guernsey"*.²⁵⁵ BUPA operates as a for-profit in Australia. There have been worrying reports of poor care in nursing homes operated by these private equity groups and BUPA in the UK.

The story in Australia: Aged Care Crisis has been aware of the problems that developed when private equity operated businesses in vulnerable sectors for a long time. We knew of their entry into health and aged care in the USA in the early 2000s. We understood the problems that were already developing in the USA. We realised that in a competitive market companies must adopt 'successful practices' to survive. Others must follow the leaders and it is soon accepted that this is the way business is conducted. We attempted to warn Australia.

The 2007 Senate Standing Committee on Economics inquiry into Private Equity rejected the arguments in our submission²⁵⁶ and our warnings in their August 2007 report²⁵⁷ claiming *"The connection claimed - - - is unclear"*. Only a few weeks later The New York Times described these same strategies in the aged care businesses acquired by private equity, with examples of the consequences for staff and care²⁵⁸. There have been many studies and reports in the

²⁵³ *Care Suffers As More Nursing Homes Feed Money Into Corporate Webs* Kaiser Health News 31 December 2017 <https://khn.org/news/care-suffers-as-more-nursing-homes-feed-money-into-corporate-webs/>

²⁵⁴ Private equity firm made struggling care home operator take costly loan The Guardian 8 Nov 2017 <http://bit.ly/2FnFkio>

²⁵⁵ "Not-for-profit" Bupa has a complex corporate structure, with two-thirds of its care homes registered in Guernsey. Care Homes Issue 1455 <http://www.private-eye.co.uk/issue-1455/in-the-back>

²⁵⁶ Submission J M Wynne 2007 <http://bit.ly/2FdAYLm>

²⁵⁷ Senate Standing Committee Report Private Equity Aug 2007 <http://bit.ly/2FkY1TG>

²⁵⁸ At Many Homes, More Profit and Less Nursing NY Times 23 Sep 2007 <http://nyti.ms/2gow6DA>

Appendix 7 - Understanding why we go wrong (*Belief, Ideology and Discourses*)

USA and the UK about this problem since. We tried to warn politicians again after the NY Times report appeared and continue to do so. We have watched this begin among private equity and then spread to three quarters of US nursing homes and internationally into the UK and now possibly Australia.

We do not know how many companies develop these corporate webs in Australia but we usually take a few years to copy US 'innovations'. Many companies, probably including some in aged care are already using tax havens. We do not collect the sort of data that would allow us to track staffing and failures in care so we can only guess at what happens with private equity from press reports and from what staff and families say.

Conflict between discourses leads to toxic cultures

In our submissions to other inquiries we have compared the neoliberal discourse with what we have called the discourse of care – the traditional patterns of thought governing the care of those in need. We also noted earlier how the discourse of care has been analysed and refined by academics - research that is ignored by the neoliberal discourse.

We also looked at the adverse impact of conflicting discourses on the cultures within nursing homes and how this plays out in poor care and in elder abuse. Some of this material is included in **Appendix 6**. When cultures are conflicted and toxic the social constraints that constrain inappropriate behaviour break down and it is easier to behave badly.

The role of competition policy

One of the elephants at every aged care inquiry and policy debate in Australia has been the widely documented negative impact of competition for profit on staffing and standards of care and the failure of the existing system or any alternative developed to contain it. Competition has been promoted as an ultimate good. Challenging it is to discredit yourself in the eyes of the marketplace discourse and its adherents. This is prohibited in the discourse.

When challenged, policy makers and bodies like the agency have persistently over the years denied that there is any relationship between the profit motives in different types of owner and the care provided. The nurses are telling us this is happening. The data (see Appendix 2) shows it is happening. But inquiry after inquiry and government after government has refused to acknowledge it. None have tried to create a context to contain it that has any prospect of doing so.

Not a unique problem

Aged care is a part of our society and what we have described in this submission is unlikely to be unique. To anyone who has looked it is apparent that something similar has happened in almost every sector in which there is any vulnerability whether in the customers, the employees, the funding system or the tax system. Invariably someone or the country itself is exploited and harmed.

The banks are a good example. The social fabric of our society has been weakened and the patterns of relationships that should inhibit this sort of behaviour ruptured. Similar processes to those described here probably operate. There are many examples²⁵⁹.

²⁵⁹ Failed markets and culturopathy Inside Aged Care <http://bit.ly/2ryheHr>
Contracting government services to the market Inside Aged Care <http://bit.ly/2byL9ld>

Appendix 7 - Understanding why we go wrong (*Belief, Ideology and Discourses*)

Bringing this together

*The more eyes, different eyes, we know how to bring to bear on one and the same matter, that much more complete will our “concept” of this matter, our “objectivity” be.*²⁶⁰

The previous section on coping strategies illustrates how bringing different eyes (different points of view and the insights they bring) to bear on the way in which we see and understand our behaviour when we are challenged and so under pressure can give us a more complete picture of how people respond when faced with the sort of situation we have in aged care.

We can also see that even though we do not have accurate data about care, by using what we have and examining it through different eyes we can get a more complete picture of what is happening in the sector and so about care. More eyes give us more insight.

Lessons from this

If we are to address the problems exposed by the many perspectives employed in this analysis then we have to embrace a discourse that is appropriate for the sector and is soundly based on what happens there and what is needed. To ensure that it does not escape into fantasy it needs to be based on data, direct experience in giving and receiving care, and on logic.

This can only be accomplished by changing the power structure in the system so that it is balanced and one interest group cannot adopt a discourse that disregards the views of its critics. It must draw on and evaluate all points of view – many different eyes. There is already a well-established discourse that focuses on care and it should be built on without ignoring the financial realities.

This is best accomplished by continuously evaluating ideas and their application close to where care is provided so that the new discourse is constantly tested and evaluated against real life situations, modified, and then re-evaluated again. It has to be pinned to the service it provides to society to prevent it from escaping into illusions.

Power at the bedside must challenge and hold management to account so that they too are restrained and bound to what is happening there. In this vulnerable market that power must come from the community and the supported customer as well as the staff providing care.

The intention is to change the way this market operates and make it responsible to the needs of the elderly above those of any shareholders. As the staffing figures show what we currently do is not morally or ethically sustainable.

The proposals we have made are intended to gradually change the way this market operates so that it does what responsible markets are there to do - serve society and its citizens, and be rewarded when they do so well.

Having said this, it is often outsiders who see what those who are too close overlook. Transparency and openness to alternatives are therefore essential. We need many eyes and many voices in aged care.

²⁶⁰ Friedrich Nietzsche's critique of truth in his 1887 book *On the Genealogy of Morality*, Quoted by Alexis Papazoglou in *The post-truth era of Trump is just what Nietzsche predicted*. The Conversation 15 Dec 2016