Community managed aged care

An analysis

Attachment to Submission:
Inquiry into Quality of Care in Residential Aged Care Facilities in Australia by the House of Representatives Standing Committee on Health, Aged Care and Sport

March 2018
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Part 1: Executive overview

In our submissions to the 2017 Senate inquiry into Oakden and the 2018 House of Representatives inquiry into Quality of Care in Residential Aged Care Facilities in Australia we addressed the problems and the failures in a deeply flawed aged care system, a system that has been failing Australians for 20 years. We suggested an alternative way of structuring aged care in which the management and oversight of aged care would be returned to local areas and their communities. Instead of managing the system themselves the bureaucracy would support local organisations to do this.

Since the senate submission, two key reports have been released and the senate held a hearing in South Australia. This analysis is a critical examination of the hearing in Adelaide and the two available reports in order to show how our proposal would address the problems identified by the hearing and do a much better job at reforming the system than either of the two reports do. It builds on the more theoretical analyses and the proposals made in the 2017 senate submission by setting that analysis against real life events to reveal how they explain what is happening and how our proposals would address them.

The path we have travelled illustrates the path followed by most advocates, many of whom give up along the way. In order to show how far we have come we give a brief overview of our response to the terms of reference of the two most recent inquiries above and describe the thrust of each submission. We comment on reviews and then append a short review of some of the 40 plus submissions that Aged Care Crisis has made over the years to illustrate. These illustrate how the gut response of individuals and groups is always to call for more regulation rather than to change the system.

Multiple failures over time cause a rethink. An in-depth analysis then reveals that it is the system itself and the forces that are generated within it that are problematic and must be addressed if we are to escape the cycle of recurrent failures, each followed by futile attempts to patch the system.

Both the reports released repeat the errors of the last 20 years and do no more than fiddle with the regulations that have failed citizens so badly in an attempt patch something that is deeply flawed.

At most, these efforts have had slight temporary benefit and given politicians breathing space. There have been multiple opportunities to collect reliable data and reflect on a failed system that has ignored what we know about human behaviour then use that knowledge to develop a more sensible policy. Instead, the neoliberal discourse has simply been more stridently asserted and steps taken to drive the same policy harder leading to more problems.

This analysis comprises:

Part 1: Executive overview

Part 2: Introduction to Oakden and our proposal

Part 3: Examination of the Senate Hearing in Adelaide (21 Nov 2017)

Part 4: Government Reviews and Inquiries after Oakden – an examination of the reports

Part 5: The journey - submissions made by Aged Care Crisis over the years
Part 1: Executive overview

Part 2: Introduction to Oakden and our proposal

It would be a sad mistake to consider Oakden as an isolated instance rather than a red flag to a system that is deeply flawed.

We explain what we see as a way forward and how it would gradually change the way aged care operators thinks and operate – the culture in the sector.

We envisage that it would start with an empowered local visitors and advocacy service that would gradually assume responsibility for the remaining management and regulatory services and so come to manage aged care and other aged care activities locally. It would be mentored by government and other agencies, report to and be jointly accountable to community and government. It would establish a central representative body to coordinate activities and represent the community. It would grow and assume additional functions to meet the needs of the community.

Part 3: Examination of the Senate Hearing in Adelaide

In this section we use quotes to highlight issues that we identified as of interest and relevance. We show how our proposal would address the issues that we identify.

Change, please change.

The pain revealed and the call for change so that others could be spared the horrors of Oakden can be seen as a gut wrenching call for a return to the discourse of care. This is what our proposal is intended to do.

Who is responsible for aged care? The regulator has been held up not only as the guarantor of care but as evidence that it is world class. When the regulator is exposed as a sham we suddenly find that it was the providers who were responsible.

We explore this issue and explain why civil society, our communities, are and always have been responsible for their vulnerable members. It is the most effective regulator in preventing others from exploiting their vulnerability. Government’s role is to support and provide backup.

A fish rots from the head: The problems in a system that is structured and managed in a top/down manner. What happens when those at the top have no knowledge of care, come from a domain with a different discourse or have adopted a conflicting discourse.

Capture: There are many situations in which individuals, organisations and even systems can be captured. Oakden is an example which illustrates the extent of capture within our aged care system. Those who capture bring with them their patterns of thinking (their discourses) and impose them. Power, discourses and control are closely related. These issues are explored.

Culture: Culture refers to groups of people and the patterns of thought (discourses) that enable them to live successful lives in particular situations. When the dominant discourse is not suitable or conflicts with a suitable discourse then this impacts the culture with perverse social and psychological consequences. Oakden’s toxic culture was an example.

A system problem. Regulation is only a symptom: Oakden was a red flag to a system problem, not only a regulatory one. Fixing regulation will not fix it.
Part 1: Executive overview

Effective regulation: The failure of regulation at Oakden raises the question of what sort of regulation is effective. We conclude that it needs to be local and on site but centrally supported and mentored.

Accreditation and a culture of cover up: We look at the many problems in accreditation and at how they can be addressed.

Burden of accreditation: The argument that regulation is burdensome and needs to be decreased rather than increased to make it effective is part of the neoliberal discourse. We show how it can be increased and made effective without making it burdensome.

Complaining: Oakden graphically exposes the ineffectiveness of our complaints system. We look at this issue and show how our proposal would address this.

Visitors scheme: The visitors scheme took a long time to discover what was happening at Oakden. We show how building our proposal for a local visitors scheme would make it much more effective and how we could build community involvement around it.

Advocacy: Advocacy’s ineffectiveness was exposed for all to see at Oakden. We show how incorporating advocacy into our community structure would address this.

The collection of accurate data and transparency: The problems in our aged care system and in Oakden could not have developed had we collected and published verifiable data about care in Australia. There is none. Data grounds discourse in the real world and prevents it from escaping into fantasy. We explain how our proposal would address this.

Staffing: Staffing is a central core problem in Australia and this is in large part because the discourse in politics and industry saw nursing skills as unnecessary. Market pressures including plans to privatise impact on staffing. The culture in nursing homes is disempowering and give this sector a poor image. What we propose would address some of this problem.

MyAgedCare and a centrally managed system: MyAgedCare is an example of everything that is wrong with the management of aged care. Our proposal would do it very differently.

Is it a home or a hospital?: This dispute based on illusions is a root cause of problems in the system. Our proposal would put an end to this and ensure that it was both.

Market Pressures: Market pressures including the competitive drive for profits and consolidation have been a major problem for staffing and for effective care internationally and in Australia. In Oakden planning for privatisation resulted in staff reductions and a fear of privatisation was a major demoralising force. In our proposal the pressures within this market would change. This would reduce the extent of this problem.

Platitudes: There is a tendency to downplay the extent of the problems in aged care. There is no evidence to justify this. In this market it is a case of customer beware and there is little information to help.

Vulnerability: The vulnerability, lack of knowledge, lack of confidence and susceptibility to retaliation of residents and families is exposed by Oakden.

Trust: The industry cannot be trusted to deliver yet the vulnerable need someone they can trust. We address this.

Bringing back our humanity: The neoliberal agenda, its discourse and the cultures developed have made it difficult to express our humanity in caring and Oakden illustrates this. We address it.
Part 1: Executive overview

Empowerment: Both staff and resident have been disempowered. We show how to support and empower both, so that the whistle blowers on whom we depend will not suffer.

Suggesting solutions from the community: What the community at Oakden thought was needed and how we could meet that.

Suggested solutions academics and regulators: What academics and regulators thought was needed and how we meet that.

A community system or hub: Reiterates what we are pressing for.

Part 4: Government Reviews and Inquiries after Oakden

Section A: Introduction
These reports were unusual in that many problems were identified and steps taken to address them. The problem is that the inquiries have been fragmented and focused on particular parts of the system so that we are seeing a whole of system problem addressed by treating the peripheral symptoms and not the problem. In addition proposals seem to be constrained by the power structures governing the sector.

Section B: Review of Nous Group Report
This report did not look at the system only at regulation. It considered that the standards needed to be expanded. Its most significant finding was that the majority of adverse findings came from review audits triggered by information supplied to the agency so they knew where to look - information from nurses or family. That this has often followed soon after a full accreditation suggests that failures in care are more common that the figures suggest. In the model that we propose oversight would be regular and on site so that the large majority of problems would be detected and brought into the open at an early stage.

Section C: Review of Carnell/Paterson report into Oakden
This review does identify serious problems but steers a precarious and uncomfortable course between acknowledging these and pretending that the system is generally performing well when it is quite clear that it is not doing so at all and that problems are systemic.

It rejects claims that Oakden is a unique event and does not expose problems. It acknowledges that there are deficiencies in accreditation. These include a focus on accrediting rather than regulating, an excessive focus on processes that are burdensome and draw resources away from care, ignoring risk factors when accrediting, that 3 or 5 year accreditation became a ‘proxy’ for being good carers, lack of integration and of communication between regulators, and a lack of good data on which to base assessments.

It fails to acknowledge many of the major problems underlying a failed system that we identified in our submissions to the Carnell/Paterson Inquiry as well as to the senate in our 2017 submission.

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AACQA Annual Report - 2016-2017: [http://bit.ly/2qI5Dtm](http://bit.ly/2qI5Dtm) - Table 1: Accreditation status of Residential Aged Care services as at 30 June 2017: *Residential Aged Care services receiving five year accreditation were part of the “South Australia Innovation Hub”*
Comments on issues raised in the Oakden Review

Rose coloured glasses
The report tries to reduce the impact of its findings by claiming that the system is generally performing well and that the regulatory system has seen many improvements over the last 20 years and simply needs some more adjusting. Aged Care Crisis in contrast sees this as a flawed system plagued by recurrent failures, which have resulted in unsuccessful attempts to patch the system instead of changing it to one that works.

The report attempts to validate this by comparing our processes with those in other countries where similar discourses have resulted in similar failed regulatory processes so that it can still be seen as world class. Some of these countries have been dogged by extensive problems and more extensive publicity than Australia. These comparisons are done comparing processes and importantly, not data based outcomes.

An alternate view
It is clear that Oakden is not an isolated event and we describe a company where a similar failure of regulators to detect problems over a period of about 14 years might well have occurred. It has received minimal publicity and it has not been similarly investigated. Was this because Oakden escaped the federal regulatory safety net – the one protecting government?

The problems at Oakden were detected by the state visitors scheme and not the federal complaint system. It was investigated independently and not by the Quality Agency. The full horrors were exposed. Would it have been exposed differently had it gone through the normal federal complaints and then accreditation regulatory system?

Failures are systemic and widespread: Data shows that success in accreditation has increased by 53% (64% to 98%) at the same time as the acuity of residents has risen by 53% (58% to 89%) and the number of trained nurses needed to manage these sicker and more difficult patients has decreased by 35% (38.8% to 25.2%). This is simply not possible and exposes accreditation as a sham.

This is confirmed by international data comparison.

On average, Australia supplies half the amount of care by trained staff and an hour less care to each resident each day. Regulators in the USA identify some problems in care in 93% of nursing homes and 20% of these are serious. In Australia 97.8% of nursing homes are fully accredited for 3 or 5 years and only 2.2% have problems in getting fully accredited. It defies all logic.

The figures from the complaints system suggest that only 1.4% of complaints resulted in a site visit by the complaints system and 0.35% in a review audit by the Quality Agency – hardly a vigorous response to complaints.

In the changes we propose, community members would be regularly on site to see what was happening to care. All complaints would be addressed immediately by a community investigator.

Should we ‘trust’ or should we adopt a ‘buyer beware’ approach?: As the Oakden hearing revealed and the data shows, trusting this system is dangerous. In our proposal it will be safer and there will be someone independent that they can trust on hand to protect and assist them.

Accreditation as regulator: It seems likely that in 1997, in keeping with neoliberal belief, all regulation was to be removed and accreditation was not going to include regulation. It was the community backlash that saw the accreditation Agency saddled with a regulatory role. The Agency never embraced this role, which conflicts with its role as accreditor.
In 2011 the Agency asked to be relieved of it. Probably in response to this, the independent Agency was abolished and replaced by a government run Quality Agency putting an industry leader in charge. We have heard no more of this and when challenged with the incompatibility of the two roles exposed by Oakden, the issue was evaded.

This Carnell/Paterson report ignores this important issue and insists that the Quality Agency be both accreditor and regulator, even though its primary role as accreditor has undermined its role as regulator as revealed above. It is significant that although the Nous report found only review audits were effective, very few were done, particularly in response to complaints.

We recommend that the Quality Agency no longer have a regulatory role and that regulation be centred locally and supported by a different central regulator.

Terminology: The use of terminology is loose and inexact. In comparing our regulation with that internationally, it refers to all of them as accreditation. This is incorrect. While all can be criticised for what is called regulatory capitalism, only Australia depends entirely on accreditation for regulatory oversight. It is not clear if this is deception or ignorance.

Selective quotations that do not reflect the thrust of submissions: The words ‘consumer’ and ‘community’ are sometimes used as if they are the same thing. Our submission is selectively quoted to support arguments which we are very critical of. It is noted that the funding of community organisations that advocate for those they serve is currently being threatened so discouraging criticism.

A role model: The report seems to use regulation in the UK as a role model, but although it is more transparent the regulator in the UK has been even more heavily criticised than the Quality Agency.

Rating systems: A star rating system and Quality Indicators are both recommended but these have not always been reliable elsewhere and star ratings would depend on the Quality Agency’s findings and as we reveal, these are unreliable.

The role of regulation: The report continues to make positive comments and define the role of the regulator as providing assurance to the community and protect it, which it is where it claims the regulator has fallen down. But the Agency has been very good at assuring the community but we feel that this is not its primary role.

Its role is to regulate and that is where it has failed. If it regulated effectively and publicly exposed and stigmatised failures, the public would be reliably assured because it would be able to protect itself by avoiding those who provided poor care and put them out of business.

The report lies within and adopts the neoliberal agenda. In doing so it avoids confronting the conflicted situation we described in our other submissions. Instead of changing and rethinking regulation, the Carnell/Paterson report is patching additional bits onto failed regulation.

Responsibility: The report repeats the claim that the providers and not the regulator are responsible. This is a naïve expectation when all of the incentives within the system put contrary pressures at the heart of its operation. Such a system depends on regulation and we do not have a regulatory system that can counter these pressures. It is the community supported by government that must assume this responsibility.

Probity – restricting providers and owners to those who are responsible: The report totally ignores the flaws and contradictions in the approved provider process that were introduced in 1997 when the approved provider system replaced probity requirements. It does not understand
the distinction between owners and providers and the way this opens the system to potential criminals and exploiters.  Probity requirements protected us from predatory market operators.  One wonders if they actually read the regulations they reference.

In our system local communities would vet the suitability of those seeking to provide aged care services to them before letting them operate there.  The interests of vulnerable citizens would trump the right to provide services.

**Transparency, data and support groups:**  The report recognises and expresses surprise at the absence of data about care but fails to understand why this has happened and the way in which the industry had reneged on their promise in 2003 to collect data and aided in doing this by a review commissioned by the Agency in 2007.  We cannot blame Carnell for this as she only joined the board in December 2008 but she might have become aware of it.

While the report claims that the regulators are increasingly making information available after 20 years, there is still not much evidence nor any indication of what the data available will be.  Given the track record of the industry and the Quality Agency, we should not have any confidence in this.  We must insist that the community have a central role in evaluating care and performance as well as informing prospective residents, their families and the community.  They are the only group not conflicted who can be trusted to be there to support the residents and the staff who care for them.

**The value of resident and family opinions:**  We welcome the focus on collecting feedback from residents and families, but we have reservations because of the risks of their views being influenced by the circumstances.  Surveys like this can be notoriously unreliable in detecting system failures when ‘good people’ are responsible as the abused and exploited identify and relate to them.  Solid data must support these assessments.

**Community visitors and advocates:**  While the report is supportive of advocates and would like visitors to report any problems they see, it does nothing to release them from the funding and legislative restraints that limit their capacities, to give them effective investigative powers or to bring them closer to the bedside more often which is what we want to see.

**Fragmentation:**  The report identifies the fragmentation of all the centralised regulatory processes and the lack of community but does not consider the lack of on-site local integration.  It seeks central integration and control while ignoring the much greater need for local integration and involvement within communities.

**Supporting consumers and their representatives to exercise their rights (P v111):**  Awareness of consumers rights is low.  Involving and empowering the community to support and guide their fellows as we suggest will increase knowledge and be much more effective than simply educating them as the report suggests.

**More effective regulation and complaints monitoring (P ix):**  The report documents the call for more rigour in the accreditation system and claims to be doing this.  But this call for more regulation has been repeated every few years and attempts made to do so are without success.  It is important to recognise that the system is fundamentally flawed at a much deeper level and while the proposals will be effective this will once again be temporary.  A whole of system strategy is needed and this is what we are pressing for.

**Enhanced complaints handling:**  The complaints system has been tinkered with even more often without success and proposing increased statutory powers will not fix it.  There needs to be a local complaints system.
Responsive Regulation: The report devotes considerable attention to the theory of responsive regulation. The report considers that Australia “aligns well with some accepted best-practice”. The theory is sound but we think its application can be problematic.

The problem lies with the whole of the system and addressing regulation alone will not fix the problems. We identify these by examining where and why we have gone wrong in the past. It must be solved by addressing the patterns of thought that are not congruent with the needs of the sector.

Solid data is needed to support change and keep it on track lest it wander into fantasy. Regulators still visit infrequently which allows gaming. It is essentially a carrot and stick system which can become impersonal and lead to the pursuit of rewards rather than engaging with our humanity and the vulnerability of others. It does not address the issue of distributive justice. It impacts individuals but is less effective at addressing community attitudes.

We prefer a system where the core of responsive regulation resides in communities where it is tightly linked to real life situations in which humanitarian behaviour is a dominant requirement. It would be supported by formal regulation, which would handle the extremes where sanctions are required or formal awards for performance awarded.

Conclusion: The optimism expressed about the recommendations made in this report is based on the assessments in the report that we have criticised above. We think this optimism is not justified. Instead we should examine the history of what has happened, examine the data that is available, consider what other data is needed and collect it, understand human behaviour and consider how the social structures we plan will affect it. There are major core issues that have been ignored. They need to be confronted, closely examined and addressed.

Criticism of the Oakden Review report recommendations

The recommendations are not in our view all soundly based. Further, the guiding principles that underpin the recommendations are desirable but not congruent with the sort of system that we have and its regulation.

The report lists specifically:

- Integration by centralising
- Informing consumers and supporting them
- Effective accreditation and compliance monitoring
- Enhancing complaints handling

But all of these are problematic within the present system. All would be better done and more effectively delivered by a local organisation supported by central services. Aged care is provided in the community and that is where we should be focusing our management and regulatory activity.

The reasons offered for the recommendation, the plusses of what is proposed, the criticisms and the alternative that we propose are addressed for each of the 10 recommendations.

Note that here we address only what the report recommends not the issues which they ignored. We referred to them earlier and have addressed these in our submission to the senate in 2017.
Part 1: Executive overview

The recommendations in the Carnell/Paterson Oakden Review report were:

1. Establish an independent Aged Care Quality and Safety Commission to centralise accreditation, compliance and complaints handling.
2. The Aged Care Commission will develop and manage a centralised database for real-time information sharing.
3. All residential aged care services in receipt of Commonwealth funding must participate in the National Quality Indicators Program.
4. The Aged Care Commission will implement a star-rated system for public reporting of provider performance.
5. The Aged Care Commission will support consumers and their representatives to exercise their rights.
6. Enact a serious incident response scheme (SIRS) for aged care.
7. Aged care standards will limit the use of restrictive practices in residential aged care.
8. Ongoing accreditation, with unannounced visits, to assure safety and quality of residential aged care.
9. Ensure that assessment against Standards is consistent, objective and reflective of current expectations of care.
10. Enhance complaints handling.

In regard to the processes suggested by the review

Our suggestions would be more effective in “immediate detection, and swift remediation by providers” than the improvements suggested by this report. It would address most of the problems that have turned aged care into a system that has failed Australians.

Part 5: The journey - submissions made by Aged Care Crisis

Over the years we have watched (rightfully) angry advocates and groups that have had bad experiences or been horrified by what they have seen rise up and demand that government do something – usually increase regulation. This anger drowns out carefully considered opinion and reflective examination of the problems. We have seen a cycle of scandals, community anger and reflexive but ill-considered regulatory responses to this. These have all failed.

We have come to realise that the system we have has serious flaws and is incapable of addressing the problems. These need to be understood and addressed, but this challenges deeply held beliefs so is not welcome. Part 5 describes our own journey from horror at what we have observed, calling for government to do something, to reflection, to insight and a search for alternatives.

In Part 5 we first address the terms of reference of the senate inquiry and of the inquiry in the house of representatives. We explain that aged care is a system whose design ensured that it would fail, our response to this and the efforts we have made to explain how and why this happened.

We comment on the group dynamics over time of aged care advocacy groups then look at the patterns of behaviour and the response of regulators to this. We explain how we have gradually come to realise that the best way of addressing the problems in this system lies with communities.
rather than government or market. It will ultimately depend on their willingness to engage with the sector themselves and so take the matter in hand.

We track our own path along this advocacy continuum starting for some of us in the early 1990s as we gradually came to realise that the market, politicians and bureaucrats were trapped by the system and incapable of addressing its failings.

Our best hope lay in taking this out of politics by persuading politicians and bureaucrats to hand aged care back to the community and then support the community in sorting it out and setting a new direction. We illustrate this by reviewing some of the 40 plus submissions that we have made since 2005 tracing our own path.

We believe that if politicians and bureaucrats understand the social processes and where along the path the submissions they get come from, they will be in a much better position to resist the temptation to respond instinctively by more patching of a failed system. This will delay effective action by another 5 to 10 years and many more will suffer as a result. Part 5 is an attempt to address this.

**We ask you to carefully consider the limited data available and the logic of arguments then look critically at the problems within current dogma. Instead of appealing solutions that can be marketed to the public, we ask you to look at a way forward that will break the deadlock and engage everybody in collecting the information we need, examining and reflecting on it, and then developing a logical program that can be tried and tested.**

We can then build on that as we develop a sustainable system that accomplishes what we need and all want. It should be constrained only by the resources that we can make available for care.

At the end of Part 5 we look again at the poor staffing that is a consequence of the system we have and a cause of the problems in care.

We need to understand the importance of developing a system that values, supports and rewards good staffing as a core value. The market will not do that on its own and will instead seek to use staffing problems and failures in care to coerce more profit from our resources. More money will be needed, but we should not do that until we have some control over how it is spent.

We look at the role of regulation in the current system and suggest that regulation that prescribes how society should function and seeks to drive it down ideological paths should be replaced by flexible regulation that listens, analyses, supports and responds.
Part 2: Introduction to Oakden and our proposal

Aged Care Crisis have argued for the last 8 years that placing the community at the centre of and in control of local aged care services is the best way of addressing the many problems in the sector. We live in a democracy. Entrenched political dogma and industry self-interest cannot be allowed to take precedence over the best interests of citizens and this has happened in aged care. The only way to address this is to create a knowledgeable and involved civil society that has the power to insist that government governs for them and that the market operates in their interests and not at their expense.

We start this analysis by explaining how a community based and organised management and oversight system would address the findings, criticisms, desires and problems exposed in the senate hearing in Adelaide on Tuesday 21 November 2017. We illustrate this by explaining how what is described might have been prevented or rapidly addressed had the community been actively engaged in managing and overseeing services.

In the public hearing the extent of the failure of our aged care system, the anguish it has caused for probably thousands of elderly Australians and the core reasons for failure were finally revealed. The important issues raised go to the heart of the problems in aged care that Aged Care Crisis have identified over the years. It is an opportunity to illustrate how it can be addressed.

2.1 Avoiding a mistake

It would be a grave mistake if Oakden were dismissed as an isolated incident as some in the industry have tried to do. Few of those who gave evidence thought so and it is clear that many of the factors that are responsible for the problems in Oakden are responsible for the many failures across Australia since 1997.

The failures at Oakden are so bizarre that we might want to discount them as an aberration, but Oakden is a red flag that tells us graphically and unequivocally what is happening across a significant proportion of aged care facilities. Aged Care Crisis and many others have been complaining about them for many years. Without accurate data we don’t know how many facilities but clearly it is far too many. The pain and the needless suffering is laid bare.

These are issues that our politicians have been ignoring and they continue to do so at their peril. That they are now occurring in government run facilities and it is government supported and funded regulation that has failed so badly, illustrates the pervasive adverse consequences of these policies.

2.2 No solutions offered

While all the participants wanted something done, none of the them suggested changes that would fundamentally change the way those in the system think and behave – the discourse on which it is based. What we propose will change the way those in the system think about aged care. It will address the many issues raised by the contributors by changing the way those in the system behave.
2.3 The problem for a government that is unwilling to change

We have examined two of the recently commissioned reports (Nous and Carnell/Paterson reports) and looked at the meetings the government and its industry supporters are planning. It is clear from the speakers and the discourse reflected in the words used, that what is being proposed is not real change.

We worry that the problem for politicians and the market is the exposure and the publicity that threatens them rather than the problems in the system that causes the publicity and the suffering of those receiving care.

**While the responses claim to improve the system we have, it can also be argued that it is being set up to more tightly control it centrally and so contain any further problem exposures like Oakden.**

2.4 How we got here

Oakden and the many other failures are the logical consequence of what happened in 1997 and the unwillingness of any party to challenge what was done then and acknowledge the errors made. Every solution we have looked at including the Carnell report is an attempt to shore up the present system without addressing the reasons for its failure. Benefits will consequently be temporary.

2.5 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 submissions we have 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 Roadmap fails to do this. We should scrap it and build another road instead.

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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.

2.6 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.

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.

2.7 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.
2.8 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.

The examples we give in this analysis give some idea of where this might go as it develops – what the possibilities are.

2.9 Illustrating the proposal

In our submission to the senate committee in August 2017 we did an in depth analysis of the reasons for the system’s failure at a broad theoretical level indicating how our proposal would make the changes needed.

We start this analysis at a practical level by looking at the real world problems, the emotions revealed and the assessments made at the senate hearing, identify the social forces at work and explain how what we propose will address these issues. We refer to what we have said before. We start each section with a selection of phrases from the senate inquiry transcript as a reminder of the content, the flavor and the emotion.
Part 3: Examination of the Senate Hearing in Adelaide

3.1 “Change, please change”

Family members and others pleas to the committee:

a) I would “like the people to be respected and be treated like human beings, - - Be passionate about what you’re working for. I just want to see change, so it never happens again to anybody - - just change. Just try to make change”,

b) “- - the people who are working in these institutions should be people who care about people - - They shouldn't just be anybody”.

Mr Johnston: “an absolute shake up, from the ground up, of the accreditation system; - - The only way to truly implement zero tolerance after an event is by having in place a completely overhauled framework”

Professor Ibrahim: “I think we have dropped the ball as a country on that for a long time — and that goes to parliament, not specific governments. - - bad things happen every year in every state - - a systems-wide issue - - how do we change society's view on ageing? - - All approaches are up for discussion. Rethink how we’ve actually geared up aged care”.

Senator Polley: “What confidence can Australians—not just South Australians, but all Australians—have in the accreditation of aged-care homes in this country?” - - “How can we progress this so that there is a huge change and we don’t repeat Oakden elsewhere?”


The public hearing in Adelaide revealed the pain of those whose lives had been devastated by Oakden and the guilt that they suffered because they had failed to see what was happening and failed to act because they had been intimidated. While Oakden is now closed, they knew that this was not isolated to Oakden and occurred elsewhere. Their suffering in reliving their experiences was to protect others. They saw this as a system problem.

Repeatedly they called for “change – please change”. Their pain was endured because of “not wanting any other family to go through the experience they had gone through” (p25).

The pleas here can be seen as a call for the discourse of care to be the foundation of our aged care system and to permeate it and our society. This is a discourse that resides in our communities and in the caring professions. It uses the language of the heart. It expresses our humanity and our vulnerability. It was absent in Oakden and is deficient in many other facilities.

Politicians, government and market have different discourses built around very different priorities and using very different impersonal words that place a barrier between them and their humanity. These discourses dominate the discourse about care in our aged care system and our society.

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The real discourse of care calls for something very different to what is expected within the structure of the current system. Those who currently embrace the discourse of care do so in spite of the system, must confront the dominant discourse and then impose their human values on it. Too often, as at Oakden, this does not happen and those who try to do so are stigmatised or pushed out.

The problem with our system is that good care comes in spite of the system and not because of it. When the discourse of care is lost we get many Oakdens but expressed in different ways.

**Our proposal**: We are all human and with few exceptions have the capacity to empathise and express our humanity. By placing the community and its discourse at the heart of the aged care system and making other discourses subservient we can release the humanity of all those working there and stigmatise those who resist. That is probably the single most important step in making changes.

### 3.2 Who is responsible for aged care?

**Mr Ryan (Quality Agency)**: “Clearly, the fundamental responsibility rests with the provider”. (p13)

“We are part of a regulatory framework where the key responsibility lies with the provider, -” (p14)

“ - - frontline staff members are responsible, but the ultimate responsibility rests with the provider, - - “ (p18)

**Senator Polley**: “You're still taking no responsibility whatsoever for your agency” (p14)

**Ms Barkla (ARAS)**: “As noted by the Hon. Ken Wyatt AM, MP, the community expects the Commonwealth regulation of aged care to be able to assure it that people in residential aged care facilities are safe and well cared for and have a good quality of life”. (p52)

“It is the responsibility of a civil society to ensure that older people who are at their most vulnerable can be supported to exercise their rights and also live a life free from abuse and exploitation”. (p53)


The Quality Agency’s attempt to deny responsibility by redirecting it to providers, and then to minimise it by suggesting that Oakden was unique, was criticised by Senator Polley.

In their report, Carnell and Paterson also claimed that providers were ultimately responsible for care. Both supported their assertion on the basis that this was a part of the 1997 *Aged Care Act*. That providers whose focus was primarily on profitability could be trusted to do this was an example of the fairyland that existed in Canberra in 1997. They were repeatedly warned but were not listening.

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The nature of our regulatory system including the department, the Agency, and the complaints system has been the rock on which the legitimacy of our system has rested. It is used to market our system to the world\(^7\) and on multiple occasions to confront and discredit any critics of the system. With such a rigorous system, failures could be denied and when this became impossible, became rare exceptions rather than red flags. There was no doubt then who was responsible for ensuring that care was good and who we were expected to depend on.

Citizens were led to believe that these regulators were responsible for detecting problems in the system. We wonder what the reaction of the local and international communities would have been if they had been told repeatedly that responsibility had actually been handed over to the providers themselves.

We argued in our submission to the senate that centralised regulation, unsupported by community (ie civil society) is incapable of regulating effectively at the bedside and that the current regulatory systems in western countries (described as regulatory capitalism) have been captured by the marketplace discourse and are particularly ineffective. None are really capable of meeting this responsibility and there are multiple examples of failures in Australia and other western nations.

**Responsibility and Community**

We are social animals and social animals have bonds and responsibilities to one another. Not only do we teach and coach our new members into patterns of thinking and behaviour, but we use powerful psychological and social processes to guide and constrain each other. We have responsibilities to one another and to society as a whole. We are all responsible for those in need of care. Over the centuries we have been repeatedly warned not to trust the market and history is littered with its abuses.

The social interaction that builds communities is based on our capacity to imagine the life of others, empathise with them and to take responsibility for helping and protecting them – something we describe as our ‘humanity’.

Civil society has been the primary and most effective regulator of its members and it was well equipped to do so. Formal government regulatory structures have been created to support and reinforce this process and step in when it fails. Government cannot fulfil, and so should not assume the role of civil society, but this is what it has done leaving civil society confused and weakened. Both are needed.

**Understanding why we went so wrong**

**Our weakness for illusions**

We have a unique weakness for simplified idealised ideas that allow us to escape the complexity of the real world. We readily drift into fantasy and illusion. All too often those illusionary ideas have challenged our humanity and led to enormous harm. These have been responsible for the horrors of the 20\(^{th}\) and early 21\(^{st}\) centuries. We understand why we are so vulnerable to ideological systems of thinking and know what to do about it. But we are trapped by our beliefs and struggle to develop the insight needed to do that.

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Countering illusions
One hundred and thirty years ago when confronted by similar problems the philosopher Friedrich Nietzsche explained that "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." Those many eyes reside in our communities (civil society) and the more knowledgeable and educated our communities are the more discerning will those eyes become.

Those many eyes threaten the legitimacy of fantasy and to succeed ideas based on fantasy must escape or mask the many eyes in civil society. This they did in the late 20th century. We are now struggling to emerge from the period when this happened. As our current political turmoil shows, and aged care illustrates, political fantasy is on the nose and is no longer sustainable. Because those community eyes are still dimmed there is a danger that instead of opening our eyes fully and looking around we might escape into fantasy again. We need to re-engage and rebuild our society around its core functions in order to prevent this.

Aged care is a core community responsibility. It has suffered more than any other sector from this and is well placed to start addressing it.

Hollowing out community

Ms Barkla (ARAS): “ARAS does not have any statutory powers, except for the right to visit a resident at their request”. (p53)

Senator Polley: “Because you are funded by the Commonwealth government and the state government, how can you give an independent assessment of issues - - - biased in making any assessment because your funding might be in danger if you’re too critical”. (p55)


The two quotes from ARAS (Aged Rights Advocacy Service) and Polley illustrate the way the effectiveness and capacity of civil society organisations like ARAS to act have been legislated away - and the way their funding by government can restrict their effectiveness. Systems built on fantasy always find ways of neutralising any potential challenges.

We can understand why, in a system that was bound by legislation and funding to the fantasies of the 1997 legislation, rocking the boat would have had consequences. ARAS for example, were nowhere to be seen during the 10 years of the Oakden debacle. We described these two problems in our advocacy system in our August 2017 submission to the senate. Braithwaite identified both as problematic in his 2007 book “Regulating Aged Care”.

The recent changes to advocacy do not address this problem and by creating a single organisation they increase control and reduce the risk of embarrassing disclosures. This is how fantasies respond to threats.

But it goes much deeper than this. In their introduction to Yapp and Howell’s paper ‘Community Sourcing and Social Care’, its publisher the Centre for Welfare Reform® in the UK indicated what has happened in western societies.

“... 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 ...”

® Yapp C and Howell C Community Sourcing and Social Care Centre for Welfare Reform 2013 http://bit.ly/2lVt5xM
Part 3: Examination of the Senate Hearing in Adelaide

Addressing these issues

1. Our proposal places local communities and community organisations in a controlling position and makes them directly responsible for the care given to their vulnerable members. All of the regulatory processes will operate through local community structures and be integrated there. Instead of usurping the role of civil society government will marshal its resources to support and mentor it.

2. Our proposal broadly engages all of society, building knowledge, insight, experience and confidence. It redresses the erosion (called hollowing out) of civil society and creates a forum of debate within which the many different eyes will become more discerning.

We are not alone in concluding that the current system is incapable of managing and regulating humanitarian services. It is incapable of being a vehicle for our humanity. In the same comment The Centre for Welfare Reform went on to say that:

“...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 ...”

3.3 A fish rots from the head

Dr Stubbs: These seem like management issues to me. -- In those four levels, between perhaps the nurse manager and you, has anyone been in any way counselled, reprimanded or moved on?

Corcoran (Visitors): management support lacking - frustrated by difficulties in getting issues addressed. -- struggled for 5-6 months to get issues addressed. 2 months to meet chief executive of NALHN

Ibrahim: What we've had is a top-down approach—directives leading to how you want people to behave. There is no bottom-up. - not the workforce with the experience and the knowledge - power differential between the managers and the workers is substantive and much greater than you'd ever see in a hospital. There is no intermediate group - - If we really want to change things, then we need to get better engagement and better preparation of people who are delivering the care, to be asking those questions with support. (P37)

Neil Baron: --- there was a concerted effort by all concerned—staff and management at Oakden, the Department of Health and Ageing and the Aged Care Standards and Accreditation Agency—to maintain the status quo: keep it as it was; don't rock the boat - - Lack of knowledge in management -- a toxic culture in that place.

Neil Baron: --- The state government's not going to do anything about it. I don't think the Commonwealth government's going to do anything about it, and I think we're just going to shuffle this off, put it away - - Of course there was collusion. How else could the agency, the department and ACH, all working together, come up with these solutions? (P41-42)

Johnston: 'We know the abuse has always been happening. There's no real increase. All that's changed is that people are now aware and are reporting it, so we can't keep it quiet anymore.'

The message coming from almost every contributor was that the problem came from the head, which was rotten. It came through all the hierarchy of state government management and all the levels of federal government regulation. The rot spread down both systems. Together they tried to put a fire blanket over what was happening by refusing to listen and respond effectively. For those who have been listening to the messages coming out of aged care, this has been happening since 1997.

**Government:** If we look at the powerful government committees, the businessmen that sit on them, and the endless consultants that authoritatively produce the sort of reports wanted by their paymasters, we are left wondering how many of them have the experience to make the decisions they make. How many of those who make decisions about staffing know of the work that has been done based on the nursing needs of the recipients or know the incidence of pressure injuries, an important marker of inadequate staffing? How many have had any real experience of care? They bring an accounting and managerial mind-set to a system that requires much more insight.

**Managers:** In a hierarchical system those who think and behave in the ways their seniors want will be promoted and become managers. They will be those who have adopted the dominant discourse and performed well within it and usually not those who have clung onto a discourse of care. Nurses promoted into management are likely to be those who have moved further away from care. As they climb the ladder they will become more distant from it.

**Owners and Providers:** A similar conclusion can be drawn about the large corporate chains whether for-profit or non-profit. The power rests with owners who insist on their profits and with management sitting in their offices and make decisions that affect staff profoundly and impact on care a long way from those offices. They are trained managers, accountants and businessmen, many of whom would have had little real experience at the bedside. They set the tone. The culture at the bedside is too often a consequence of that.

Professor Ibrahim goes to the heart of the problem and that is the power structure built into the system. As he indicated in health care in Australia, doctors are a powerful intermediate group whose interests are aligned with the consumer and whose ethical traditions impose an obligation of responsibility for their wellbeing. They have acted strongly to constrain the excesses of the marketplace. Aged care does not have an intermediate group with the power to contain corporate excesses and insist on adequate staffing.

**A way forward:** By putting local communities in the driving seat we create a context where regular discussion between individuals and groups is institutionalised and power is balanced so that multiple different points of view are brought to the table. This would be close to where the care was being given and in close communication with the staff. With the redistribution of power in the system those at the coalface would be empowered and a bottom-up management structure established. Evidence and logic would determine policy and practice above belief.

A central representative body would form so that the community would have central representation. Increasing knowledge, skills and involvement would create a civil society with the skills and knowledge needed to make decisions. They would be well placed to fill rolls on central committees and influence policy. A broad balance of power and opinion is required in a sector like this. Currently the sector is controlled and managed by people who have had no experience of aged care or have left it a long way behind.
3.4 Capture

**Dr Stubbs:** “I think the dilemma there is that the danger is that you get captured - there’s a balance there between making sure someone’s not captured by the organisation - The more you understand it, the more you’re able to ask probing questions. - having someone who understands the organisation and understands where to go for the real answers” (p10).

**C Baron:** 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.

**Olsson:** the health system in this state is the most nepotistic department that I’ve ever worked in.


**What is capture?**

By capture we mean that one person or group is able to take over and control the perceptions of another person or group and so control how they think, how they behave and what they do. It is closely tied to the power, wealth, credibility and standing of the two groups. We can understand it better if we recognise that those doing the capturing bring with them their discourses (patterns of understanding and behavior) and the power to impose those discourses on others.

Work done by the philosopher Michel Foucault in analysing society links discourse closely to power. By controlling the discourse, the powerful control the thinking of the less powerful and so ‘govern’ them. They change the way they see and do things. Dominant discourses capture and replace existing discourses that challenge them.

Capture occurs:

- Within providers as one group comes to dominate others. We see nurses being captured by corporate and managerial discourses which challenge and replace the discourse of care.

- Within regulatory bodies created by politicians and bureaucrats. They are colonised by industry managers via a revolving door of appointments to senior posts, regulating boards and committees. The discourse of politics, bureaucrats and industry managers has captured aged care regulation and rendered it ineffective.

- Individual assessors can be captured by the organisations they assess as well as their own management.

- Governments are captured by the powerful and the wealthy as they depend on their support and their donations.

- Inquiries and reviews can be captured by the discourse of the politicians that set them up. Their recommendations can be ignored when those with power whether in parliament or outside it are opposed and take charge of the discourse so preventing or skewing implementation.

- Civil society itself can be captured by governments or by industry because of their power, wealth standing and their ability to control media. Branding and marketing are powerful tools.

We can see how discourses can take over, dominate and control sectors or society itself and how they can be based on illusions rather than evidence and logic. While the discourse may be illusionary, its consequences can be devastatingly real.
At Oakden, everyone and everything seems to have been captured in some way by discourses that had nothing to do with care and the consequences were horribly real. When we look at this through the lens of discourses we understand that we are looking at something that is pervasive across the sector.

When we talked about the fish rotting from the head, we were talking about heads that had been captured by a discourse that was not based on an understanding of care. That discourse was then driven down into the rest of the system where it did not work. We will look at the consequences in the next section.

In aged care we are concerned with individual assessors being captured, the regulatory process being captured, governments being captured and civil society being captured.

Capturing individuals

Dr Stubbs was worried about the accreditation assessors who can be captured by the impressiveness and the token processes put in place by providers. They fail to look behind the tokens to see what is there. The debate is whether independent outsiders are more or less likely to be captured than those who regularly assess the same facility, which may have been a problem.

He makes the point that it is knowledge and understanding that are important in resisting capture so that at times the same assessor who knows a facilities weaknesses may be more effective.

When a provider is able to select which consumers or which members of the community it will engage with as happens in the 2012 Community Partnership policy, then capture is more likely. That policy is languishing and has not been embraced in aged care.

Capturing the regulatory process

In our 2017 submission to the senate we looked at the way the regulatory system had been set up and structured within the marketplace discourse, the revolving door that existed with industry, the way that marketplace figures were brought in to sort it out when it was threatened or when it developed insight and challenged the role it was given.

As we described in our 2017 submission to the Senate Inquiry, when the ‘independent’ Agency challenged its regulatory role and asked to be released from this, the government moved it into a government department and put the CEO of industry group LASA (Leading Aged Services Australia) in charge. We have not heard any more unhappiness from the Agency about its regulatory role. The Quality Agency did not respond to this issue at the public hearing in Adelaide.

Those who described what happened at Oakden describe how this regulatory role rendered the regulator ineffective and encouraged a culture of concealment.

An example of the way in which the Agency had been captured by the neoliberal free market discourse is revealed in its submission responding to the draft Productivity Commission Report ‘Caring for Older Australians’ in March 2011. The Agency had asked to be relieved of its regulatory role. In this discourse regulation is seen to be harmful and to impede the successful operation of the free market, which is seen to be self-regulating.

As we explained in our senate submission, the exposure of appalling standards of care in the early 1980s in an increasingly profit focused industry had been followed by closer regulatory oversight including disclosure of how money was spent and what staffing levels were.
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There were regular on site reviews by state based investigators who were trained to detect cues that suggested there might be a problem and then bore down into what was happening.

There were rigorous probity requirements. Improvements in care and staffing were driven by increasingly frequent and rigorous audits. Although the focus was not on data collection, studies suggested that this approach was working and superior to other countries.

The for-profit providers hated this and vilified it. The new neoliberal philosophy of the 1980s supported them and they challenged the validity of the regulations in court and lost. After regrouping, the for-profit aged care sector bankrolled the Howard government’s election win in 1996. Doug Moran, the driving force in this claimed that he had written much of the new 1997 Aged Care Act 11.

The state regulatory system was dismantled and replaced by accreditation. The requirement to disclose how they spent their money and their staffing ratios was abolished as were the probity regulations. Any corporate entity could buy into aged care regardless of its record. All they had to do was meet the accreditation standards. They could spend the money as they liked and take as much profit as they could, provided they met the new process and paper based accreditation standards.

That accreditation was a child of the discourse in 1997/8 and was still captured by it in March 2011 is revealed in the Agency’s submission (see second quote below) asking to be released from their regulatory role. As the quote they used in their submission reveals, accreditation was set up to assist the providers not regulate them and, as we have indicated, to protect the government whose accreditation process was being ridiculed, from embarrassment:

Hansard 30 November 1998, reports Minister Moylan as 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. That becomes a very important feature of the whole accreditation process. It is not one driven by waving the four by two around and having a very policeman style of monitoring, but this is an accreditation system that seeks to assist, aid and educate facilities so that they can continue to provide the best possible services available.

“.........

“A change to an enforcement and compliance monitoring arrangement as suggested in the PC Report - - seems to be underpinned by a belief that enforcement will promote continuous improvement. It would be a return to the practices of the late 1990’s. This is a retrograde step that is contrary to international trends and would undo what the current arrangements have achieved.”


It may have been the indignant criticism of accreditation inside and outside parliament in 1997/8 that caused government to burden the Agency with this regulatory role – something that it was not really expected to take seriously as the industry was expected to regulate itself. Later this same ill-fitting extra role became the rock on which the system’s legitimacy and international reputation would rest.

11 Senate Community Affairs References Committee, 24/04/1997, Funding of aged care institutions http://bit.ly/2HYbsaA

Aged Care Crisis Inc

Attachment: Quality of care in residential aged care, March 2018
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Keeping the faith: As in Australia, international trends have been driven by the same discourse. In aged care, that discourse has been challenged by repeated scandals and accreditation failures in these countries. Oakden is a glaring example of the consequences, yet a year later in 2017 that discourse is still alive and actively defended. The government and its Carnell/Paterson Review are keeping faith with the discourse. They are not prepared to examine and address the issues responsible for failure.

Capturing governments

Senator Dastyari: whether or not you think the changes to the aged care accreditation process alone are enough to ensure the safety and wellbeing of residents, or will we have to look at going beyond simply making recommendations for the accreditation process—whether it is a more of a holistic failure or a specific accreditation failure.

C Baron in reply: I looked back at the Senate inquiry of 2005. Many of the recommendations there have not been fulfilled or have been poorly fulfilled. - - you need to see somehow that those recommendations are followed up and somebody needs to evaluate the effectiveness of the action that's taken

Johnston: - - those at the top commission the very same negligent framework of people and personalities to implement the findings, or be seen to, with a large implementation window of years

Senator Polley: the questions need to be asked of the oversight agency and governments, both the Commonwealth and state. They are the ones that really need to have the questions asked about. - - We want to do everything humanly possible to make sure this doesn't happen again.


What happened in 1997 is a graphic illustration of the way in which corporate donations and marketplace support has captured the political discourse and bent the political process to meet their needs. This has remained a major factor in political outcomes and a constant threat to our democracy.

Capturing aged care inquiries: Inquiries are often set up by opposition or independent senators as a response to government appointed inquiries that are not addressing the issues. This is illustrated by what happened in 2005. They identify the problems and make recommendations that would work but they are ignored by government. When the opposition party that initiated the 2005 inquiry gained power in 2007 they too, did nothing. When it came to action they too were captured and trapped. They appointed a Productivity Commission to review the sector and then saddled us with the Living Longer Living Better (LLLB) advertising campaign. Who were the donors during those years?

If Labor gains power will we get a do nothing minister as happened in 2007 when Senator Jan McLucas, who had been so critical, was replaced with the inexperienced and junior minister Justine Elliott. Then instead of doing something will they again be captured and appoint another Productivity Commission Inquiry and saddle us with another Living Longer Living Better advertising campaign and a similar roadmap.
In 2014 Rob Oakshott who was one of the independents holding the balance of power in the hung Gillard parliament wrote\textsuperscript{12} “It (money) has sent many necessary policy reforms to the doghouse, and it keeps many others on the short chain. Our key decisions for the future of Australia are now being outsourced at a level never before seen. Parliamentary democracy is going through its own sort of privatisation”.

Being captured traps the political process within the marketplace discourse. It is unable to enter the everyday world of care, acknowledge its own failures and embrace the challenges facing community and environment. Politicians are left talking at us and selling obvious illusions that leave us all powerless and angry.

Capturing civil society

Society is readily captured when is it not closely linked to the real world and to the management of its own affairs. It comes to accept the discourse that comes with branding and marketing.

Preventing capture

Aged Care Crisis has suggested a viable way out of the aged care mess yet no one is prepared to seriously engage in a discussion of this and examine it carefully. It seeks to empower community and so replace the currently dominant marketplace and managerial discourse with a discourse of care.

Risks to our proposal: There is a risk that individuals or even local community groups in our proposal for a community based and controlled aged care system will be captured, particularly in the early stages. This will be one of the potential weaknesses monitored. The risk will be reduced by recruiting people with experience in health, aged care and other human services, creating a diversity of perspectives, and having regular and close contact with staff, residents and family members. This will build knowledge and understanding. The many eyes in the community as well as the mentoring and support by government and other agencies will create a diversity of perspectives that should reduce this problem and identify it when it occurs.

The community: Giving a local organisation, which has a discourse of care, control over data and making it responsible for advising prospective families and community will counter deceptive marketing and branding.

Making change happen: Change extends beyond changing processes. It means identifying the flaws in our thinking and building better frames of understanding on which to base change – a discourse appropriate for the sector. We have a government that claims to embrace innovation but is itself frozen in obsolete 20th century thinking.

Aged Care Crisis is challenging this frozen discourse and the way the system is constrained by it. We will not get change or free up the system for real innovation until we do that. We are seeking a way of changing that discourse.

Current social analyses reveal discourses are closely tied to power. To change them the balance of power in the aged care system will need to shift. That is what we are talking about. The power to change the discourse must shift from the market to the community. This is where our humanity and our values lie and where ultimate power belongs in a democracy.

\textsuperscript{12} Rob Oakeshott: How big business hijacked parliament - The Saturday Paper 8 Aug 2014  \url{http://bit.ly/2qN2mJh}
3.5 Culture

**Stubbs:** The people who worked there didn't recognise what they were doing, or walked past it. - - I'm not speculating when I say they were intimidated, in relation to using any of the external agencies --- people who could have complained were intimidated.

**N Baron:** There was a toxic culture in that place. The staff could not have cared less. The ones who could were trampled on. (agency staff who cared indicated) 'I'm not coming back here', and they wouldn't come back -- There were inappropriate resident-nurse interactions. - - outdated and incompetent nursing practices. - - There was behavioural mismanagement, with high rates of restraint. - - , it was a nudge-nudge wink-wink thing.

**Stojanovic:** - - this male nurse was there and he said to me, 'I'm just waiting to get a payout. I'm just waiting, and I don't care.'


**What is a culture?**

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 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 UK[^13] where the abuse of residents was even 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 similar[^14]. 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.


[^14]: Corey Lucas stressed about work when he abused Clarence Hausler at nursing home, court documents show Adelaide Now, 27 July 2016
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 drug-affected 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 2005 one of us 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”.

A way forward

You can put on a show for the occasional visitor but you cannot hide a culture that is inappropriate from those who are in regular attendance when they have knowledge. You can ignore uncertain residents and their families but not those with the power to put you out of business.

An empowered community would insist on a discourse of care being a primary concern and that other discourses inform rather than dominate it. Not only would an empowered community insist on unsuitable staff being replaced but if there was a management that did not conform, the owners would not prosper unless he/she was replaced.

The community would also become a reference point for staff. Their praise and support would play an important part in building a culture of care, which staff could identify with and so build strong and resilient social selves. The sort of staff those at the Oakden hearing wanted – staff ‘who care about people’ and who are ‘passionate about what you're working for’.

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3.6 A system problem. Regulation is only a symptom.

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*Ibrahim:* (It is a) fallacy to focus on the agency and say that strengthening regulation is going to dramatically change what happens on the ground - an issue related to the culture and leadership in residential aged care.

The thought here about, 'We will strengthen regulation and action will occur,' is unrealistic. We haven’t equipped the aged-care sector to deliver what we want. That's not their fault, that’s our collective fault.

*Whitehead:* about a policeman—an external accreditation of aged care facilities. You have to have them but they are not the solution.

*N Baron:* -- there was a concerted effort by all concerned—staff and management at Oakden, the Department of Health and Ageing and the Aged Care Standards and Accreditation Agency—to maintain the status quo: keep it as it was; don’t rock the boat. - - residents and families suffered far more than they needed to because the system did not work.

*Mr Johnston:* Oakden has been the tip of an iceberg

*Glowik:* Oakden was a perfect marriage of chaos and maladministration


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We have a fundamentally flawed system. Our failed regulation is only a symptom which illustrates what is happening and what is wrong. As those who have examined Oakden and seen what happened realise it is the system that needs to be fixed. Those giving evidence make that clear.

When you have a discourse that is unsuited and not fit for purpose, the problems will be endemic and systemic. Oakden illustrates that. Resisting them will depend on exceptional and dedicated people. They are in short supply. There are not enough to go around.

But it is destabilising to challenge the thinking that underpins our society and citizens, even leaders shrink from this. Our response when things are very wrong is to call for more regulation and politicians will respond by regulating. This is rarely the answer.

Our difficulty is that the first response of those citizens who suffer harm themselves, or who see others suffering harm, is to call for more regulation rather than major reform. New community groups follow this path as we did. Much later you realise that regulatory systems have their limits. When the system is fundamentally flawed, they simply do not have the capacity to prevent or stop what is happening.

The response of government and the Agency has been to focus its attention on the failure of regulation and not on the system that failed and so needed regulation.

**A way forward**

Fixing regulation is only fixing a part of the problem, the least important part. To fix a system you need to critically examine the way people conceptualise it - the discourses that underpin and give the system legitimacy. The next step is to gather all the data you can and create a context close to the problem where people with many different patterns of thinking are involved in what is happening.
Part 3: Examination of the Senate Hearing in Adelaide

It is here that they can develop a new discourse that is appropriate for the task and within which participants can build successful and fulfilling lives. That discourse must be pinned to the real world through data and direct contact to prevent it from escaping into simplistic illusions. When groups who have their own agenda can shape the discourse the process will be subverted.

**Ibrahim:** Then you have a whole lot of different interest groups about what is needed for each respective group rather than: ‘The purpose of providing the service is to look after older Australians, and are we doing that?’ - - I think we always end up losing sight of the person that is occupying that bed, because each individual discipline, craft group, stakeholder or peak body has a view.


By moving the day-to-day control and regulation of aged care into local communities and empowering them we take aged care out of the silo created by the discourse within which it is trapped and open it to change and ultimately less constrained innovation.

What we propose is a change that moves the debate close to the residents and their families, into communities and close to the data being collected. While it will be informed by and initially embrace the traditional discourse of care, it will examine the new contributions that are being made in academia. Hopefully it would become a forum for informed and constructive debate, one that moves forward, learns from the past but is not shackled to obsolete ideas. We see a system in which management has to become a part of that debate at the bottom and then moves it forward into practice. Academia will be there to inform and question.

The intention of the aged care system is ‘to look after older Australians’. We seem to be looking after government and the providers instead. As suggested by the Barons, even the nursing unions can be more concerned about the nurses than the elderly they are there to look after.

We want to change the system by changing the discourse. Changing the way it is regulated can be an important part of that if we use it to change the discourse. By taking oversight and regulation as well as management and support to the bedside on a day-by-day basis, making it part of the process of caring, we introduce a new intermediate group that has power. This will sit between the provider, the government and the vulnerable staff who are also victims of the current system and its discourse.

The community will be the only group whose sole interest in the system is the residents and they will have the ultimate power to control the discourse. Input from academics and other outside observers will be encouraged. What we propose will be an enabler and contributor to any research done. If fully implemented and developed over time it would become the portal through which most aged care activities would be integrated and managed.
3.7 Effective regulation

**Glowik:** How possibly can this ever have occurred?

**Olsson:** I encountered nothing but blocks, demoralisation. I was thwarted at every turn. - - the cover-up was more at senior level than at base level. - - Commonwealth department of ageing, and that just got us nowhere -- health rights commissioner,- told she didn’t have the resources to help us, that we weren’t really going to get anywhere and we should look after our own careers.

**N Baron:** some obvious flaws -- poorly worded standards that fail to provide clear guidelines and expectations to all concerned. - - lack of identifying and recognising bias resulted in inconsistencies at all levels and that I believe resulted in significant failures - - I guess we can look at accreditation as like selling your house. If you want to sell your house, you try to present it the best way possible. - - First of all, the accreditation system was good. - - But it is aged now and it is a very subjective process. - - It has motherhood statements that are open to interpretation.

**C Baron:** - - we’re saying, ‘You’ve got to clean up your act,’ and the agency come in and go, ‘You’re doing a great job here—we can already see improvements.’ So we’d talk to them and they’d go: ‘Buzz off. The agency says we’re doing a good job.’ -- They said, ‘Why are you bugging us about that? That’s compliant. Even the agency says it’s compliant.’ - - Put the band aid in place for the agency and move on.

**Senator Patrick:** there was a protection racket. It seemed like someone was standing in your way, **Olsson response:** The directorate management team, which was made up of the CEO, the executive director and the head of safety and quality.

**Ryan:** - - vital for us to benchmark our activity against international systems,

**Mr Johnston:** Publicity allowed aged-care abuse to finally be exposed as a national issue.


In our 2017 submission to the senate we described the way the entire regulatory system had been captured and was incapable of taking any action that might upset the status quo. It was stacked by executives from industry and management with little knowledge experience or insight onto aged care. It has become subservient to the discourse and protective of it.

We described the development of “regulatory capitalism” in response to the problems created by neoliberal markets in vulnerable sectors and how this had developed within the neoliberal discourse in multiple countries. We explained that claims to a world class system on the basis that we compared well with them were self-serving as they were equally deficient. Because more data was available they were subjected to even greater criticism.

Regulatory capitalism is best described as ‘Clayton’s Regulation’ - the regulation you have when you don’t have regulation. This sort of regulation is not only captured it is a long way from the coalface and visited infrequently so is incapable of being effective.

Like the non-alcoholic Clayton’s drink advertised, it looks like the real thing so nobody notices. This distance facilitates the perpetuation of illusionary ideas about rigour, effectiveness and world class. The process and the words it is shrouded in become tokens for the real thing.
Effective regulation: In our current system we rely on whistleblowers from within the community and within the nursing homes and their only allies are the press – and an occasional politician.

These are often staff or families, but sometimes even more effective are individual community members with well-developed social selves who look in from outside and in doing so see more clearly. They are not saddled with the discourse, confronted by the dominant people in the industry or as easily intimidated.

Our proposal: Our proposal brings the community, those outside the system back into it. It empowers them and enlists their regular support in overseeing the system. Many of them will have a different discourse which sees more clearly and their involvement will build social selves. In doing so our proposal frees up families and staff to speak up freely to them and to be immediately vindicated and protected. Because whistle blowing then becomes unnecessary and attitudes do not have time to harden the normal processes of an engaged community come into play. Social pressures become preventive because they change attitudes and behaviour.

It will be supported by the more formal regulatory processes and they will be mentors. Refractory problems will be detected early and funnelled back to them for action. Because the community structures are transparently accountable to their communities, have centralised representation and voting power the central regulatory system is also held accountable to the community and its risks of capture are markedly reduced.
3.7.1  Accreditation and a culture of cover up

Ms Wunsch (Agency): having open disclosure as a fundamental principle in accreditation is one that you will see replicated across the world, and we are very keen to see that as a fundamental principle of the way that we conduct accreditation in aged care.

Ryan (Agency): there was a culture at Oakden of not being forthright.

Senator Smith: If there is a culture of cover-up, or cultures of cover-up, and you're moving away from a discovery function, how can you then be confident that cultures of cover-up are not being allowed to fester, to grow?

Ryan reply: We think the move towards providers being ever more open about what's going on—good and bad—is important for regulatory oversight and consumer confidence.

Senator Smith: What's the incentive, in this particular case, for someone to have self-disclosed?

Ryan: There might not be an incentive but, if there's an obligation under the regulatory system to disclose,

C Baron: (what is said when she returns as an auditor for the agency) ‘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.

- it has become a very competitive industry, and people don’t always take kindly to having a director of nursing from another organisation assessing their organization - ‘Oh, they're going to steal all my good ideas!'

- after 2008, XXXXX went on to be on the board of the agency. 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.


The greatest problem for accreditation is that a process that is there to help motivated providers improve the care they give and which depends on the trust and cooperation of the providers has, in the competitive market, become, on the one hand a marketing tool to boost business and profitability and on the other an investigative and punitive regulator which threatens their success by exposing failures and exposing them to customers.

All of the pressures are towards gaming the system to get a perfect score that can be marketed publicly and a culture of concealment to escape detection.

In the senate transcript, those speaking for the Quality Agency have no answer to this and no way to prevent it. Carla Baron describes how the attitude changed when she became an auditor for facilities where she had previously been a trainer. Other conflicts arise when the auditor is a nursing friend or alternately from a competitor, both situations where confirmation bias might be present.

Many senior members of the industry have been on the Agency board and we have drawn attention to the problem this creates in our past submissions. XXXXX was not only on the board of AAAAA Group, the group who took over from the Barons in supervising Oaken. The Barons claim he was at the time also on the board of Central Northern Adelaide Health Service (CNAHS). Under AAAAA Group’s tutelage, Oakden was soon fully accredited again. It remained accredited while abuse continued until the whistle was blown in late 2016. This does not seem to pass the pub test.
**Frequency of oversight:** The rigour and success of any oversight and regulatory activity will also be related to the time spent in a facility as well as the frequency of the visits. As was revealed in the transcript, the Agency held thorough formal announced visits lasting 2 to 3 days every 3 or 5 years and visited more briefly every year. They failed to detect serious problems for nearly 10 years and then only after it was exposed by a whistle blower and the visitors scheme.

The visitor’s scheme which is given credit for exposing what happened, visited every month between 2011 when it was set up until 2016 when Mrs Spriggs blew the whistle to them. In spite of the glaring problems in the facility, they either did not detect the problems or did not act for 5 years. Did it really work well?

**Our proposed local community scheme**

Accreditation was never intended to be a regulator and the philosophical discourse that underpins its operations is unsuited to both the neoliberal discourse and a regulatory role. It is consequently conflicted and ineffective. Having to regulate compromises its role in teaching and accrediting as well as its training and support activities.

Being used as a corporate branding exercise in the competitive free market encourages providers to hide deficiencies and claim excellence rather than openly seeking assistance.

We are pressing for the regulatory function to be transferred either to the department or to a new regulatory body. This would work through the community organisation we are advocating for. It would support and mentor and this organisation would be the front line regulator. The central regulator would act as the backup regulator when further intervention or sanctions are required. Because referrals would come through the community who were often on site and knowledgeable branding would be less important and if it was unrealistic alienate those advising and supporting prospective residents.

Our proposal would see local people filling the role that the visitors schemes in South Australia and Queensland do and with the same powers, but in a much more effective way. Their sole interest would be the wellbeing of the residents. They would be in there talking to residents, families and staff at least weekly and usually more frequently so would know the residents and the families and be trusted. They would soon learn of any problems. They would have in depth insight and there would be much less chance of their being captured, gamed or missing problems.
Part 3: Examination of the Senate Hearing in Adelaide

3.8 Burden of accreditation

Senator Fawcett: increasingly, they are spending time filling out paperwork as opposed to delivering care to the residents.


Providers and staff have complained of the additional burden that regulation placed on providers. Nurses describe how it is gamed and how ineffective it is. This was also something complained about in the more tightly regulated system used in the 1990s.

Our proposal

The local community regulators would be far less intrusive and burdensome as this regulation would be part of the system of care, continuous and ongoing monitoring as community visitors worked with staff providing care to collect data. They would speak to and support the nursing staff and if needed would support them as they engaged with management. They would notice whether safe practices were being followed and be reporting their findings to management, the regulator and community so that everyone would be examining the issues.

3.9 Complaining

Johnston: - - the confusion experienced about where to lodge a complaint, how to lodge a complaint and whether it’s safe to lodge a complaint

Corcoran: Complaints Commissioner needs more teeth. - - courageous to make reports - - important to have a level of independence of anyone investigating any of these complaints and it's important that they have the skill sets—the investigative interviewing skills—and a background in enquiry and in making objective independent assessments.

Ms Olsson: (Describing response of intimidated staff member after asking about her complaint) 'Look, I don't want to make any more troubles, it's bad enough;

Senator Polley: Aged Care Complaints Commissioner - - there does need to be more teeth given to that position. - - it is courageous of families to make complaints - -

Costa: we decided not to complain anymore in case my father continued to be mistreated.

CHAIR: the issue around guardianship has come up when people complain. This committee has heard on a number of occasions where a provider or an institution has sought to change guardianship because somebody complained about the service.


Oakden illustrates the problem with complaining and with the complaints system well. It has been a problem since 1997 and the complaints system has been revised and fiddled with on multiple occasions without addressing the real flaws. It was set up in 1997 within the discourse and has been part of the regulatory response. That is unchanged. The Aged Care Complaints Commissioner has done her best but she has had to work within a system which is incapable of delivering.
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Walton’s review\(^\text{16}\) of the then Complaints Scheme in 2009 identified the serious problems in bureaucracy. Aged Care Crisis was supportive of the recommendation that complaints should first be dealt with locally, but were disturbed that this was done without any local support to these vulnerable people. We had recommended that they be supported by a community advocate who would immediately collect data and then mediate the matter with the resident and the provider.

Instead as is so well illustrated by Oakden, the residents and their families were thrown to the wolves. They were no match in assertiveness or in knowledge and lacked confidence. It was a bruising experience for them and few went further than this.

When complaints were lodged with the complaints system they found themselves in a bureaucratic maze which lacked the personal touch that is so essential in situations like this.

By the time the complaints system or the Agency gets to the facility, any damning evidence has been dealt with, lawyers consulted and staff carefully coached.

The vulnerability, the lack of knowledge, and the difficulty for families and even staff in bringing themselves to take that massive step of complaining are well illustrated. Put simply the system is not fit for purpose.

Addressing the problem

The community organisation that we propose would do what we suggested to the Walton Review. This is exactly what one family member at Oakden asked saying “just that one person that will come and see you that's independent to the facility”.

There would be an organisation with people who came around regularly to talk to residents and families as well as nurses. They would get to know them, be there to talk to. They would pick up problems themselves and talk to the staff and family about it.

They would examine the documents and talk to staff and then either go with the family to talk to management or address it on their behalf. If this needed to go further, then it would go up the system and the family would be continuously supported and briefed. It is important that the family be involved throughout the process and be satisfied that their concerns have not only been addressed but that real change has resulted.

3.10 Visitors scheme

Mr Corcoran (role of visitors) visit and inspect acute mental health units - - powers under the act - - required to be visited every month. - - community visitors are volunteers - - semi-retired or retired and professional people -- run the mum test over it, -- we can request anything that we think is relevant to the care and treatment of patients in facilities. - - the power to refer matters and issues of concern; - - played an advocacy role in regard to the system

(difficulty with Oakden) - - in trying to get responses over a five-month or six-month period. - - we had attempted to meet with the executive, the director of mental health services at the time. - - It was hard to get a response.


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How we would build on this

The Visitors Scheme established in 2011 took 5 years to discover what was happening at Oakden. We worry that it too may have been captured. Similar schemes in Victoria and Queensland have been more effective. The empowered Community Visitors schemes in Victoria, Queensland\(^\text{17}\) and South Australia have been our inspiration in pressing for a community managed aged care system. We build on these systems and think they form a solid basis from which to develop community involvement and integration.

In our proposal the visitors scheme would work through local communities. Members of each local group would be given the same legislative powers to collect information and, much as is done in hospitals, residents and families will be asked to give permission for access to their data or to care procedures for research, teaching and oversight purposes. Others would only get de-identified data. Other community members will talk to them if they identify or hear of issues that need access to confidential patient data to resolve. These visitors would also be active in the community checking on care given at home.

Members of the community would be around the facility talking to residents and families or, if they had the skills, participating in activities. They would know what was happening and if they thought something was wrong they could explore more deeply, or arrange to be there more frequently. They might come in at weekends or at night on occasion to see what was happening.

Minor issues would be dealt with directly, major issues or unresolved issues by the executive of the community organisation, often in consultation with the mentoring regulator and if necessary escalated to a formal regulatory process.

A record of actions taken would be kept for discussion with management and for entry to a database, for preparing reports for management, community, regulating body, government and accreditation Agency. Data would be analysed centrally.

Advocacy

**Ms Barkla ARAS:** “ARAS does not have any statutory powers, except for the right to visit a resident at their request”. we rely on the goodwill of service providers to facilitate resident representative education and to encourage staff education sessions. (P51) - -

“The majority of our funding would come from the federal government - -“ (p53) -- conducted by phone and/or face-to-face, depending on the circumstances and the needs of the older person - - team of three residential advocates - - don’t have the ability to proactively stay in touch -- last education request (ie Oakden) was in 2011 --- We do send brochures, at the request of the organization.”


The evidence given about Oakden confirms the relative ineffectiveness of the current advocacy system. Its powers are restricted by government legislation, it depends on providers and its activities are constrained by its funding from government. It has all recently been consolidated under a single body, which makes it easier to put pressure and limit the ability of any group to rock the boat when problems are encountered.

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It cannot intervene until it is asked to do so and from what was said we conclude that it only provides education or brochures when it is requested to do so. Oakden is a graphic illustration. They only have 3 staff for the whole of South Australia so most work must be done by phone.

Addressing the problem

Once again advocacy should be provided locally and if it cannot be included in the visitor’s scheme then there could be a mentor and a backup team ready to assist in the event of problems.

The community organisation would clearly be advocating and supporting its older members and would be equally vocal in:

1. advocating for a system that allows them to evaluate the ethic of responsibility and the quality of service provided by any organisation seeking to provide services in their community - seeking their endorsement before doing so, and

2. advocating for improvements in the system

3.11 The collection of accurate data and transparency

**Ibrahim:** (We) could only access data on deaths because of our legal system—not because of our health system and not because of our aged-care system. - - - The only aged-care data that is publicly accessible to researchers or anyone is the fatalities. We don't have data on serious injuries or serious events that do not lead to harm but are high risk. - - - There is virtually no research in Australia specific to how you would practise in Australia. - - I think transparency is a driver. - - As I said, the only transparency we currently have is through the Coroners Court.

**Whitehead:** When you are at board meetings you have a lot of financial metrics but what you don't have is to know whether you are actually delivering good care. - - ask what the outcome is. - - no such measure really existed for that. - - - (WE have developed) the instrument - - , which is a patient experience measure. - - - this instrument does correlate with quality of life,

(Facilities need to) self-reflect and look at their own data and information - - probably not a huge expense, - - consenting everyone at the ACAT stage to allow their data to be linked - - - (a great challenge is) the disconnect between academics, scientists and practitioners. - -

What cures a problem like Oakden is transparency. - - - There is data produced by it but it is all siloed, and no-one has ever linked it together. - - - we need much better data so that we can explore these relationships between community care, residential care, hospital and home, - - - teaching, research, quality and service. –

If you have all four of those, you develop good outcomes. - - - I think we could do much better. - - - Where we've made leaps and bounds in our own services, (when) we measure what we do. - To my mind, that's pretty basic.

**Ms O'Bryan:** It cost us $25,000 to purchase ACFI data, which had to be siloed. - - - There is a large volume of existing data that you can't get hold of because of the rules around confidentiality.

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Because the US system has not worked in spite of extensive data collection and because of Braithwaite’s aversion to what was done in the USA during the 1990s, the suggestion that we should collect data invariable gets argued against on the basis that we don’t want to follow the USA and get their system.

There is virtually no reliable data about care collected in Australia. In almost all of the reports commissioned by government and other industry organisations there is plenty of financial data, but no data about the standards of care provided.

Success is consequently measured by economic performance and those making money are assumed to be good.

When one considers the financial dynamics we see that income from government and most users is relatively fixed and the only way of making more money is to reduce costs and nursing staff are the largest cost. This compromises care. So from the community and the resident’s point of view, it is likely that the good performers are in fact the worst providers of care. That this is so is readily confirmed by examining data from the USA. We need accurate publicly available data in Australia.

Example: 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%18. When his speech was transcribed on the department website, it appeared as 10.3%19. When his advisers were asked for the source of these varying figures, the 10% figure was removed from the transcript20.

When pressed, they then referred to figures between 3.4 and 5.4%21 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 32 to 46% (average 34% close to the minister’s figure of 32%).

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.

Pressure injuries is one of the voluntary quality indicators being collected but not published. Someone must know what the average number in this selected group are, but no one is saying.

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.

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Data and transparency: We can only endorse what was said about data during the hearing. It is essential for managers and providers if they are to keep improving but when the bottom line is the measure of their performance, they will not want information that would challenge this performance. For the market to work data is needed by customers although many will struggle to understand its significance, particularly when it is competing with skilled branding and marketing. It is more important that customers be advised by someone they trust and that their informed advisers have this information.

Policy makers and politicians require this information as do inquiries and reviews. Funding bodies require it to measure the effectiveness of their funding measures and to make sure the money goes where it is needed.

If all these people need data then it must be transparently collected, transparently assessed and transparently evaluated from several different points of view so that its significance is teased out and it is used effectively.

Available data: That we are still confronted by large databases that won’t talk to one another and where data sits in silos that cannot be de-identified and accessed is an indictment of politicians. This was a problem in the 1980s and ways of addressing it were being developed. It is still not resolved. It illustrates what happens when competition is allowed to reign supreme and is not constrained by the values and norms of society.

Some reservations: Professor Whitehead is enthusiastic about the collection of data from residents and families and has shown that this correlates with quality of life and we are sure there will be some correlation with standards of care as well. I agree that this information is valuable, but relying on it alone is unwise.

Experience in medicine and in dysfunctional social systems shows quite clearly that the perceptions of citizens and patients is heavily influenced not only by marketing but by the way in which those around them, those who are administering the service or the treatment, identify with what they are doing and are enthusiastic. Surveys can reveal a high degree of satisfaction even when care is poor. This is why double blind trials are so important in medicine.

The most difficult problems to deal are those when the participants identify with and are enthusiastic about what they are doing. Those receiving care will identify with this. Providers will reject accusations and point to their popularity. This has been a particularly problem in health and aged care. When staff have become enthusiastic about what they are doing because of its profitability and people have been harmed those harmed have not realised this. Regulators, particularly those captured by the discourse, are captured by it and have ignored obvious evidence of poor care.

It is important that objective data about care also be collected and evaluated. When there is a discordance between the hard data and the perception as reflected in consumer’s opinions then there is likely to be a serious and quite extensive problem that no one is recognising. This is going to be particularly difficult to deal with because those involved, sometimes including those who have been harmed will resist strongly and if not carefully monitored the providers conduct will relapse.

Self-reported data: Self-reported data is always suspect and when the pressures in the system are strong there will always be people who will manage to justify manipulating the data they report. Others soon follow. This has for instance been a problem with quality indicators in the USA. The only way to ensure that data is accurate is to put its collection in the hands of those who need to know but don’t have a vested interest in the outcome. In this instance the community itself is the obvious choice as it is onsite and involved. Its only interest is in knowing what is happening.
Subjective assessments: We should not ignore the impressions we get from just being there, talking to people and observing the changes we see. The quality of peoples' lives is most readily determined. The more often we are there the more likely are these observations to be valid. It is difficult to maintain a false impression over long periods. By themselves they are not sufficient but when supported by data they can be very informative in understanding what is happening and fixing it.

Addressing the problem

One of the main and most important roles of the proposed community based system will be to work with staff in the nursing homes and in the community collecting data - data that can be used by all of those who need it and in research. This will become part of the day-by-day activity in each facility so not overly onerous. This data will be evaluated locally to inform the providers, the community and those advising prospective recipients of care.

This will be discussed and contributed to by the mentors from the various central organisations. It will then be sent to the central community representative body where it would become part of a central database and integrated with other databases.

Academics, researchers and statisticians would study the data sets, generate reports and publish research papers. Data about each facility and each provider would be made available on something like the MyAgedCare website. When assessing the suitability of a particular provider to provide services to their community, local groups would look at this data and then talk to groups in other communities particularly those who had identified problems. This would increase accountability across the sector.

3.12 Staffing in aged care

**Ibrahim:** We do not have the workforce in aged care that is able to drive the change - - there is not a gerontics training course. You do not need to be qualified in aged care to work in aged care. - - (changes needed) The second would be to value the staff

**N Baron:** There was a clear lack of nursing leadership and clinical supervision. No senior nurses were in the clinical area, - - are under- educated and under-resourced - - need specialised gerontic training

**C Baron:** whole place was staff-centric.- - Everything was about, 'don’t upset the staff, we have to look after the staff.' (Where was the Australian Nursing & Midwifery Federation during all of this?) - - They were protecting their members.

**Costa:** You actually need people who have lived with these people for a long time, not just someone who's going to work every day - - need to be people like us, - - understand how these people need to be treated. It's not just that you go to work and get a pay packet. It's not like that at all.

**Glowik:** - - takes great understanding and staff that can cope with this, and there are staff who would, quite frankly, be dangerous cutting your lawn

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It is difficult to know where to start. Staff are essential for the heavy lifting the physical processes of care. Their clinical skills, nursing, paramedical and medical are needed to maintain health and wellbeing. The caring relationships they form with residents are the foundations of a good quality of life. Australian aged care has too few trained staff as well too few total staff to provide safe and effective care.

They find themselves at the critical point where the discourses of the market and managerialism and that of care rub against one another. Their incompatibility boils and bubbles creating a poisonous mix within them. That has a negative emotional, motivational and cultural impact.

They need to be trained but also humane, able to empathise and enter into the lives of those they care for. It’s the relationships they form that are so important for the life of the residents.

As Professor Fine’s work reveals, this leads to a culture of care. He analyses what is happening and shows how difficult this is when the culture and relationships with management and between staff are compromised by conflicting discourses – although he does not use the word discourse. He refers to “a conflict between the cultures of ‘hi-tech’ and ‘high touch’ care orientations”.

He argues that cultures of care cannot be simply “reduced to financial incentives and labour market opportunities – traditional cultural values and ‘care ideals’ are deeply linked to a sense of personal identity”.

There are many aspects of staffing that need attention. The numbers, the skills, the training, and the motivation of staff are all deficient in Australia. The culture within our nursing homes is often poor and the staff are simply employees and have little input or control over the way they provide care so do not own the process or identify with it.

People talk and understandably nursing in aged care has acquired a poor reputation and struggles to recruit. That large non-profit companies like Southern Cross and Blue Care are reducing numbers in order to meet financial benchmarks set by financial advisers rather than meet the needs of the residents is very demoralising. Too often it has become a dumping ground for those who can’t find work elsewhere.

Promoting a positive image: The industry tries to address this by marketing a positive image into schools and elsewhere. Nothing could be more unproductive. When these enthusiastic newly trained staff have to confront the reality of what aged care has become their disillusionment will be profound and we have seen several examples of what is likely to happen.

Increasing salaries is necessary but that alone will not attract the right sort of people – those who are motivated to care.

Addressing the problem

What we propose will not address the costs of training or the financial considerations. What the community can and hopefully would do would be to create a bottom up system where nurses would regain control over the care they give and would come to own it and set the discourse within which it was provided. Ownership brings dedication and motivation. There would be a group that would mediate between staff and management to be sure that the outcomes were in the interests of the residents.

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The community by its presence and its interest in care would create new objectives and some role models. By encouraging, praising, criticising and mentoring and by providing a receptive ear to problems experienced it would build a culture of care and so make nursing a far more attractive profession. It would help make nursing an enjoyable and fulfilling profession. It could make a major contribution to the staffing problem.

It is interesting that closer regulatory oversight and increasing penalties in the USA (the sort of regulation that was abolished in Australia in the 1990s) has led to a 33% increase in the number of doctors who focus only on nursing home care. 21% of the doctors who provide care in nursing homes are now specialists in aged care.

Professor Ian Maddocks, senior Australian of the year suggested a move in this direction in 2014 but it was not welcomed. This is a contentious issue because patients do not want to lose touch with their long-term general practitioners. A compromise where the benefits of both are retained might be in their best interests.

### 3.13 MyAgedCare and a centrally managed system

**Polley:** My Aged Care website, the portal into what's supposed to be the avenue—I consider it to be the maze—into this sector, a lot of money has been put into that. It's failing miserably.

**Whitehead:** In terms of the data, I think My Aged Care is a significant problem. - - I think that's the real problem with the My Aged Care system: we tolerate, and older people tolerate, enormously inadequate services.


MyAgedCare is a product of the bureaucratic mind in which structure and process alone are seen to be sufficient and that messy and problematic human interaction can be avoided. It has been a dismal failure.

Care is built around relationships between people and it cannot be structured in this way. Computers are a valuable supporting resource but there are many areas where they cannot replace people – real people sitting next to you that you get to know and trust.

It is part of the centrally controlled, structured, complex, process driven age care system that has been created. It is rigid, impersonal and difficult to understand and navigate. It is inflexible and unable to respond flexibility to needs. People readily fall through the cracks.

### Addressing the problem

These are the sorts of things that Yapp and Howell from the Centre for Welfare Reform indicated that needed to be done locally. MyAgedCare is a useful resource for those who are advising and helping residents as well as providers but the ordinary person needs to talk to a real person across a table as well. Most of what the MyAgedCare and central bureaucracy does would be better handled locally with the central bureaucracy acting as mentor and supporter. This would restore empathy and flexibility to the system and allow compromises and exceptions when this was necessary.
3.14 “Is it a home or is it a hospital?”

**Ibrahim:** We wax and wane depending on what suits us. We will say, 'It is your home,' when we want to ask people to pay more money, and we’ll call it a 'hospital' when care isn't delivered.

**Whitehead:** think the policy dilemma that the government has is whether this is your home or a place of health care intervention, when in fact it is clearly both.


We need to consider the history of this dispute. In 1997 a US aged care company called Sun Healthcare bought some hospitals in Australia. At the time, industry consultants in the USA were advising businessmen going global to play on local politician’s pain.

Sun Healthcare’s chairman promoted himself as an aged care authority and then told politicians what they wanted to hear including to butt out and leave it to the market. He insisted that there was plenty of fat in the system (money to be saved) and you did not need trained nurses to look after the aged – all they apparently needed was ‘showering and wiping their bottoms’.

He visited Australia in 1997 and met our politicians. He promised to provide care without spending as much money and they were soon mouthing his catch phrases. Around this time all staffing requirements were removed. Businesses would have been listening and the illusion persists.

His company failed probity requirements in Victoria and was soon bankrupt in the USA and Australia as a consequence of his practices. But people who grab hold of beliefs that they identify with, seldom remember where they came from.

In the real world we age and die because our organs degenerate and function more poorly, degenerative diseases. We and our organs become more vulnerable to infections, malignancy, autoimmune diseases, hypertension, heart disease and a multitude of other diseases and one of these is what finally kills us.

Almost all of us suffer like this as we get older. The health domain and those who work in it seek to prevent, cure, or support the systems that are failing. Typically, we take a myriad of medications to enable this.

This is why we are living so long and why we continue to live better and more comfortably until the day we die. It enables us to enjoy our lives. Everything else is built on top of it. Nursing homes are actually hospitals but because there is no point in treating disease if people cannot benefit and live a good life, they also need to be their homes and be tightly tied into and be part of the community that they have lived in. So, quite clearly they need to be a hospital, a home and a meeting place for the community – where social intercourse takes place. They fail if any of these are lacking.

The myth that the aged are not patients and its not health care they need has been repeated by those who see themselves as authorities many times over the years.

In 2014, Abbott moved aged care out of the Department of Health and into Social Services. Geriatrician Dr L Mykyta said “... the aged care system is administered outside the health care system. They are like ships that pass in the night but don’t get close to hailing range ...”. Aged care was eventually moved back into the department of health by Abbotts successor.
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In a 2015 article, Professor Whitehead who gave evidence to the hearing in Adelaide said:

“The idea exists [among bureaucrats and politicians] that RACFs are just homes. That is clinical nonsense”. Professor Gerard Gill said given the adversarial nature of the politics of this area, the commercialisation of the RACF industry and familial neglect for some older people, I think we have more hope of seeing pigs fly than reasonable reform”.

Source: Aged care “broken” - MJA Insight, 7 Apr 2015

In a personal blog²⁶ in 2016, a leading industry figure, director of residential and home care companies and of the industry body Leading Aged Care Services (LASA) recently proclaimed that “Age is not a Disease – Aged Care does NOT belong in the Healthcare Domain”.

These fairy tales that were created to support the discourse that aged care was subjected to in 1997 are alive and well in leaders of the industry 20 years later.

A recent article in The Conversation said:

The idealistic yet impractical philosophy took the focus away from nursing and medical care. So now, the bulk of personal care is provided by a pool of untrained and unregulated aged-care workers supervised by a very small number of registered nurses.

Source: Australia’s aged care residents are very sick, yet the government doesn’t prioritise medical care - The Conversation, 20 Dec 2017 http://bit.ly/2E3XMrO

The capacity that we poor frail humans have to create fairy tales when its what we want to hear never ceases to amaze, but it is dangerous when businessmen and politicians who make decisions and assume responsibility for others do so. Many suffer the consequences, although it is never them.

Addressing this problem

Fairy tales do not stand up when they have to confront data and rub against the real world of human frailty and suffering. In our proposal those who would lead the community in examining clinical issues would be those doing the work, nurses, doctors and other health care workers. Most of them look at the evidence and don’t believe in fairy tales.

3.15 Market pressures

Mr Johnston: -- nine for-profit conglomerates that report to the stock exchange and shareholders, and their level of care and expenditure is in reality, but should not be, consciously decided on a budget aimed at maximising profit and margin to shareholders -- when there are vast sums of money to be made, maladministration, vested interests and blatant corruption are always bubbling under the surface

Mr Corcoran (Visitor’s scheme): Staff had been advised that the staff had been streamlined and trimmed down in readiness for a possible tendering out to the non-government sector and that it would no longer be a government service -- the uncertainty for staff. -- the number of agency staff -- enormous pressure on a number of other staff -- important allied health services staff such as social workers and OTs were quite often vacant -- the need for a visiting geriatrician for complex medical conditions -- discontinuation of funding for a social worker

Ibrahim: Then you have a whole lot of different interest groups about what is needed for each respective group rather than: 'The purpose of providing the service is to look after older Australians, and are we doing that?' -- I think we always end up losing sight of the person that is occupying that bed, because each individual discipline, craft group, stakeholder or peak body has a view.


Stewart Johnston went to the heart of what is happening across the sector when he spoke about profit and large corporations – a growth industry that depends on generating an ever increasing income stream by cutting costs and maximising opportunities to be more profitable. These strong competitive pressures to build profitability put pressure on the funding for staff and care. They impact directly on the culture within organisations and indirectly by the conflict they create between the strong commercial discourse and the discourse of care that first motivated staff to become carers and that was reinforced during their training.

In our final supplementary submission to the senate workforce inquiry in November 2016, we documented the extensive international evidence showing the direct relationship between the pressures for profits in different ownership types with poorer staffing and greater numbers of failures in care. We documented the evidence that suggested this was happening in Australia.

In spite of the evidence, Government, industry, and even the Quality Agency, whose own data shows this, all deny it. Government policy of competitive marketisation and consolidation continues in the face of evidence. It is clear that this policy is in order to allow our corporations to compete in Asia but the evidence shows that this is at the expense of care in Australia.

But it is interesting to see Mr Johnston coming out so strongly about the profit motive and the corporate sector when this is a government run facility. Of all facilities this should be least affected and the market least to blame for this. But Mr Corcoran (from the visitor scheme) explains how the pressures from a strongly profit driven and consolidating market ripple through the entire system.

The threat of privatisation seems to have loomed over the facility for several years. These nurses are at the coalface and they know what happens in facilities that are strongly profit driven. They have friends and colleagues who have been there.

There have been studies that reveal the way the new management systems that have accompanied neoliberalism have changed the discourse - the way nurses think and behave in mental health, hospitals and nursing homes. Others describe the way increasing pressures result in an increased rate of missed care. This is occurring across all facilities.

Consolidation is driven by government policy that sees government run facilities privatised and consolidated into ever larger corporate entities so that analysts currently predict that the number of approved providers of residential care will fall from 1200 to 600 by 2021 and then to 300 by 2031. Oakden staff would not have seen these figures but they would know that the number of providers in Australia were going to shrink rapidly. They knew that those who survived would be the most aggressive and profit focused.

The management at Oakden was already cutting staff in preparation. If they were to sell at a good price they need to keep costs down and show that the buyer was buying a facility that was going to be profitable. Not only staffing, but also social workers and medical staff were dispensed with. Management were clearly totally detached from the facilities, knew nothing about aged care, and were blissfully unaware of what the consequences of their actions were for the staff and the residents.

The steps taken would have been seen as foreshadowing what was about to happen when the facility was privatised. Corcoran describes the demoralisation of staff and the culture that developed. There have been similar situations in for-profit nursing homes in Australia and the UK.

What happens is that senior staff in both government and private facilities are appointed because of their managerial experience and not their record of care. They are drawn from accountants and business schools. As we indicated on page 84 of our 2017 senate submission, Oakden in many ways resembles the Mid-Staffs hospital scandal at Stafford hospital in the UK.

Understandably, the threat of this to government and non-profit organisations and the impact on their staff is profound. The future is uncertain and they fear the worst. The evidence and discussion in the Community Visitor and Baron/Olsson session described some of the impact of this on the numbers of staff. Staff at Oakden were “unnerved by impending changes”. There was a lack of motivation at all levels. People were only doing a job and nothing more.

**Our solution:** With the community in a commanding position and advising families the appointment of managers like this by any provider would be a costly mistake. It would be strongly resisted and new residents advised to go elsewhere. With the community in control, in possession of data and with first-hand experience the excesses of competition policy and efficiency would be modulated and controlled.

Success would depend on being socially responsible in meeting the residents’ and the community’s requirements in the nursing homes rather than entrepreneurial adventurism in the marketplace. There would be a much more stable and less risk prone market. Staffing and staff morale would be a key concern in the community and any changes in staffing would have to pass the pub test.

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Community values would be required and a culture based on human values would be essential for success. Motivated staff who embraced this and were motivated by their humanitarian values would be cultivated and valued by the community who would protect and support them.

3.16 Platitudes

**Ibrahim:** Overall, the system's really quite good - - And mostly it's okay. I will go to work tomorrow and recommend residential aged care to some of my patients without any qualms, because the system is okay.

**Johnston:** Quotes Cameron O'Reilly from the Guild ... a few hundred thousand people being cared for ... sometimes there will be incidents of quality failures that are regrettable ... I don't believe that, relative to the past, there's been any deterioration in quality, but there is more opportunity now with residents and consumers to expose where there have been failings.


We are always reluctant to alarm or upset the community as we don’t want to build distrust or make something sound worse that it is. The medical profession depends on trusting relationships and does not like to create distrust. Professor Whitehead describes some good groups he has worked with and says something similar. Good aged care depends on trusting relationships.

The industry does not want to be confronted by an angry community. We want the system to be OK. We are all a bit paternalistic in this way so don’t tell it like it is. But when the system is not serving us well, this is a mistake. Discourses are resilient and we may need to rise up and call a spade a spade if we are to change them. It’s a bit like not telling patients that they have cancer or are incurable, thankfully something that has been abandoned.

This is now a competitive market and that is a very different context to the one we felt we could trust but many still hang on to this. Sadly, as we look at the many market failures around us the adage ‘customer beware’ is appropriate. Adam Smith the father of economic theory 300 years ago described businessmen as “that body of men” whose interests were not those of the community and whose ideas should be carefully examined.

There is no evidence that the system is world class or even quite good. Those statements are a matter of faith. As our submission to the senate showed, the limited evidence we have is that our staffing levels and skills are so poor when compared with other countries that we cannot have a good standard of care and what we are providing cannot be safe. The evidence suggests that the care is generally bad and not even ‘quite good’.

Later when we write about the Carnell/Paterson report, we show just how bad it has become and how unwise this attitude is.

**A way forward**

That care is likely to be suboptimal has to be accepted and our community needs to know that. That we are failing residents much too often cannot be contested and if government won’t act then the community must make them. Citizens need to be part of the change so need to understand what is happening and why they need to step up and be a part of it – else they themselves might soon become victims.
3.17 Vulnerability

Mr Johnston: - - naively allowed to be fobbed off and dismissed
N Baron: not so much for relatives; most of them were out of it and didn't understand
Ibrahim: the person who goes in dies—that is almost guaranteed—so there are no repercussions


Two and a half thousand years of human experience and knowledge was thrown out of the window in 1997 by the neoliberal free market discourse which characterised humans as driven only by self-interest. Somehow expressing and capitalising on our self-interest in an unconstrained way would benefit us all. In fairyland vulnerability was not acknowledged and we were all seen as self-interested in making choices for ourselves and capable of doing that.

Typical is the Aged Care Roadmap and the new focus on ‘choice’ as a virtue above all else. Arguments that embrace our humanity, our interdependence and our vulnerability are excluded from the discourse. Words that expose our vulnerability and those that express the emotions that come from imagining the plight of others have been replaced in the discourse.

Markets are impersonal processes and unless restrained by the humans who work there are predatory. They will exploit any vulnerability that exists. Strong competition for profits makes restraining them very difficult. We are surrounded by examples. Aged care is not unique.

Our solution

By bringing the discourse of care back into aged care as a driving force and placing the community at the heart of care we can turn a market that rejected social responsibility into one that embraces it. We can set the limits of what is acceptable and give every resident and their families the support and oversight that will protect them and allow them to be effective customers. Those in the system will be released from the bonds that tie them to the business of making money above all else and allow them to behave empathically and responsibly.

3.18 Trust

Mr Johnston: - - There was always a guarded apprehension about nursing homes—generally nice places on the outside but concern existed when no-one was looking.
Senator Smith: It's hard for anyone in our country, let alone in South Australia, to have a degree of confidence in the system at all if no-one is ringing the alarm bells, if people aren't speaking.


Trust is very important for the vulnerable in society. They need someone they can trust to turn to and hang on to. Under stress we all look to someone outside ourselves for help and hang on to them. In the community it may be God or a manager. When sick it is the doctor and when old it used to be the community and is now the nursing home. But in a strongly competitive market we should hang on to distrust to protect ourselves – something we struggle to do when we are desperate for help.
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Addressing the problem

With the community in charge it is the community who will be there for you, to watch over you and to ensure that you get the care and the support that you need. If there are problems they will act with you and on your behalf.

3.19 Bringing back our humanity

Senator Fawcett: -- none of you had anyone that you could go to - - who you know and trust could refer you to, whether it's an ombudsman type person or a point of reference, would that have assisted in your journey?

Krecu What would be nice is if you actually had a person that comes and sees you a month or even a week or so later - - - But if you have just that one person that will come and see you that's independent to the facility—no-one from the facility; independent

Stubbs: NEED much greater involvement of family and carers. Often these people are isolated. They don't get visits. - part of the real answers in these situations is the consumers themselves and their families and carers.


People in desperate situations desperately need someone to turn to. The message coming from the sector is that in aged care there is no one there who cares enough. The families spoke of their difficulties in having their concerns addressed, their lack of knowledge and confidence, the difficulties they had when they did complain and their fear of retribution. This is what families and staff have been saying for years but no one is listening.

They spoke about the problem of trust, having no one they could trust to turn to for support. What they wanted was an independent person who comes and sees you to find out if there are any concerns. Those who don’t have families to support them are in greater need.

Addressing this issue: This is exactly what we are proposing. By integrating services locally and delivering them through community based organisations we would have community members whom the residents and families know and trust in the facilities asking them about their problems and supporting them. They would also be looking closely at and talking to those who don’t have families. They would be doing all the things that the regulatory system should be doing but was not designed to do.

We are not excluding either the residents or their families (the consumers) but alone both are vulnerable. They are a part of the community, a much larger and more effective group and they should not be separated from this community when they enter a nursing home. In a sense the whole is greater than the parts and together they can get what is needed. ‘Consumers’ will not only get support, they will get the backing that enables them to make changes.
3.20 Empowerment

**Johnston:** - unsolicited private calls on my mobile suggesting that I shut up, that it is in my best interests to shut up or that people have friends in high places and I need to be careful.

- I was told by a senior state government adviser that, with my decision to inform the public during one particular radio interview here in Adelaide of reports of in-house carers being found to have questions to answer regarding abuse, I had made every elderly person scared to be in the home.

When I pushed her for evidence of an elderly uprising during my interview, she conceded that in fact the state government had been contacted during my interview by many numerous private providers, telling them to basically shut me up, and, 'Who the hell is he?'


Anyone who has been a whistleblower will have a story to tell of being labelled to discredit, intimidation, isolation, law suits and more. People who believe in what they are doing are aggrieved and upset. They behave like this. Yet the detection of problems in aged care has been almost entirely dependent on people who do speak up and who continue to speak up in spite of this.

**Our solution**

By bringing a totally independent group whose only interest is the welfare of the residents to the bedside they will have support and protection. While it is still possible for the community to be captured and so become a part of this it is much less likely and if the concerns are valid there will be some who will lend support. Whistle blowers will hopefully be protected.

3.21 Suggesting solutions from the community

**Johnston:** Independence. The establishment of a hotline and the ability for people to come forward anonymously and report, including staff members in facilities. - - “independently investigated at arm’s length from every current watchdog, player, provider and vested interest” - - the ability for people to come forward anonymously and report, including staff members in facilities.

**Cole:** not enough funding -- culture -- training -- community need to broaden our knowledge and understanding that that could be one of us one day

**Others:** choices - - Educated staff - - also got a good heart


We have already indicated what the doctors and the various regulators involved thought was needed. It is interesting to also look at what the families of the residents felt was needed and see how that fits with our proposal.
Meeting the families’ solutions: ‘Independence’ is always problematic because someone appoints the regulator and someone always has a point of view that limits their objectivity. We have instead opted for the many eyes of the community but included input from the various central regulators through mentors so that any lack of objectivity is challenged. This ensures that there is a direct path and a requirement for action. If a hotline was needed it would not be a problem but having trustworthy people on site and available to be contacted when needed offers a more personal mechanism that meets the other objectives.

When “funding” was needed the community would obviously advocate for it at a local and central level as well as at the ballot box. It would be armed by data and direct experience in doing so.

It would play a role in changing culture and support better training of staff and recruit those in the community with a ‘good heart’. Autonomy and control are important for a fulfilled life at all ages. Being able to choose between options is important for this. A good supportive culture enables this while guiding us away from serious mistakes.

One of the consequence of this community involvement would be increased knowledge and understanding. Without this our proposal would be ineffective.

3.21.1 Suggested solutions academics and regulators

**Polley:** But what we can do is change the system so that we don’t see a recurrence of that

**Ibrahim:** Increasing transparency and actually having some sort of statement that says, 'Residential care is a complex environment, and we're not looking for a simple solution for a complicated problem,' would take us part of the way there. - - Making residential aged care part of the community is probably the biggest step

**Professor Whitehead:** I would say that the aged-care system in Australia is not designed to improve itself. - - It needs to be self-reflective and aimed at improving

**Ms Olsson:** By opening it up one of the things I did was have a relative and a consumer on the quality improvement committee. Maybe the health standards monitoring people need to look at incorporating some consumer people, as well, as part of the review.


Our suggestions translate well here. Transparency would be built into it. We address its complexity by bringing multiple eyes with their different perspectives to the table. By engaging in discussions where people are all empowered we create a ‘constructivist’ context in which all points of view must be considered constructively. Dogmatism will be challenged. People learn from one another and are unable to impose their views. We are bringing residential care back into the community and making it the focus of community activity and support.

By bringing all those eyes into aged care and engaging in debate we make the system reflective on itself setting the stage for improvement and real innovation. And in regard to accreditation there will be consumer focused community constantly around and they will feed information back to the Agency when processes are not followed or when failures occur so they will know where to look and where to focus their educational and remedial activities. They will not be constrained by having to regulate.
3.21.2 A community system or hub

We have borrowed the term ‘hub’ from Professor Maddock’s and taken it much further than he did to include the community as well as doctors and nurses although they would provide the knowledge base needed to get this underway and knowledge would spread out across the hub.

It might take several different forms and we are not being prescriptive. We now know that community services work best when the communities design what they want then own and run the service. They need to have ownership with responsibility and identity within it. They must decide. Several different models might be tried before the best one emerges.

Concept

We see this hub as being supported and mentored by both central and local government bodies and its board at least initially appointed by but not necessarily from charitable and other community organisations. It would be a hub for organizing and integrating aged care services and activities within the community as well as managing and overseeing aged care services. Its executive would play an important role in liaising with local nursing homes and managers. Its tentacles would spread through the community, touching and involving many of those there.

There would be a central representative body elected from the regions and this would control, support and integrate the local groups activities. The central body would work with other representative bodies and would deal directly with government. It would be responsible for collecting and collating data then making it available.

It will require some permanently funded staff but many of its activities will be voluntary. It will draw heavily on new retirees no longer caring for children but many still with elderly parents in care. They are likely to have up to 20 years of active life to contribute before they too need care so will have an interest in the system.

Funding

The hub would be more independent if government and industry funding were kept to a minimum because funding restricts effectiveness. Bodies do not bite the hand that feeds them even when it needs to be chastised. Depending on the local situation it might take the form of some form of nonprofit community organization. It would keep costs down by being primarily voluntary.

Hubs would probably need some setup funding from government, and in impoverished regions this may have to be more permanent. Other funding could come from donations, research grants, community grants, bequests etc. Community activities including activities for the elderly might attract a fee to boost coffers.

It might be structured as an accountable nonprofit community business providing advisory and other support for a fee to those able to afford this. There has been interest in this sort of business activity in supporting and building community in the UK

Part 4: Government Reviews and Inquiries after Oakden

The response to the revelations of long standing systemic problems in both state and federal regulators has been the creation of multiple separate reviews and inquiries of which three will be under the supervision of trusted neoliberal supporters, two of them will be held behind closed doors:

1. **Review of National Aged Care Quality Regulatory Processes***
   - (Carnell/Paterson Review - initiated by Minister for Aged Care)\(^{31}\)

2. **Australian Aged Care Quality Agency:** "Interval review" into Oakden\(^{32}\)
   - (Nous Group Report)

3. **S.A. Independent Commissioner Against Corruption:** Investigation (behind closed doors)
   - (ongoing as at Jan 2017 - final report expected mid Feb 2018)\(^{33}\)

4. **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 practised *(public)*\(^{34}\)

5. **House of Representatives - Inquiry:** Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia *(announced 7 Dec 2017 - submissions close 1 Mar 2018) (public)*\(^{35}\)

***The Review announced by Ken Wyatt invited public submissions through an online survey, relying on a confined format of a prescriptive online question/answer including multiple choice (there was provision to add an attachment on the last question - unlike previous departmental online consultation surveys).

### 4.1 Section A: Introduction

In the case of Oakden there had been a serious failure, which could not be denied as it was exposed by a state group outside government control. The *Yes Minister* objective would be to minimise the damage and show that something was being done but without rocking the boat.

**Identifying problems:** As cynics and critics of these reviews we were surprised at how extensive and accurate the identification of problems and failures in the regulatory process was in the two reports available. Aged Care Crisis has been complaining about these for many years. The review concluded “*that reform is necessary*”. (P4) It was not what was said but what was omitted that concerned us.

We welcome this acknowledgement that there are serious problems in the regulation of aged care. The changes proposed are significant and will appeal to the sectors critics and might have appealed to us when we first looked at this sector many years ago.

**A whole of system problem:** We now realise that the problems really lie in the system itself and not only in its regulation. As those at the South Australian hearing indicated, fixing regulation is not going to fix the system.

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\(^{33}\) ICAC SA: [https://icac.sa.gov.au/content/oakden](https://icac.sa.gov.au/content/oakden)

\(^{34}\) 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 practised: [http://bit.ly/2u6shZQ](http://bit.ly/2u6shZQ)

Part 4: Government Reviews and Inquiries after Oakden

In addition, simply trying to improve the performance of the current regulatory system fails to acknowledge that this form of regulation is in itself deeply flawed and not suitable for the sector. It needs to be changed, which is what we are suggesting, rather than adjusted, which is what the report does.

In our view, there will be some improvement if these changes are introduced but they are not the fundamental changes that are needed to address the underlying problems in the system.

The cycle of scandalous failures, community anger, reviews, token reforms, apathy, then once again the exposure of ongoing failures will continue. This cycle has characterised the sector for the last 20 years. The problems in the system as well as in its regulation are clearly far deeper and more pervasive than these reviews are prepared to acknowledge. We addressed these in depth in our 2017 submission to the senate inquiry. In our criticism here we will show the extent to which the Nous Group Report and the Carnell/Paterson Review fall short in addressing these issues.

This is not to suggest that the two reviewers were not genuine in what they did and said but they were trapped between their horror at what happened on the one hand and their loyalty to government and the system of which they are a part. They were trapped in the neoliberal market discourse and the flawed regulatory system that has evolved in response to it in most countries. (called regulatory capitalism)

A fragmented solution: What we are seeing is a whole of system problem fragmented and broken up into multiple separate inquiries and reviews. The outcome is likely to be a mishmash of solutions that attempt to address small bits of the problem of a failed system and so overlook the deeper and more fundamental problems that affect them all and are the prime reasons for its dysfunction.

The two reports examined below suggest this is happening. The Carnell/Paterson report specifically leaves staffing issues to the industry led taskforce appointed by the government (page 75). But it is staffing figures that expose just how badly regulation has failed and the reason for that.

By not looking at staffing, this report totally misses the most revealing information about regulations and so fails in what it does. It avoids addressing the thorny problem of understaffing, which needs to be more effectively regulated.

We attended the first workforce taskforce summit. Because that is led by industry and is similarly constrained in perspective, we see the same happening there.

Political reality: The Carnell/Paterson Review received 423 submissions and 345 of these came from individuals. Many were critical but real change was not possible because there were two powerful forces at play. The first was the powerful right wing of the liberal party whose baby this aged care system was and whose marketplace agenda was being challenged.

The second powerful group was the industry that was the driving force in creating this system and who were powerfully represented on government bodies and among political donors. They have built their empires within this system. Without their acquiescence nothing could be done. Neither would allow significant change.
Example: Retaining the practice of provider self-assessment against the Standards as part of the accreditation process was identified as important for provider engagement with the process and quality improvement. (pg 166).

If the providers want to do a self-assessment as a check when working with the Quality Agency that is their option. It should not be part of any regulatory process. If it is part of regulation it might require the assessors to challenge a powerful company and so compromise their confidence and objectivity.

The significant action in these reviews would have taken place in discussion between the reviewers and these groups, of whom they were a part. Both reports make a genuine effort within the restraints imposed and the only way for them to address many of the fundamental issues was to simply ignore them and focus on what was possible.

4.2 Section B: Review of Nous Group Report

Nous Group were commissioned to examined and advise the Quality Agency where it had failed at Oakden. It received information from the Agency and did not look outside this and interview others. It did not examine any other failures and examined Oakden as a unique event that might have relevance for others and not as an example of systemic issues in the accreditation process which it was positive about.

It did not look for or consider that there might be fundamental flaws in the system. It described the special features at Oakden which made it unlike most aged care facilities, placed it at greater risk of failure and made it more difficult to detect problems – ie a unique event.

It was “complex governance and management arrangements that differed from typical aged care facilities and created an environment where multiple regulatory models applied. As a facility operated by the state health department, Makk and McLeay operated with systems, processes, infrastructure, staffing arrangements and a culture determined by that system.” (P7)

It did however recognise that Oakden did reveal “shortcomings in the current audit model” and offered “opportunities to improve”. Its recommendations all focused on methods of improving the accreditation process by considering which facilities were at greater risk of failure, concentrating on those and making it more responsive and flexible. Much of the Agency information is never released publicly. Overall it was simply more of the same.

Interesting points:

a. Instead of reducing the standards from 44 to 8 and making them more general as the government is planning to do, the report recommended expanding “the standards to explicitly allow the appropriateness of the overall service model to be assessed” and focusing on areas of weakness or expected problems.

- There may well be some benefit in this provided the government does not undo it all by privatising the accreditation process as they have planned to do.

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b. The review acknowledged that “there has been an expectation (by the Quality Agency staff and Providers’ staff) that all Expected Outcomes would be met at accreditation audits” in keeping with Braithwaite’s 2007 observation that full accreditation rather than effective regulations was the performance goal and the measure of success for the Agency.

It was "relatively uncommon to identify care failure in the assessment contact visits (announced or unannounced)". In addition "the self-assessment prepared by the provider provides the guide for the audit". We can understand why the Carnell/Paterson report found the providers insisted on this process and did not want the assessors to stray away from it. It was what "surveyors wanted to and expected to see" and clearly made the whole process much easier for them. They would not have been encouraged to deviate from it and create difficulties.

Almost all adverse findings came from review audits which had been triggered by reports from whistleblowers, the complaints Agency or the government. These pointed to the problems so the reviewer knew what to look for and had often been supplied with evidence so had little choice but to respond. The other much more frequent announced and unannounced visits were ineffective in detecting problems that were subsequently exposed.

Ultimately the majority of the information that precipitated a review audit would have come from families or staff in these facilities. Many families lack the confidence or are frightened of taking action because this can rebound on the residents. Nurses fear for their jobs so only a fraction of what happens in nursing homes is reported in this way. ACC has long maintained that the problems are more extensive than has been recognized and this is one of the reasons. The Nous document does not acknowledge this problem and gives no advice for protecting, encouraging and supporting the whistleblowers on whom the accreditation system depends for detection of problems.

If only the review audits are detecting problems and all of the others are failing to do so, then it is possible and even likely that the incidence of failures in care are many times more common than is realised.

Our staffing levels and skills would be considered dangerously inadequate in for example, the USA37. The extent of the unhappiness among staff at the coalface, the people who know, has been ignored. It is difficult not to conclude that the system is failing our elderly at a totally unacceptable rate. Our ‘world class’ aged care system seems to be no more than an illusion in the minds of those who need to believe.

Example comments to Aged Care Workforce Inquiry:

Please, please change things. At the risk of sounding melodramatic, the aged care system is truly a hidden humanitarian crisis. - - - have seen nursing care for the elderly decline to an abhorrent level - - - regularly dismayed at the treatment endured by the residents - - - litany of distress and needless suffering - - - the organisation talks the talk but does not walk the walk.38.

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37 Aged Care Crisis Submission to Senate Inquiry August 2017: Part 2: Comparing Australia with the USA and the UK (p29) http://bit.ly/2A4Uu6x
38 Those who know - Inside Aged Care https://www.insideagedcare.com/aged-care-analysis/19-years-of-care/those-who-know
c. Problems were exposed locally and arrived at the Agency via the complaints system or the government. In many instances they have, as this report reveals in the case of Oakden, not been available to the Agency when it did its inspections. This is not surprising as the complaints Commissioner’s has herself complained that her ability to disclose issues is limited.

The Health Department has been found by a review to have a toxic culture and is so unresponsive to information of dysfunction in the aged care system and so resistant to whistleblowers, that its own staff had to go to the media to expose what was happening in aged care. They had been told to ‘look the other way’ as it did not affect them. Simply recommending that these discordant groups work together is unhelpful.

**Dept Health Capability Review:** it is beset by a culture of ‘inappropriate behaviour’ including bullying and harassment, a command-and-control approach by top bosses and an environment where mistakes are not tolerated.39

**Whistleblower comments:** It’s just so unethical. It’s corrupt. The scale of the rorting is huge. It's taxpayers’ money. - - - We were told to look the other way, tick it all, let it go through - - - I was told many, many times it was not my money - - - The industry needs a clean-up, it stinks. The Department needs to get its act together because it stinks too.40

**A community model:** ACC has not argued against accreditation or the principles that underpin it provided they are applied in context and where they work. It seems to be an effective educational process helping to maintain and improve standards. It is, as this review suggests, ineffective as a mechanism of oversight and of little value as a regulator.

We have suggested that it would be better if regulation was moved elsewhere and that these different and disparate processes should all work with and through local organisations based on and run by local communities. This is where the actual oversight and primary regulation should occur, where activities should be integrated and where it would be most effective. It would address all three problems above:

a. Local organisations that draw on local expertise and involvement would be less regulated and process drive so able to diversify better and focus specifically on the problems and risks in each situation whether in residential care or home care. It would avoid the simplified one size fits all solution. When accreditation was done it would be guided by and build on ongoing local knowledge and experience. It would build on hard data already available.

b. Not only would the local organisations know what was happening and be the people family and whistleblowers came to with their problems but they would be quietly investigating the issues while or immediately afterwards so that the facts would be clear. They would be there to watch over families and staff to see that they did not suffer if their identity could not be concealed. Every audit or regulatory investigation would be forewarned of problems and assisted.

c. Local integration would be much more effective than central coordination because any issues would be addressed by an early local response and would be available to all of the central organisations so that each would be more effective.

The Quality Agency accepted all the recommendations and set out a timetable to introduce them between 2017 and 2019.41

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4.3 Section C: Review of Carnell/Paterson report into Oakden

The review, unlike most previous reviews with the possible exception of the 2005 senate inquiry, identifies the serious problems in the accreditation process and its failures. It had little choice. Although the report acknowledged that “a number of other residential care facilities, have demonstrated serious flaws” and describes it as a “sentinel case”, it did not specifically look at or compare what happened at Oakden with the many other examples where accreditation had failed to detect problems in nursing homes over the years.

Too often, as in Oakden, it was whistleblowers who had lodged complaints. Often their only effective means of ensuring exposure and action had been to go to the press. This omission has allowed some to continue to argue that Oakden was unique and not representative although the report does not.

The Agency’s history of recurrent failure over a 20-year period hung over this report like a dark cloud and was the unstated subtext in what it said. That it was a fundamentally flawed system built on a flawed belief that was dysfunctional in the context of aged care was never acknowledged.

The report focused on the regulatory system and ignored the problems that had resulted in an aged care system that was so dysfunctional even the rigorous regulation that all parties claimed existed could not prevent these recurrent and ongoing failures.

This is a system whose legitimacy, as we indicated in our senate submission is based on its stellar performance in a rigorous regulatory system. The response was to identify problems in the regulatory system and this was not difficult to do because critics have been complaining about these since the 1990s.

We have no arguments with the issues they identify but we are very concerned about the ones they ignore. We have grave doubts about the effectiveness of what they propose as they do not change the regulatory system significantly and do not address the causes of the real problems they identify. They allow these problems and so the failed system to continue unchallenged.

4.3.1 Identifying problems

The report gave the appearance of having thoroughly examined and identified the clear failures in the system and of denying self-serving claims by industry.

1. It rejected claims by industry and COTA, the consumer organisation that supports industry and government, that Oakden was unique, insisting that “most of the issues were attributable to failures that any service could be vulnerable to.” and “the characteristics and needs of its residents were not unique”.

The argument was made that the increasing success rate in being compliant with accreditation showed that care was good and that Oakden was a rare exception. The report rejected this on the basis that there could be cases elsewhere, but it did not explore this further to see if there were any. (P37-40) Later in the report there was an admission that “there is evidence to suggest that accreditation may not be adequate in delivering quality care outcomes for consumers” (P 62)

2. It revealed how easily the system was gamed by identifying that Oakden had a “focus on getting through accreditation” and in completing documentation in order to give them what “surveyors wanted to and expected to see; and better at ensuring staff knew what to say” while being “no better at providing safe or better quality care”. Yet the problems were “persistent and widespread, and should have been detected”. (P44)
3. The processes “place excessive emphasis on processes, with insufficient focus on consumers and outcomes” without looking for evidence. (P44)

4. Preparing for planned accreditation was “drawing significant resources away from the two activities that should be the backbone of Agency”. Note that effective regulation was not one of the two and that “less than two per cent of facilities were accredited for any period other than three years”. (P45)

5. Little attention was given to risk factors and most facilities are returned to full three yearly accreditation as rapidly as possible regardless of risk factors. “The problem is the system design” (P45-7)

6. As indicated in our 2017 senate submission accreditation became a ritual and so a token for good care. The report described “three-year accreditation as a proxy for being quality carers, instead of focusing on care”. Accreditation for a shorter period was seen as a penalty and threatened the brand this is “inconsistent with a risk-based approach to accreditation” (P47-8)

7. The fragmentation and the lack of integration and communication between federal and state regulators. (pg 48-50) It must be pointed out here that it was the state visitors scheme that became aware of the problems. This was because Oakden was unique in that it was also an institution for mental health and so overseen by the state visitors scheme. The aged care visitors scheme lacks any powers and is ineffective as a regulator. Without the state visitors scheme the problems at Oakden would never have been detected. This suggests that similar problems in nursing homes readily pass under the radar.

8. The report acknowledged that multiple criticisms have been made of the accreditation process, many of which Aged Care Crisis has made in previous submissions. It then suggests that the new Single Quality Framework reducing the number of standards from 44 to 8 is addressing these issues. We strongly dispute that. Later it acknowledges the lack of data about outcomes stating the need to “focus on standards that measure quality of care through genuinely targeting outcomes, rather than only processes”. (P65) Presumably this is referring to Quality Indicators.

4.3.2 Failure to acknowledge major structural problems

The report did not recognise:

1. the revolving door with industry and regulatory capture,
2. the potential contribution that empowered visitors and advocates could make to the regulatory processes,
3. the pressures on regulators created by using successful accreditation as a measure of regulatory performance,
4. the problems in the process and the ineffectiveness of regulation described by Braithwaite,
5. the conflicting discourses in the sector and its regulation so that protection of the dominant discourse became a priority, and
6. the conflict and difficulties created by having to be both accreditor and regulator.

Information in regard to these matters was included in our submission to the Carnell/Paterson Review and in our first submission to the senate. In the first senate submission and in the analysis of the Adelaide review above, we show how a community controlled aged care system would address these problems.
Comments on issues raised in the review

4.3.3 Rose coloured glasses

The report like many of its predecessors tries to reduce the significance of its findings by immediately reassuring us that “In general, residential aged care facilities provide a high standard of care to older Australians - -” and “the majority of residential aged care providers that are committed to providing good-quality services”. (P1) It claims the system has “undergone significant reform” since 1997.

In referring specifically to changes in 2014 and 2016 the report claims to “have seen significant improvements in the quality of residential aged care”.(P3) This claim is made on the basis of changes that provided choice and of another set of changes to the complaints system.

No evidence is provided that either have been more beneficial.

It also supports this by quoting the National Aged Care Alliance’s (NACA) claim that ‘quality care’ is:

consumer-driven, have a wellness and reablement focus, are affordable for the community and individuals, sustainably provided, and are inclusive of the diversity of older people according to their needs

It goes on to support the heavily criticised proposal for a “Single Aged Care Quality Framework42” that reduces 44 standards to only 8. The report uses it to bolster the illusion of good care. Many feel that this is retrogressive and will be even less effective than the system that has just failed so badly.

Groundhog day: In contrast Aged Care Crisis sees this as a regulatory system that has made multiple ineffective knee jerk responses to recurrent failures over the last 20 years. These past responses, like this report, are no more than attempts to patch a deeply flawed system and do not fix it.

This report, which we see as a lot more of the same is a response to a lot more unhappiness. It still asserts that we have “an extensive regulatory system in place aimed at ensuring that people in residential care homes receive quality care. This regulatory framework has evolved over the last two decades, and continues to do so” (P6).

One of the problems with this report is that it repeatedly contradicts itself by supporting the current system positively and then criticising it. It is serving two masters and trying to please both.

It acknowledges that the “Act has been amended many times in an effort to establish a regulatory framework that protects consumers - - “(P6) and then later “gives the impression of being the result of multiple incremental changes, rather than system-based design - - “. (P 28) It does not acknowledge that this has been because of repeated failures or that it was going to disregard the reason for these many failures and do this all over again.

The report contradicts its claim to an extensive regulatory system by pointing to the introduction of CDC (Consumer Directed Care) within the discourse of a “consumer-driven, more market-based and less regulated”(P6) system as set out in the Aged Care Roadmap. It claimed this as ‘reform’.

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Like the Aged Care Roadmap, this ‘reform’ is no more than a restatement of the 20-year-old neoliberal agenda that gave us the 1997 legislation and the failed system that we have. The reviewers are reaffirming their belief in this system of belief and clearly they do not intend to do anything that would compromise it. It suggests that the reviewers may be trying to make it even less regulated than it is now – and yes they are supporting reducing the 44 standards to 8 and abolishing many of the existing accreditation visits without replacing them with anything new.

Comparing failed systems: The report claims that our regulatory system “has been favourably compared” (P3) with other OECD countries. This is based on an OECD review written from within the same discourse and looking at the structure rather than the performance of our system.

On page 51 an attempt is made to compare our regulation with “Best Practice Principles” and with international regulation while admitting that there is little data on their performance. It found that the system was not always well aligned with best practice. But the best practice described is based on a centralized neoliberal regulatory model and this has been ineffective in the countries we have looked at.

We have referred on multiple occasions to the cycle of unsuccessful attempts to patch the system whenever a new set of failures occur. None of the claims made are backed by data and this is not the message that is coming from the staff and the families whom the system has failed.

MyAgedCare

The review is blind to the many criticisms of the MyAgedCare website and promotes it positively as “the window to the aged care system for consumers”. (p8)

Aged Care Crisis and others are critical of the complex, impersonal and process driven top/down MyAgedCare system built around a difficult to navigate web site that effectively eliminates the important person on person services that bring empathy, perspective and flexibility to the services that consumers receive.

We have a complex ever changing system of individual circumstances that cannot be contained within narrow processes and rules created by bureaucracy. MyAgedCare and the bureaucracy around it takes the humanity out of human services to the aged. As The Centre for Welfare Reform in the UK commented “Many problems can only be solved at the level of local communities”.

Many submissions to the Tune Legislated Review highlighted much unhappiness about the MyAgedCare website and echoed our concerns.

4.3.4 An alternate view

A systemic problem: Oakden and the multiple other recent failures are red flags pointing to a deeply flawed system. The consequences for elderly residents demands that we assume that these are red flags to systemic problems until we have independently collected data which clearly shows that it is not so.

When the multiple and recurrent failures that have forced repeated reviews, inquiries and tinkering are considered, the lack of data, the unhappiness of many staff, and the progressively poorer staffing levels recently revealed are considered, then it is clear that there are serious problems in the system and that they are systemic.
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Oakden not alone: As what happened at Oakden revealed (P4) and the Nous report confirms, understaffing, poor care, abuse and many other problems can be undetected for many years before some whistle blower plucks up the courage to speak out and has the determination to fight the system until the issues are addressed. Until we have data that shows otherwise we must assume that there are many other Oakdens. One seems to be a company called ZZZZZ.

ZZZZZ had serious problems in its two nursing homes in the 1990s and the early 2000s with 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 2010.

At the same time at Oakden there were multiple ongoing and recurrent problems between 1999 and 2008. Recommendations by the assessors that the facility be closed were overruled. (P30-33). In spite of problems found during annual visits it was fully accredited every 3 years from 2010 including in February 2016. It was not the Quality Agency that exposed the problems later in 2016 that closed the facility down. They learned about what had been happening there for about 8 years from the press.

ZZZZZ’s owner was a political donor with a powerful ministerial contact. 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 owner’s main contact resigned from parliament under a political cloud in 2016.

Oakden too had a powerful industry figure in a position to influence decisions. He was on the government committee managing Oakden until that was dissolved in 2007; then for several years he was CEO of the group that replaced the Baron’s as consultants overseeing the rehabilitation of Oakden after its 2007 problems and at the same time a board member of the Quality Agency that regulated it.

We are not suggesting that either of these people exerted improper influence or did anything wrong. We are drawing attention to a system that makes it possible to do so and looks bad. This situation exists because it is not underpinned by the principle of distributive justice and the balanced oversight that it creates. It is done behind closed doors and not transparent.

In 2017, ZZZZZ’s two nursing homes were finally closed down 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 ZZZZZ’s founder and owner donated almost $20 million to the Tel Aviv University.

ZZZZZ 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. Was this another regulatory failure like Oakden? 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 it the regulator rather than Oakden that was different? In comparison with Oakden, ZZZZZ’s failures like many others did not even create a public ripple. Unusually the problems at Oakden were detected by the state visitors scheme and investigated independently by a medical team. Because of this the full horrors were exposed.

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43 ZZZZZ Health Care, Corporate Medicine web site [http://www.corpmedinfo.com/nh_milstern.html](http://www.corpmedinfo.com/nh_milstern.html)
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We must ask whether it would it have been different had it been the complaints system that first became aware of problems and the Quality Agency that investigated. As Braithwaite also suggested both were well practiced in containing publicity and protecting industry and government.

Was the public exposure and the outcry that followed Oakden because it was different and so escaped the federal safety net? There have been many nursing homes that have failed badly but the fallout has generally been more effectively contained.

**Distributive justice:** There are issues that arise from this for the Carnell/Paterson report. Instead of addressing the issue of distributive justice it centralises all of the regulatory processes under the control of a single committee in order to integrate and so reduce fragmentation. While this might facilitate management, there is limited if any benefit for those receiving care.

This compounds the problems created by conflicts of interest and makes it easy for government to stack this with industry representatives who will be able to control the system and prevent any individual and group from stepping out of line and challenging what government wants. The temptation can be irresistible and it threatens democracy. In 2014 we saw the CEO of the industry body LASA put in charge of the Quality Agency, the body that regulates standards of care in the industry and whose findings result in sanctions. This put him into an impossible situation.

**The regulatory system has been concealing failures:** The early failures were during 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.”

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.

It was in 2007 that the Agency commissioned the review of accreditation that absolved it of the need to collect objective data about standards of care and 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.

Carnell joined the Agency’s board in December 2008 so was not on the board during this period. We think that it is significant that in a review of the performance of the regulators the reviewers did not at any point refer to or reference Braithwaite’s critical book ‘Regulating Aged Care’ or the many quotes in our senate submission describing his findings. Had they done so they would have been compelled to consider the implications.

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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 (64 to 98%) improvement in accreditation success was due to departmental policy - 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 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 occurred. This is simply not credible. The logical explanation is that facilities were being accredited to meet a target and not to protect residents.

This was impression management and a branding exercise for the industry on a massive scale.

Confirmed by comparisons

Staffing: As revealed on pages 32-33 of our first submission it is clear that there are not enough staff to provide care when we compare our staffing with that in the USA where extensive studies have been done to determine safe staffing levels and where minimum levels are advised.

**Part 4: Government Reviews and Inquiries after Oakden**

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<th>AU: SB Recommended Benchmarks</th>
<th>USA: US Average</th>
<th>AU: SB Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registered Nurses</td>
<td>0.75</td>
<td>0.36</td>
<td>0.8</td>
<td>0.37</td>
</tr>
<tr>
<td>Enrolled Nurses (equivalent)</td>
<td>0.55</td>
<td>0.34</td>
<td>0.8</td>
<td>0.33</td>
</tr>
<tr>
<td>Nurse Aids (equivalent, eg PCAs)</td>
<td>2.8</td>
<td>2.22</td>
<td>2.4</td>
<td>2.08</td>
</tr>
<tr>
<td><strong>Total nursing time:</strong></td>
<td><strong>4.1 hrs</strong></td>
<td><strong>2.9 hrs</strong></td>
<td><strong>4.0 hrs</strong></td>
<td><strong>2.8 hrs</strong></td>
</tr>
</tbody>
</table>

*Total rounded to 1 decimal point.

CMS = Centre for Medicare and Medicaid Services (15,000 facilities)
SB = StewartBrown (800 facilities)

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**Australian nursing home residents receive less than half as much care from trained nurses and an hour less care each day compared with the USA.**

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

**Regulatory effectiveness:** When we compared regulatory failures what is revealed is even more startling. In spite of the differences in staffing, in the USA 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](chart5)

![Blue have no problems](chart6)

*Chart 5: USA deficiencies = 93%*

*Chart 6: Australia deficiencies = 2%*

Interestingly, it appears that no one on the Executive Team of the Quality Agency seems to have any nursing or clinical expertise.*

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Part 4: Government Reviews and Inquiries after Oakden

Complaint handling: The Carnell/Paterson report shows (P41) that probably roughly 0.35% of about 3500 formal complaints in a year result in a review audit by the Quality Agency. The report documents (P174) 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 the failure to achieve any outcomes.

The report itself indicated that “Many respondents had no confidence in the complaints-handling processes”. (P 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” (P173).

The data indicates that we would find extensive problems in the care provided to residents in nursing homes if we 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 seriously ineffective and why care has been so poor. This report is not addressing that problem or many of the others. We have a system that has deceived us and this report continues to do that. It is protecting an industry that is not delivering and as a community we should be furious. Unless we as a community can take this in hand ourselves we are not going to find out. Until then we can only fear the worst.

Our proposal: What we propose would place oversight of what providers do, the way data is collected and the way the system is regulated in the hands of communities so that everyone would know exactly what was happening and would have the power to act when necessary.

The same local people, the ones who know what happens in the nursing homes, would be working with prospective residents and their families guiding them through the complexities. Families would have the empathic person on person support they need and with the flexibility to help them meet their needs as well as funding permits.

Care would be rationed in order to get maximum benefit from the funds we are able and willing to devote to care. Currently care is rationed to feed the profits of the providers, support a system of consolidation that favours those who provide poor care above those who provide good care, and drives Australia’s participation in similar aged care commercial enterprises in China and elsewhere. The national budget is being placed ahead of the welfare of dispensable citizens.

4.3.5 Distrust and a ‘buyer beware’ approach is now essential?

We worry about statements like “allegations of abuse and poor care of nursing home residents are damaging to public confidence and raise questions - - ”. (P1) There is a perception in the industry that the publicity and not the service they are providing is the problem and that this is what requires attention. Restoring public confidence is not the same thing as changing the system so that failures actually do become rare exceptions and the data does confirm they are the only ones.

In a marketplace where survival depends on competitiveness in making a profit, a healthy distrust based on a lack of confidence is essential if families are to protect their spouses and parents by helping them to make the best choices.
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The Nous report shows that the exposure of failures and so the effectiveness of the regulator depends on family and staff who are distrustful enough to look critically at what is happening and have someone on hand to complain to.

As we saw in the senate hearing into Oakden in Adelaide, it was because families were trusting, did not expect to have to fight to confront the system, and did not have anyone available to support them, that it took so long to expose what was happening.

If we are to make the effective choices from competing providers that the Aged Care Roadmap is selling to us as the way of the future, then we need to look very critically at the offerings (eg. on web pages). Having confidence in this system is not going to help us.

The government is urging us to shop around and to choose wisely. “Choice” has become the new buzzword. In this system government and industry cannot logically offer us choice and at the same time urge us to trust the system. In a competitive market with vulnerable customers, choice and trust are very uncomfortable bedfellows.

We think trust and trustworthiness are important and it is what the elderly and their families expect in this sector. But that is not the sort of market that government and industry insisted we have 20 years ago. The data shows that buyer beware must replace trust. It is sad that it has come to this, but we cannot have it both ways.

A sector where trust and trustworthiness have always been important has been turned into one where success in obtaining services depends on a healthy distrust. Yet government and industry are encouraging us to continue to trust the system.

We can see this as another of the basic conflicts in a system where inappropriate marketplace discourse and a system built on them have been imposed on a sector where they don’t fit. As with the banks, participants have to say one thing to create an image and look credible to be successful but then must behave very differently in order to compete successfully. Those who can’t handle the mental gymnastics go under.

**Our proposal:** The changes we propose would put the community in charge of the system. They would be in a position to ensure that the services provided were the best possible with available resources. The intention is to turn this market into a less competitive, less profit-focused one that ‘consumers’ can cautiously trust to meet its responsibilities. But it will still be a market so we will have someone the residents and their families can feel comfortable with and trust regularly visiting the nursing homes and always locally accessible.

4.3.6 Accreditation as regulator

Accreditation has a particularly poor record as regulator and has failed to detect serious problems on multiple occasions in health care in the USA and as this report confirms in aged care in Australia. Its mode of operation is underpinned by patterns of thought (paradigms) that see it closely aligned with and supporting the providers that it accredits, paradigms that are inappropriate and unsuited to a regulatory role.

**The accreditation Agency did not want to regulate:** The report ignores the then Accreditation Agency’s strong view expressed in its March 2011 response to the Productivity Commission’s 2011 draft report ‘Caring for Older Australians.

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The Agency asked to be relieved of its regulatory role on the basis that it was not a regulator. It said:

“... The Accreditation Agency's responsibility is to support and encourage a quality environment that supports quality care and improvement in aged care while identifying where homes have failed to meet the standards. This approach is in the interests of the residents, who are usually frail, vulnerable and elderly. To do this role adequately requires a strongly collaborative approach with their stakeholders. This does not align with an inspectorial policing approach...”

and again:

As argued in Campbell (2005), there has been much discussion about the inherent contradiction of combining the support of quality improvement in an open and transparent environment (e.g. the accreditation objectives) with compliance objectives that can result in penalties and may not reward open disclosure. “Accreditation is intended to perform a different function from government regulatory systems” (Campbell report, 2005, p105)

This issue came up again when questioning the Quality Agency at the senate hearing in Adelaide on 21st November 2017. Ms Wunsch and Mr Ryan both indicated the extent to which the Agency was focusing on self-disclosure yet, as was remarked on by senators, there is no incentive for providers to do so when the Agency is also the regulator and this may lead to sanctions.

The regulatory role and the pressures in a highly competitive market leads to a culture of cover up. In their evidence Neil and Carla Baron described how accreditation was seen as a punitive exercise and stopped staff from speaking freely.

Government never intended it to be an effective regulator: Another comment in that 2011 submission confirms our view that the government in 1997 was interested in supporting the providers rather than regulating them. Regulation was contrary to neoliberal belief which thought markets regulated themselves. Effective regulation that exposed failures was threatening to a government that at the time was strongly criticised and unpopular adding an impetus to remove all regulation.

The Government created an ‘accreditation agency’ and defined its role along the lines of an accreditation body not an inspectorate or a regulator

Source: (Mrs Moylan Hansard 30 November 1998)

It was only later when government was under pressure to regulate that the Agency was saddled with this unwelcome task for which they were ill-suited.

Agencies independence terminated: We agree that the Quality Agency should not be a regulator and have argued for an alternative for years. But we suspect this reluctance by the Agency to fill the regulatory role saw its independence terminated in 2013. It was transferred into a government department and an industry heavyweight, Nick Ryan, the then CEO of industry group LASA. put in charge. We have not heard any more about the difficulty in being both accredditor and regulator from them since then. Ryan ducked questions about this at the 2017 hearing in Adelaide.

The report ignores this: It is revealing that in describing the current regulatory system the Carnell/Paterson report indicates that the Department “relies heavily on the Quality Agency to visit sites to assess compliance issues against the standards and collect information”.(P 19) But the Agency has in the past insisted that the department is the real regulator. This makes the department equally ineffective and limits its ability to assess and prosecute offenders effectively.
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The report perpetuates this problem. It indicates “- - the Agency we propose will be a regulator, overseeing an area of high and discrete community concern”. (P vii) while at the same time the report accepts that it is a support organization and engages “actively with the sector and support providers to meet expected standards of care” offering “targeted education services and workshops, as well as standardised training packages” and assisting “the home’s process of continuous improvement”. (P 9, 10 & 13)

In our view any changes that do not address these issues by separating regulation from accreditation will be ineffective and will not address the problems.

The Nous report found that review audits triggered by information supplied to it were most effective in detecting problems and addressing them. Yet in 2015/16 the Agency did 858 site audits and 3,380 assessment contacts but only 13 review audits. In the following year only 14% (501 of 3656) of formal complaints were referred to commonwealth regulators. (P41) If the same number of review audits were performed then less than 2.6% of these and 0.35% of all formal complaints resulted in a review audit.

Given the poor and steadily falling staffing levels, the concerns of nurses and the widespread unhappiness about the system this does not suggest much enthusiasm for pursuing regulatory issues.

Our proposal: In our proposal regulation will be moved elsewhere and members of the community will be regularly on site supporting residents and monitoring care. When problems arise they will be in a good position to advise the regulator that action needs to be taken because policies and practices are inappropriate or insist that the provider ask the Agency for assistance in improving standards and then follows their advice.

4.3.7 Terminology

The report’s use of words and terminology is suspect. In reviewing regulation the word “accreditation” is used in regard to all regulatory effort when comparing Australia with other countries. On page 64 the report states “Like Australia, most regulatory systems use some form of accreditation to authorise aged care providers. Two-thirds of OECD countries have compulsory accreditation or certification as a condition for receiving government funds”. Certification is not the same as accreditation.

While we don’t know how accreditation is used in all these countries, only Australia uses accreditation as the only form of regulation and in most countries where it is used it is very secondary. In the USA for example, Ronald Reagan’s attempts on two occasions to make accreditation the only regulator in aged care were rejected by community and the government. Only about 10% bother to be accredited.

What the report seems to be referring to in these other countries and Australia is the flawed regulation (called regulatory capitalism) that developed in response to the way neoliberal policies unleashed the predatory nature of markets. While ostensibly to address these problems, control of regulation by neoliberal politicians and industry ensured that it would also protect the neoliberal discourse from embarrassment and so both government and industry’s image ahead of its intended objectives. Accreditation is part of this but it has major additional problems impeding its effectiveness.

4.3.7.1 Is this deception or ignorance?

At first we thought that this loose use of terminology was deliberate in order to muddy the waters for the uninformed and allow international comparisons by seeming to compare like with like. But could it be that they simply don’t know enough to understand the difference?
As we read on to page 9 we discovered that the reviewers also did not know that in Australia the regulations governing approval to provide services were restricted to providers and not their owners. This is a major flaw in the regulations they were reviewing.

Any organisation that has exploited the vulnerability of citizens elsewhere can buy a company that already has approved provider status and then appoint the managers it wants to run the business and potentially exploit them in the same way.

We wonder if the reviewers have read the legislation, studied the history or read the many reviews that have preceded theirs. Do they have enough knowledge of the system and its regulations to understand what they are doing and make recommendations that will work?

### 4.3.8 Selective quotations that do not reflect the thrust of submissions

The words ‘consumer’ and ‘community’ are muddled and confused in this report as if they are the same thing, switching from one word to the other. Quotes were selected from our submission to support the report when it is clear that our criticisms and proposals were being ignored.

For instance, on page 80 it quoted our submission about community before immediately returning to the word consumer and then including consumer peak bodies and advocates in their discussions as if these were what we were referring to.

*The community, the repository of our social values and our humanity [which is] so important in this sector, has been marginalised and has little input.* (Part 2 P 24).

This quote was used to support the objectives of the Aged Care Roadmap which we consider to be misguided and inappropriate. The next sentence read “The Aged Care Roadmap places the consumer at the centre of care”. In our view vulnerable seniors will be at high risk of exploitation if the roadmap is followed.

Our submission was critical of the focus on vulnerable consumers and the neglect of local communities who we felt should be there to support them because the Agency was incapable of doing so. This report does nothing to empower the community as an effective regulator and a close supporter/protector of the vulnerable consumer. That is what we were pressing for.

On page 1 of the report it quoted us saying “aged care is a sector where trust and trustworthiness are vitally important” but omitted “but these are qualities that are in short supply in the predatory marketplace”. (P1 of Part 2) It ignored our subsequent criticism that strong competition in this predatory marketplace had created a situation where “distrust has become integral to care provision and with good reason”. (P 46 Part 2) The effectiveness of a market whose success is measured in profitability depends on the customer being distrustful and carefully evaluating the product – buyer beware. The design of the current aged care marketplace deprives the customer of the information needed to avoid poor providers so ensuring failure for many customers.

**Definitions:** It is important to understand that consumers are the vulnerable seniors and their anxious families and while they may be a part of society and a community they are vulnerable and disempowered in aged care. Community refers to the local communities within geographical areas, the sector of society whose vulnerable seniors are in need of care. It has the capacity to be a far more powerful entity and so to support and protect the vulnerable consumer.

Multiple communities comprise civil society, the society that elects our politicians and whom they are there to serve.
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Consumer peak bodies and advocates do speak for sections of the aged care population but many receive funding from government, a government which at both federal and state levels is returning to Johns Howard’s late 1990s strategy for muzzling critics. Both governments are currently attempting to muzzle criticisms by threatening the funding of charities that speak up for those they serve.

4.3.9 Selective in what it chooses to look at and reference

The Carnell/Paterson report is highly selective both in which of the 436 submissions it chose to consider and refer to and the references it quoted.

It quotes quite extensively from Braithwaite’s work and uses the responsive regulation model and escalating regulatory triangles that Braithwaite advocates to assess the Agency’s performance and compare it favourably with other developed countries that have different aged care systems.

But most of them are subject to the same regulatory discourse and so of “regulatory capitalism”, a term used by academics who study regulation to describe the centralised government regulation and the self-regulatory processes established to counter the market failures that have become the hallmark of neoliberalism. Similar problems exist in these countries because of this.

As indicated the report inaccurately describes these regulatory systems as “accreditation” which they are not. Braithwaite and others describe the regulatory systems in these countries and in Australia as regulatory capitalism – a response to the tensions and failures of neoliberalism.

Braithwaite has focused on regulating aged care throughout his long career, studying it in the UK, USA and Australia. In 2007 he published “Regulating Aged Care”, his analysis of this work.

In this he reported his recent study of Australia’s regulatory system and particularly accreditation, which he had previously criticised as unsuitable. His analysis was very critical and in depth.

He found that regulators were motivated by and proud of their success in demonstrating their achievement in getting a high percentage of facilities accredited. They were not focused on effective regulation. He gave multiple examples indicating that regulation had been captured by market values. He implied that regulation was protecting the system rather than the residents.

He said “Things have to be bad for non-compliance to be recorded or strong criticisms to be made in an accreditation report.” He referred to his team’s “observation of indefensible ratings of compliance during our fieldwork”. He was also critical of the complaints system and the way in which the advocacy and visitor’s schemes had been structured to prevent them contributing to regulation.

51 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

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

52 Braithwaite J et al Regulating Aged Care’ Edward Elgar Publishing Limited 2007
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The Carnell/Paterson report draws on the works of both Valerie and John Braithwaite when they support the reports arguments but it ignores and fails to reference John Braithwaite’s book on *Regulating Aged Care* in which he very strongly criticised the system because it had been captured by industry and was serving their interests. They were aware of this because we quoted from it in our analysis attached to our submission.

### 4.3.10 A role model

The report looks to the UK’s Care Quality Commission for a regulatory model to use. (Pages v, viii, 64 and 136) and says that “The simple and readily understandable rating information published by the CQC in England provides a useful example” (pviii). While the UK collects and publishes far more data than we do and the CQC is much better than the Quality Agency in this regard we need to remember that the CQC has been far more extensively criticised as not being fit for purpose than Australia’s Quality Agency. We should be wary and perhaps look for a different model.

### 4.3.11 Rating systems

The report calls for a star rating (Pviii, xii, 64, 101-) although it acknowledges that England had problems with this. (P73). The rating will be based on the accreditation standards whose utility and reliability are questioned by ACC because of the many failures, lack of objective data and only yearly visits.

In a strongly competitive market the incentives to inflate performance is strong and when data is self-reported (eg Quality Indicators - QI) it has been found in the USA that top performers in QIs were sometimes very poor when inspected.

### 4.3.12 The role of regulation

The failed role of the regulator: The report started by focusing on the role of the regulator in assuring the public that residents “are safe, well cared for and have a good quality of life” and concluded that the “current regulatory mechanisms do not consistently provide the assurance that the community expects” (Pv)

But that is not the problem. The problem is that regulation has consistently and successfully been assuring the public that this is the case and that we have a world class system, when we have had a substandard system that is failing Australians far too often. The report accepted that Oakden was not unique.

It has not been doing its job of regulating and exposing failures and the public are understandably up in arms about this and feel deceived.

The report does challenge some of the neoliberal dogma about market self-regulation and considers the government does have a role in regulation asserting that “the market is an inadequate mechanism to ensure the safety and well-being of highly vulnerable residents”. But as our first submission revealed government has an impossible and deeply conflicted role which renders it ineffective. Even if it wanted to be effective it is on site so infrequently that it cannot do so effectively. It requires an on-site presence and government cannot be there often enough. It cannot do it alone.

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53 Care home inspections are futile  The Guardian 1 May 2014 http://bit.ly/2hGv59g
(Whistle blower) Former CQC inspector says elderly are being left to suffer The Telegraph 20 Sept 2013 http://bit.ly/2mn8uf
One in 10 NHS watchdog staff should not have got the jobs The Telegraph 9 July 2014 http://bit.ly/2qStTRU
Part 4: Government Reviews and Inquiries after Oakden

The report sees the “primary role of quality regulation as consumer protection” (Pvi) but the role of regulation is to expose failures, to prosecute and stigmatise the offender and to enable the victim to seek compensation. When regulation exposes failures and stigmatises offenders then customer and community can take steps to protect themselves.

The current system: The report describes the current regulatory system under the heading “The National Aged Care Compliance Program” (pages 17 to 28) including the Quality Agency, Health Department and Complaints system.

In our 2017 submission to the senate we described the deep conflicts within the regulatory system, the way it had been captured by the market discourse and how ineffective it was. But any centralised regulatory system that is so seldom on site, and is bogged down in process, is incapable of containing unopposed strongly competitive market forces in vulnerable sectors. Aged care is not the only vulnerable sector where this is happening.

The problem lies with the neoliberal agenda which the report supports, in their comments about the proposed reduced oversight in the “Single Quality Framework”, and in the role of the Aged Care Sector Committee, and its roadmap to “transform the current aged care system into a sustainable, consumer-driven and market-based system” (P27)

This roadmap is the response to a system that has been failing for nearly 20 years because of a market based discourse and policy that is not suited to the sector. That is why it is so difficult to regulate. Social analyst and editor of The American Project, Robert Kuttner described this problem 20 years ago. None are as deaf as those who truly believe

There is at the core of the celebration of markets relentless tautology. If we begin by assuming that nearly everything can be understood as a market and that markets optimize outcomes, then everything leads back to the same conclusion—mktetitize! If, in the event, a particular market doesn’t optimize, there is only one possible conclusion—it must be insufficiently market-like. This is a no-fail system for guaranteeing that theory trumps evidence. - - - It does not occur that the theory mis-specifies human behavior.

Our regulatory system has failed to deliver. You cannot protect someone when you visit once a year and after the event. You can only deter them so that they and others are less likely to do it again. The best deterrent in the marketplace is one that destroys the brand. With a 98% rate of successful accreditation it is clear that this is not happening.

The role of regulator in supporting the marketplace: The regulation also “aims to promote consumer choice and control by raising awareness of provider performance” (P 23) but this expression of the neoliberal discourse is tokenistic and impractical in the context of the vulnerability of consumers and the tensions that surround admission to a nursing home.

The regulator does not collect objective data and is seldom on site so does not know what is happening. With a 98% success rate there is little comparison of performance.

Like other countries with failed regulatory systems, Australia is tacking additional bits like Quality Indicators, star rating systems and greater consumer engagement on to a failed system in order to bolster the neoliberal agenda and try to make it look legitimate. What is needed is structural reform that acknowledges the problems in the neoliberal thinking that has given us a failed system and a failed regulator. It must address the faults with the system that make it so difficult to regulate. This report does not do this. The problem is the system and the regulatory failure is only a part of that.

As we have seen so often before, placing the world “quality” before a word is likely to be a branding exercise. This allows you to redefine it in a way that undermines its role and effectiveness by sliding it into the realm of illusions. It readily becomes tokenised.

**Our proposal:** Accreditation does provide some consumer protection by ensuring that providers have effective processes in place and know how to provide care. It should continue to do that. As the evidence to the senate committee in Adelaide showed having responsibility for regulation as well renders this much less effective. We argue that checking that care is effective and that safe processes are being followed is the role of a regularly on site regulator. This can only be done locally.

### 4.3.13 Responsibility

The report argues that “Ultimately, responsibility for the provision of high-quality care lies with the provider”. But traditional market wisdom considers the provider of services to be driven by self-interest and to be ‘an order of men ... who have generally an interest to deceive and even oppress the public’.

On page 9 the section headed “Approved Provider Responsibilities” refers to the multiple often unquantified expectations set out on government documents such as “maintaining sufficient appropriately skilled staff”. But these are expectations rather than measurable standards.

The problem is not that we do not have motivated people but that we have a system that encourages profit focused providers to do the minimum they can get away with and many now enter the sector primarily because of its potential profitability. This places contradictory pressures at the heart of the system and this impacts on staffing, culture and performance. Those who are motivated by a mission to care and so do their best can struggle to compete. A system like this depends on regulation for its effectiveness and we do not have a regulatory system capable of handling those pressures.

It is the customer and the community (civil society) who together hold the provider to account and are ultimately responsible for ensuring the service is good. Government is there to support them but in Australia it has reneged on its responsibility to citizens and supports the market instead.

**Our proposal** seeks to address this situation and the incentives within it by ensuring that those who care for the aged will succeed to the extent that they meet or exceed our expectations, and those who fail to do so do not prosper. This is what a market is supposed to do.

### 4.3.14 Probity – restricting providers and owners to those who are responsible

Probity is the requirement that those providing the service to vulnerable people be restricted to those who can be trusted to behave responsibly. Those whose track record shows a disregard for other citizens or the system are excluded. Government’s plans to bring in some decidedly unsavoury multinational health care companies in the 1990s were blocked by state regulators using the probity provisions in their licensing laws. Ownership was the prime consideration and the risk was measured by the holding the offending entity held in the provider.

This was seen as an illegal and unethical restriction on basic rights by the neoliberal movement.
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Probity legislation was abolished in aged care in 1997 and replaced by an approved provider system which considered that the owners who held the purse strings, made policy and were sometimes “turn around specialists” were “passive investors”. They did not need to be regulated or approved.

As a consequence any local or international criminal can buy into aged care provided the company they buy is already approved and then appoint its own staff to manage the subsidiary. They are not seen as responsible for what happens in the facilities they own.

The Carnell/Paterson report has no issue with this sort of regulation. It indicates that the department regulates “the ‘gateway’ for providers to enter the system where they become eligible to receive government funding, by approving providers for the type of care they provide”. (P7)

It is interesting that on the next page it says “The provider seeking approval is not the specific aged care facility, but its owner and / or operator”. (P9) A search of the department of Health’s “Guidance For Applicants Seeking Approval To Provide Aged Care” reveals that the word ‘owner’ is used only once in order to define the difference between for-profit and non-profit facilities. The word ‘provider’ appeared on 17 of the 22 pages in the document - often more than once. The guide defines and then refers only to ‘approved providers’. In the Quality Care Principles 2013 itself the word ‘provider’ was used 252 times but the word ‘owner’ could not be found.

Either the reviewers are deliberately seeking to deceive the public or they have not read the regulations and are ignorant of the regulatory system they are reviewing. Incredibly we have seen this so often in aged care that we suspect it is the latter. Outsiders who know little about aged care are brought in to manage it, to sit on regulatory bodies and to review it and often then graduating to be government advisers or to sit on policy committees.

But then we see “In practice, the regulation of approved provider status appears to place emphasis on financial and governance aspects, but these are only part of what the Act says approval requires”. That this was so was our impression as well but the reference they use is this same guide. If they did not read it as this suggests then someone else did and gave them this information without ensuring that they understood the legislation they were reviewing or that research shows that ownership was one of the most important factors in performance.

On page 19 of our submission to the Carnell/Paterson inquiry we wrote about probity and the international and local evidence revealing the importance of ownership. With more than 400 submissions to read they must have missed this.

Our proposal: Under our proposal the community’s representatives would play a prominent role in deciding on whether an applicant should be allowed to operate in Australia when its past conduct and the conduct of its owner was examined. The local community would decide whether a provider should be allowed to operate locally after examining its history elsewhere. The interests of vulnerable citizens would trump the right to provide services wherever a provider chose.

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4.3.15 Transparency, data and support groups

The report supports all three, but we wonder why ‘information’ was qualified by the word ‘quality’. Is this a new sort of information? Too often words like this have been tokens for something that was not there. The report does not specify what solid objective information is to be collected or how it will be collected, interpreted and reported. Putting quality in front of it does not do that.

If the report is simply referring to data collected by the current or the new reduced accreditation process and the complaint’s system, then it is not reassuring. Accreditation does not collect objective data and by the time anyone gets to the nursing home after a complaint, deficiencies in documentation may have been corrected and witnesses coached.

The report is surprised that the “absence of reliable, comparable information about care quality in residential aged care is a striking feature of the current system” (Pvii). When writing about Best Practice and doing international comparisons the report found that we performed poorly stating that “Historically, there has been a significant lack of publicly available data and policy-relevant evidence on residential aged care” (P61).

The reviewers did not mention that the industry had promised to collect data in 2003 or that in 2007 the Agency commissioned an external reviewer who advised that data on failures of care were now to be renamed as “indicators” with “the clear understanding that they were being developed not to measure performance”. The consultants advised that this “should be confirmed to the sector”.

The story: The industry promised the Joint Committee of Public Accounts and Audit to collect data in 200357. 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”.

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”.

When industry reneged on this promise the (then) Accreditation Agency once again came to the rescue. In 2007 the (then) Accreditation Agency employed Campbell Research & Consulting to review accreditation58. The Agency were advised to inform the sector that failures in care were not to be used as a measure of performance. This is the same year that John Braithwaite published his book describing the extent to which regulation had been captured by industry.

57 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=Id%3A%22committees%2Fcommjnt%2F6844%2F0003%22

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.

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; (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 Carnell/Paterson report used the 2007 Campbell report to support some of its recommendations and we worry that despite all the talk of data this data will still not include the rates of failures in care - eg. Pressure Injuries.

The reviewers claim that “The three regulators are increasingly making information available to consumers to help them make more informed choices” – a process which after 20 years is still “in its early stages”. (P7) With a track record like this we wonder what sort of data and how much we will get, particularly when, as happened in 2007, the angst generated by the current failures is no longer in the headlines.

Another data problem: Campbell’s Law indicates that when items are selected for specific performance evaluation there will be pressures to concentrate on them, while other non-evaluated aspects will be neglected and suffer.

Addressing all these issues: The track record of industry and the regulatory bodies that support them gives us no confidence in these belated attempts to look as if they are doing something. This is no longer acceptable or credible.

In our proposal the community service will be participating and overseeing all data collection and will be observing the performance of a facility so the data collected will be verified and any simplification and easy to understand measures like star ratings and QI’s will be accurate and will be assessed in the context of the entire picture.

Because the prime guidance to prospective residents will come from the community that have been doing the assessment and know exactly what the home is like the potential distortions in data and service associated with QI’s and star ratings are less likely to arise and when they do will be promptly recognised.

4.3.16 The value of resident and family opinions

The report also indicates that “Meaningful input from residents, families, community visitors and advocacy groups is also essential - - -” (Pvi). The increase in the percentage of interviews with consumers and the use of consumer experience reports (P 15) is welcomed provided these are confidential and those reporting cannot be selected or pressured and that the limitations are recognised.
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Opinions from recipients of care and their families are valuable when they leads to investigations that reveal problems but, while it may confirm a good quality of life, it is of much less value in assessing standards of care. When surrounded by positive marketing and strong beliefs residents will identify with these beliefs even when the care they are given is poor. They lack knowledge and confidence so do not know any better.

We know that many staff are strongly motivated but unable to provide good care because of understaffing or poor training and ignorance. Residents and family will see that motivation and dedication and reflect it in their responses.

We know that medical research that relies only on the opinion of patients is unreliable and few reputable journals will publish it. To show improvement and be credible the results must be based on objective data or blinded studies with a control group. We should learn from this.

4.3.17 Community visitors and advocates

The report repeatedly asserts the rights of consumers to advocacy support and seeks to involve visitors by encouraging them to report problems that they see and create channels for that.

As explained in our previous submission and earlier in this supplementary submission (page 37) both community visitors and advocates need to be ‘liberated’ from the shackles imposed by regulation, distance and funding. Funding can easily be withdrawn by government and so inhibit effective action. They need to be given investigative powers.

They should be empowered by new regulation that:

- places them in regular attendance at nursing homes as part of a community led process,
- recruits people with and gives others the skills needed
- gives them investigative powers,
- makes them accountable to local communities. and so
- releases them from government funding constraints.

In the nursing homes and community they will be talking with staff, residents and families so will know what is happening and where to look.

This report does not really advise any of that and at best thinks about it as possible in the future.

4.3.18 Fragmentation

The report identifies that “The current regulatory system is fragmented” (Pvii) and supports the creation of a single centralised regulator as suggested by the 2011 Productivity Commission. That suggestion came from BUPA, a provider that has a close relationship with government and has been represented at the highest levels on government committees.

While this sounds attractive and could be useful, it also allows far greater control of the different arms of the regulatory process. In a system that credible researchers claim is captured by and serves government and provider interests over residents, it makes it easier to control any part of a system that might forget that its primary role is ultimately the protection of government and industry from embarrassment.

As we have indicated it is local integration in the delivery and regulation of care that will make a big difference. Because this would be accountable to local communities the risk of capture would be removed and central integration of the type suggested might well complement this.
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The three commissioners suggested would be useful particularly if the “Aged Care Consumer (or preferably Community) Commissioner” were elected by and represented the community organisations we suggest. After all, as the report says this is “an area of high and discrete community concern”.

A more suitable name for this central body that distances itself from the language of the current system might be “The Aged Care Oversight and Regulatory Support Commission”.

4.3.19 Supporting consumers and their representatives to exercise their rights (P v111)

The report comments that awareness of consumer’s rights are low and given the complexity of the entire process this is not surprising. Educating the public as suggested in the report is unlikely to work because of the complexity of the entire process. Empowering community to be involved and support those in need will be more effective because those with the knowledge to do so will be selected and will have the motivation to become well informed. Involvement and ownership engages and involves.

4.3.20 More effective regulation and complaints monitoring (P ix)

The report records that the “need for improvements in the rigour of the accreditation system was a persistent theme in submissions”. This gut reaction is to be expected as each new generation is confronted by the ongoing failures in care and in the regulatory response. For several years Aged Care Crisis also called for more rigorous regulation.

Groundhog Day: But multiple failed attempts over the last 20 years to respond to the recurrent failures in the system and the regulation that is supposed to protect the elderly, by increasing the “rigour” of this regulatory system have caused us to look more deeply at why it is not working. We now recognise that there are both structural and ideological problems that make it impossible for this system to regulate effectively, and for politicians to accept that they have failed their citizens. We are urging politicians to look more deeply at root causes and address those.

We are urging governments to address both the problems that lead to a system that depends on regulation to protect residents, and to change the regulatory system to one that works when it is needed. We have indicated how that could be achieved. In the final part of this supplementary submission we describe and supply links to many of our previous submissions to show how our thinking evolved.

The problem with this report is that it does abandon the most ineffective forms of oversight and does once again make it more rigorous. But in time the limitations of this system and the underlying factors that have not been addressed will play out again in the same or similar ways. In another 5 to 10 years a new generation will have to rise up, get angry and force more reviews. We can only hope that they will be more mature and will have learned to look at the past, learn from it and so understand why it has gone so wrong again.

4.3.21 Enhanced complaints handling

The complaints process has been a never ending source of unhappiness and it has been rejigged several times over the years. Once again the report documents “dissatisfaction with complaint outcomes” and once again proposes “increased statutory powers” but this is not the cause of the problems or the answer to them. This is another groundhog day!
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The problem is that there is no one there for residents when they need someone. It's a long way away and its impersonal and process driven so lacks the human touch. It needs to be taken to the bedside and be exercised by someone they know and trust so it is there when it is needed and that is what we are advocating for.

4.3.22 Responsive regulation

The report describes responsive regulation in detail and references John and Valerie Braithwaite’s work. (P66-74) The department claims to have been developing something along these lines since 2015. This approach by Braithwaite has two pyramids. One is a “Pyramid of supports” which builds on strengths with the maximum reward for great excellence at the top of the pyramid. The second is a “Pyramid of sanctions” with education and persuasion at the bottom and extreme sanction at the tip of the pyramid.

Claimed effectiveness disputed: The report compares this with other countries admitting that there is little data and finally concludes that “Australia is far from a poor performer” and “aligns well with some accepted best-practice regulatory principles” but thinks it can be strengthened.

These platitudes are not based on any evidence. When the performance of the accreditation in achieving 98% compliance is compared with the declining numbers of skilled staff in Australia a very different picture emerges. When our staffing levels are compared with carefully researched staffing requirements as well as actual staffing levels in the USA we find that our residents receive less than half the amount of skilled nursing and over an hour’s less total nursing care each day than in the USA. It may be that regulation in these other countries is equally poor.

It is clear that our regulatory system is either not detecting substandard care on a massive scale or else is simply not doing anything about it. The conclusions reached by the Carnell report are not valid. We need to confront and accept this and do something better.

The origins of responsive regulation: As we understand it this approach had its origins in Braithwaite’s observation of the way individual regulators in both the USA and the UK were able to make poorly structured and ineffective regulation work through their interaction with managers and staff in the facilities – in effect using these positive and negative strategies.

There is nothing unique in this. It is how we all behave as we interact. It is how we control and direct our children, how we educate, and how leaders emerge in projects and manage those they are working with. At one end we praise and reward good performance and at the other we criticize and finally ostracise those who behave badly.

Braithwaite was able to formalise this process in the regulation of aged care in Australia in the 1990s using a flexible and responsive investigative approach to explore performance and then responding. This was more effective than in the USA or the UK. But he realized that to be effective regulators had to visit more frequently and he started escalating the process.

Neoliberal thinking saw regulation as restrictive and something that should be reduced. This strategy angered the providers and in 1997 the Howard government abandoned this and adopted accreditation instead.

The resurrection of responsive regulation within the accreditation process is a new development but we feel that the context is inappropriate and as the staffing and performance levels show it quite clearly has not worked here.
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**Our criticisms of this:** We understand the principle here and why it worked in the 1990s but is being less successful now. There are vulnerabilities and a number of issues which we think our proposal will address.

1. The problem is a dysfunctional system driven by a dominant discourse that does not match the system and its requirements. Focusing only on regulation does not address the failed system itself. It is only a part of it. Systems are based on discourses (i.e., patterns of thought) and without attention to the problems in the discourse we will not change the system effectively.

2. Solid objective verifiable data is essential if we are to keep ourselves focused on the real world and prevent us from escaping into fantasy. The responsive regulation that has evolved is not based around accurate data. It is consequently at risk of escaping into fantasy and so lending itself to ritualization and tokenism.

   This is why the industry’s view of aged care and its performance is at variance with that of front line staff and many resident’s families. Our regulatory system, particularly accreditation has escaped the real world and wandered off into wishful fantasy as is revealed by comparing accreditation outcomes and staffing figures. While regulation has become lost in its fantasies, in the real world the rest of us live in people are suffering.

3. This regulatory system is still a fly in fly out system as it is not possible to be there often enough to maintain and reinforce the positive and negative incentives. This is where it came unstuck in the 1990s as it became a regular intrusion. It is easier to game the system when visits are infrequent.

4. It is a system of incentives and disincentives at relative arms-length from the day to day activities of life and so detached from its emotional and reflective content. It is a form of behaviourism and some of the same criticisms apply.

   In education we found that with behaviourism students focussed on attaining the rewards and avoiding the punishments instead of engaging with the material and its emotional content. They did not become involved or interested in what they were doing and lost their moral compass in their pursuit of rewards.

   They lost their humanity and critics described behaviourism as something that turned people into rats. If we look at the role that incentivisation played in some of the major health care frauds in the USA in the 1980s and 1990s we can see that this is what happened there.

5. The assessments are made by a narrow group of trained people whose perspectives dominate. It fails the distributive justice test and biases readily influence assessments and outcomes.

6. Even when it is effective in regulating offenders, it is less effective in influencing community attitudes by stigmatising offenders and so delegitimising what they have done.

   **Currently the ultimate sanction is closing the nursing home by removing funding. All residents are forced to leave, a very disruptive outcome which inhibits the use of this sanction so that it is seldom used.**
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**Our proposal:** In our proposal responsive regulation would be set within the community and in the nursing homes on a regular day to day basis. It would respond to these issues.

1. It would be part of the everyday and so not intrusive. It would be what people do naturally. It would ensure that the discourse of care was the dominant discourse and that the market discourse was subsidiary and accommodated to it. The very opposite to what occurs today and why the system has escaped into fantasy. It would address the dysfunction in the aged care system as well as in its regulation.

   The day to day process of responsive on site regulation would feed into external formal retributive justice by the courts or the government at the end of the sanctions pyramid and into public presentations and awards for excellence at the supportive pyramid.

2. The collection of objective as well as subjective data would be within the context of the whole service and it would inform and constrain regulatory effort keeping it on track.

3. The assessments would be made during day to day interaction in facing and dealing with people and their problems. They would be continuously reinforced and gaming would be impossible.

4. Incentives and disincentives would be in context and in response to the every-day life of emotions and reflective thinking. They would be tied to and subservient to our humanity which would be fostered and supported. Caring relationships and cultures would be facilitated.

5. Assessors would be drawn from the diversity of the community (many perspectives) but would be supported and mentored by government regulators. It would meet the requirements for distributive justice. It is outsiders who see differently. They are most likely to detect system problems.

6. Instead of removing funding and so closing a facility it would be preferable to bring in a reputable provider to operate the facility so that the lives of residents and employees are not disrupted. This ultimate sanction can now be used more often.

4.3.23 **Conclusion**

*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.

The report concludes that “We believe that implementation of the recommendations of this Review will help prevent a repeat of the regulatory failures that occurred at Oakden with such tragic consequences”.

But it is not only Oakden where this system has failed. It has been failing for years and at the root of the problem is a ‘belief’ in something that is built on beliefs that are not soundly based. Beliefs and our inability to challenge them lie at the root of the problems in aged care, in its regulation and in this report.

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Instead of belief we need accurate data. We need an understanding of our past to see what it can tell us about the history of aged care, where we have gone wrong and why -- with a ‘deep exploration’ of both. We need an understanding of ‘human behaviour and how social structures are likely to influence it’. And in doing so we must be constantly aware of the existential dimension of belief and the problems this creates for us.

This report documents the failures in the system but is based on limited data and it fails to explore the history of regulation within its social contexts. It does not for instance address the issues that are excluded from serious consideration by the neoliberal discourse.

Criticism of the recommendations

4.3.24 The recommendations are not soundly based

The report sets out a number of guiding principles about consumer’s rights, effective regulation and remediation, comparable information, culture change and rewards for excellence. (P75) but these are not congruent with the sort of market system and regulatory oversight that we have so will be difficult if not impossible to impose. In this sort of system, they will become tokenistic.

The recipe offered on page 75 is:

1. Integration by centralising: It sets out key elements and the first of these is integration and it does this by centralisation. But centralisation with a top/down system of management increases control and so inhibits diversity and change. It tightens the grip of a dysfunctional discourse and protects industry and providers. It will only compound our problems. This is a long way away from where care is provided and it is easy to escape into illusion.

2. Informing consumers and supporting them: This is a complex system serving stressed and vulnerable people and a distant web site is not the answer. The market itself is conflicted by its own interests and deceived by its own public relations and branding.

3. Effective accreditation and compliance monitoring: Once a year fly in and fly out visits cannot be effective and it is abundantly clear that they have been failing for 20 years.

4. Enhancing complaints handling: But someone who is not there and arrives long after the event is incapable of doing this effectively

Stating the obvious: Aged care is provided in the community and that is where the problems are. We advocate integration locally with a bottom up system so that we get a diverse and informed discourse informed by actual life in nursing homes and the community.

Policy will be pinned to the real world of care and cannot escape into fantasy. Informing, assisting, advising, supporting, compliance monitoring and complaints handling can only be done effectively locally close to and in regular contact with the care being given.
The recommendations are:

**Recommendation 1:** Establish an independent Aged Care Quality and Safety Commission to centralise accreditation, compliance and complaints handling.\(^{60}\)

**Reasons offered:** Addressing complexity in administration and implementation, and in-effective data capture and sharing.

**Pluses:** A way of integrating central bureaucracy which could be useful and of bringing all the data together in one place which is valuable. A consumers commissioner, but drawn from the community and not appointed by government would be useful but is not a solution.

**Criticism:** Government will appoint the commissioners. This will allow individual regulatory arms to be tightly controlled by government/industry. They will still be captured and could be more effectively prevented from taking appropriate action when this will cause embarrassment. This will have little positive impact on what happens at the bedside and would continue to impede the provision of good care.

**Alternative:** Restructuring central administration to make it more effective is not problematic but this is not a substitute for local community empowerment and integration, which are not recommended by this report. The role of central bureaucracy should be to support and empower local communities so that they can effectively manage their own affairs and independently advise bureaucracy. A national coordinating body drawn from and representing the community would have central representation. Clinical representatives from the caring professions would play an important role locally and have central representation.

**Recommendation 2:** The Aged Care Commission will develop and manage a centralised database for real-time information sharing.\(^{61}\)

**Reasons offered:** Existing data currently in silos. This will be integrated. The lack of communication and sharing of information between regulators will be addressed. Academics will have the data needed to evaluate regulatory performance.

**Pluses:** Any move to collect data and make it transparently available is welcomed.

**Criticism:** The report claims that “the capture, management and publication of data is a core theme of this Report” (P88) yet much of this data, particularly the critically important objective data about failures in care will be self-reported. Centralised data is easily controlled and manipulated. Transparency in the collection of data, in its evaluation and in its reporting is not assured and is limited to regulatory performance in the report. This limits the capacity of academics to study the sector and the community to engage with and influence policy.

Data collection will still depend on the integrity of competing providers as for example “Providers should be required to update information on key risk indicators”. (P90) Verification of self-reported data is not addressed. Data management is all central whereas the maximum benefit from any data in a marketplace should be its immediate local availability and relevance.

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**Alternative:** While central databases would be maintained and are needed for developing policy, data would be transparently collected locally, verified and then used to directly and immediately address issues with management as well as to inform prospective residents and report to their communities.

Oversight by empowered local visitors will be regular and ongoing with support readily available. Support and local oversight would be strengthened in high risk facilities and when changes in management or staffing occur. Emerging risks would be recognised early. The responses would be immediate.

The problems in a lack of integration between state and government regulators would be eliminated as it would all be done and integrated locally then analysed and reported centrally by a body drawn from the community and so readily available to all federal and state agencies dealing with that facility or company. The assessment and interpretation of data would be directed towards the needs of community rather than provider and government but be transparently verifiable by both.

“Private and state-based health professionals” would be directly involved and be dealing with local regulators so that issues would be dealt with immediately and directly and not through a distant process driven bureaucracy.

The views of staff, residents and families would be constantly fed into the system and formal reviews of community views would be independently managed by the community. They would be assessed against and integrated with objective data.

Research on effectiveness based on properly verified centralized data will be supplemented by local research. There would be local groups willing to cooperate with academics, participate in local research and collect the more specifically focused data needed for this.

All of the actions on Page 92 of the report would be facilitated, be more accurate and result in more effective and more rapid action than in the model proposed in this report.

**Recommendation 3:** All residential aged care services in receipt of Commonwealth funding must participate in the National Quality Indicators Program.  

**Reasons offered:** Objective measures of care and quality of life.

**Pluses:** Does focus on easily identifiable measures of care and this is important. It finally acknowledges that “Objective measures of care quality in Australian nursing homes are lacking” (P93)

**Risks:** In a competitive market self-reported data is notoriously unreliable. It needs to be verifiable. A focus on Quality Indicators in a competitive environment causes providers to focus all their attention on the indicators so that less easily measured items are neglected causing harm. These risks are not adequately addressed by the proposals.

Also worrying is the focus on “consumer expectations of care would drive quality improvement, enabling a commensurate relaxation of regulation”. (P93) This is a reflection of the marketplace discourse adopted by the reviewers and not the discourse of care. What is needed is effective regulation which does not equate with less regulation. What we propose is more but less intrusive regulation which is what is required.

‘Consumer Expectations’ as a driving force are potentially hazardous because, as discussed earlier, ‘consumer expectations’ are readily manipulated by authority figures, advertising and branding so that situations readily arise where it can compromise ‘improvements in care’.

It does not necessarily reflect what is in ‘consumers’ best interests. It does not lead to ownership and so engagement in the care that is being given. This is what leads to knowledge and insight.

Consumer expectations need to be examined in the context of objective data as well as the knowledge and experience of independent clinically and socially knowledgeable community visitors to the facilities. Debate between the two is needed locally so that the ‘communities’ of which the consumers are a part are more informed and their ‘expectations’ more soundly based.

The report acknowledges a pressure to focus on “process-based quality indicators because they are comparatively easy to measure” rather than objective data, and that “subjective aspects” are overlooked. The review of the problems in using quality indicators on pages 97 to 100 is good but the glaring examples of failures of Quality Indicators and star ratings due to deceptive self-reporting are not mentioned.

**Alternative:** In our proposal QI’s would be verified and they would be assessed locally within a broad framework where multiple other observations would provide a context where they would be only a part of the assessment. Community and so consumers would own the care given in their communities and their expectations would be informed by their knowledge and experience in doing this.

Both objective and subjective data would be collected and integrated. It would be managed by a central community representative body. It would address the many problems documented by the report more effectively. As revealed in the USA the benefits of centralised Quality Indicators and Star ratings have been mixed.

We think it likely that the collection of relevant data locally and its immediate use in remedial oversight and in advising potential residents would accomplish all this more effectively and with less cost, less hype and less confusion. It would make the market work for residents.

**Recommendation 4:** The Aged Care Commission will implement a star-rated system for public reporting of provider performance.

**Reasons offered:** Would provide a simple graded system for assessing performance.

**Pluses:** Commendable for helping to compare facilities and addresses the problem that the Quality Agency reports do not “enable consumers to easily compare the quality of residential aged care services”.  (P101)

**Risks:** Not always accurate and need careful verification. They are to be based on the flawed Quality Agency reviews that are wrongly describes as “extensive data captured through accreditation audits and consumer feedback” (P103). This is the data that allowed the Agency to accredit 98% of nursing homes. The adage garbage in then garbage out applies. They should also not depend on the flawed MyAgedCare website. While data collection and transparency has improved care and staffing in the USA, this has not been uniform. Large numbers of providers still attract customers and prosper even when their star ratings are low.

**Alternative:** A scale of performance is essential. With our model the data would be collected and verified locally and used locally by the community in advising its members as well as feeding into a central database where it would be analysed and used for policy, planning and rating.

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**Recommendation 5:** The Aged Care Commission will support consumers and their representatives to exercise their rights.  

**Reasons offered:** Consumers do not know their rights and “more needs to be done to empower consumers and their representatives”. There is a “culture of ‘provider knows best’”. P(105)

**Pluses:** Protecting consumer’s rights is important - but what is recommended is not an improvement.

**Risks:** It is the providers that consumers need protection from. Provider’s survival in this marketplace ensures that they are more interested in protecting their own rights and the opportunities for them than in the rights of ‘consumers’.

Requiring “providers to inform consumers” (P107) and so putting them in charge of education and requiring their staff to do this is putting the vampire in charge of the blood bank. The aged care commission is also too far away to be effective.

**Alternative:** In our proposal the community would be responsible for informing and supporting their members in exercising their rights. They would be the ‘come to’ people and would be continuously informing and supporting. Families would be guided into arbitration or if necessary legal action if they are entitled to compensation. The aged care commission would provide support.

In this and our previous submission as well as in other submissions we have argued that we do not as the report claims have a “relatively effective individual advocacy system, operating under the National Aged Care Advocacy Program”. (P107” As the Adelaide hearing revealed it failed totally at Oakden, as it has on multiple other occasions.

An organisation drawn from community organisations would be a much more independent and useful advocate on behalf of the community and consumers than what is proposed in the report.

**Recommendation 6:** Enact a serious incident response scheme (SIRS) for aged care.  

**Reasons offered:** “The Aged Care Act is a weak framework for promoting the rights of older people”. (P111) The current system “does not adequately protect the residents of aged care homes from abuse and neglect”, the accreditation system does “not appear to be sufficiently robust” and compulsory reporting is “of limited value in improving the safety of residents”. (P111)

**Pluses:** Incidents need to be investigated and reported

**Risks:** The proposals depend on the goodwill of providers who have ample opportunity to cover their tracks. ‘Educating’ is not very effective without engagement and involvement. This is simply more of the same.

**Alternative:** In our proposal a local organization as the primary regulator will own the process and be motivated. When incidents occur it will be involved at a very early stage in investigating, working with the provider, collecting data and in remediation so ensuring transparency throughout. Lesser incidents will be noted and dealt with in a day-by-day manner. More serious incidents will be detected and reported.

When this is necessary data would have been protected and their investigation would be supported with inside knowledge. The community will follow through on any action and in advising on remediation, resolution, arbitration and litigation when indicated.

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**Recommendation 7: Aged care standards will limit the use of restrictive practices in residential aged care.**

**Reasons offered:** To “significantly reduce the use of all restrictive practices” realising that this often occurred “when aged care facilities are understaffed”. The report acknowledges that probably “up to one third of residents are prescribed antipsychotics” but that this is not regulated or monitored.

**Pluses:** Clearly all desirable

**Risks:** Non-compliance.

**Alternative:** In our proposal local participants would be active in ensuring that staffing was adequate. They would know what was happening in the nursing homes and would ensure that restrictive practices were rarely used much more effectively that what is proposed here.

**Recommendation 8: Ongoing accreditation, with unannounced visits, to assure safety and quality of residential aged care.**

**Reasons offered:** To “improve the effectiveness of accreditation and compliance monitoring”. In a strange feat of intuitive logic, the report is still wanting to make this a “truly consumer-driven model” in spite of the fact that “53 per cent of people” in nursing homes have dementia.

**Pluses:** Better than before but does not address the problems. As the Nous report found it is only after someone local has complained or blown the whistle that problems are usually detected. Review audits were effective if infrequently used (13 in 2015/16). Only a few were triggered by unannounced visits. There is not much evidence of regulatory will in the Agency, the complaints system or the department.

The report acknowledges that with less than 3% moving out of a nursing home “statistics do not point to a market in which consumer choice flourishes”. This statistic reveals what it is like to be old and the need for stability over choice. All the hype about choice is simply a way of selling the government’s ideology to families and community.

**Risks:** This does not address any of the underlying problems in the regulatory process and accreditation. It is common knowledge that while visits are unannounced they are seldom unexpected and unprepared for. The focus on unannounced visits has already been tried and failed. Braithwate noted that a “new waves of nursing home scandals at the end of the 1990s and in 2006”, as well as criticism of accreditation saw “more funding devoted to more frequent in-between visits”.

The worry is that this proposal does little more than relieve the industry of the burden of regular site visits. Although these unannounced visits will be longer and more like review audits this might not improve oversight much. The Nous report shows that the high percentage of non-compliance identified by unannounced review audits (50 to 80%) was because they were a response to information. They had already been told that there were problems and what they were.

**Alternative:** In our proposal the Quality Agency would be a training and support organisation only. Its regulatory role would be removed. It would be working with industry so capture would not be a problem. Its success in improving performance would no longer conflict with its regulatory role, and would be assessed by and so based on independent assessments done locally.

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Oversight and regulation would be local and ongoing but supported and mentored by a central regulator who would visit regularly to support and verify accuracy and consistency, or investigate when further action was needed. Risk assessment would be local and ongoing. Instead of occasional announced visits oversight would be ongoing and participatory so more effective in building “a constructive working relationship” and “a responsive regulatory approach”. (P131) In depth external reviews would be a response to identified problems.

Recommendation 9: Ensure that assessment against Standards is consistent, objective and reflective of current expectations of care.  

Reasons offered: Address the long standing problem of lack of consistency in assessments. There is no evidence for the wishful platitude “Most of the time, most providers are doing the right thing and doing it competently”. The declining levels of skilled staff across a sector where acuity is increasing suggest otherwise.

The report deviates from its insistence that “consumer expectations of care would drive quality improvement”. It insists that “the non-clinical aspects of standards and assessment are critical and need to be given greater prominence” (P134) while acknowledging that “dissatisfaction with clinical care, -- -, remains the top source of complaints”. Both are clearly important but clinical care is what everything else builds on and this is clearly most deficient. With so few nurses this is not surprising. It remains the primary problem.

Risks: Is largely more of the same which has been ineffective.

Alternative: Under our proposal assessment would be ongoing and local with a central regulator mentoring and ensuring accuracy and consistency. The response to any problems would be immediate. Community and its consumers would not only be engaged, they would be empowered and in a position to insist on getting what they need. Clinicians would be engaged and constantly focused on governance and clinical processes.

Recommendation 10: Enhance complaints handling

Reasons offered: Improving “a key mechanism for ensuring the voices of consumers and their representatives are heard, and for identifying and remediying care problems”.

Risks: More wishful thinking. For example, the 10% increased incidence in complaints is far more likely to reflect more failures in care and poor staffing than “greater awareness of the Complaints Commissioner’s role” as suggested in the report.

Pluses: None as the problems are not addressed

Alternative: Complaints would be handled immediately locally by collecting information and addressing them with the provider so resolution would be prompt. The central organization would mentor and consult only stepping in when needed.

The problems of lack of information, unfamiliarity and “being daunted by the process of making a complaint”, the power imbalance in seeking local resolution, bureaucratic red tape, fear of and actual reprisals, cultural inhibitions, unresponsiveness of providers, lack of public confidence, transparency, prompt and effective feedback to complainant, advocacy when needed, empowering
visitors and many more issues would all be more effectively addressed by an often on-site local community support and investigative community run organisation.

**In regard to the processes suggested by the review.** Our suggestions would be more effective in “immediate detection, and swift remediation” than the improvements suggested by this report.

### 4.4 Responses to the Carnell/Paterson review

**Government’s response:** The minister has agreed to implement recommendation 8 (unannounced visits) and will “work with stakeholders to finalise the details of the new assessment regime as it also weighs further legislative changes”.

**Industry response:** The industry’s response insists that Oakden is unique, operated by government and not representative of the care in the sector. A press release indicated that it was “not the Accreditation Principles or processes per se, but rather inadequacies in their application by the agencies involved” and that “it was comforting to know that the vast majority were receiving high quality care - - (meeting) - - the most stringent national standards”.

An article in the LASA magazine ‘Fusion’ is critical and they clearly do not want even this change. They insist that the current ‘reform agenda’ including the Aged Care Roadmap and the Single Quality Framework that the industry has developed with government not be disrupted.

We wonder whether the decision by the Minister for Health to call another parliamentary inquiry into “mistreatment” and to see whether regulation is “ensuring adequate consumer protection” is because of the unhappiness of multiple parties and/or their constituents on both sides of the aged care debate.

If any long term progress is to be made, then there is a real need to address and resolve the differences between the industry and its critics and that has to be an open process.

We worry that without accurate data collection in aged care, the ‘no evidence that’ argument might prove persuasive. The reviewers may not fully understand that this is the result of failure – the failure to collect data for fear of what it is likely to show.

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71 ‘Relentless’ spot checks for aged care facilities under Turnbull government plan - Sydney Morning Herald, 25 Oct 2017  
http://bit.ly/2qISikk

72 LASA responds to the Carnell Paterson Report - Media Release, 12 December 2017  
http://bit.ly/2D02Kcj

Recommendations on aged care accreditation processes signal potential change. LASA Fusion Summer, 11 Dec 2017  
https://issuu.com/adbourne/docs/lasa_summer_17_issuu_opt

73 Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia (Standing Committee on Health, Aged Care and Sport) (announced 7 Dec 2017, submissions close: 8 Feb 2018)  
https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/AgedCareFacilities
Part 5: The journey - submissions made by Aged Care Crisis

Background
In late 2017 after we had submitted our submission to the senate we decided to describe Aged Care Crisis journey from a gut response calling for more regulation to what it saw happening in aged care, through a process of reflection when more regulation did not work, to a more careful and considered study of what was happening in this system. We are finally asking what should logically be done about this and making suggestions for changes that might work.

Over the years we have watched each new generation of advocates go through this same process and most of them have disappeared after the gut response period. As a consequence, every new review or inquiry is flooded with gut response submissions and understandably the reviewers, who themselves are new to this, respond to these by trying to make what we do better. This has impeded a proper analysis of the processes at work and whether they need changing. At no stage have we managed to form a plan for collecting data on which to base analyses and decisions. Ideology has not been challenged. The reforms have turned out to be no more than temporary patches. We felt that it was worthwhile bringing this issue to politician’s attention.

Our plans were delayed because of we became involved in meetings with industry and the workforce taskforce so that we have struggled to properly review the reports that came out as well as the hearing in Adelaide which we felt was particularly revealing. This has taken us much longer than anticipated.

We have included the story of our evolving insights in this analysis and hope that this material is useful to those doing inquiries and reviews.

But before looking at where we have come from we summarise our response to the terms of reference of the two major public inquiries and outline the thrust of our arguments in those submissions. This shows where our journey has taken us.

5.1 Introduction: The terms of reference of the senate inquiry

a. 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;

b. the adequacy and effectiveness of complaints handling processes at a state and federal level, including consumer awareness and appropriate use of the available complaints mechanisms;

Three factors have been central concerns of ours over the years. We addressed these (terms of reference a and b) in our 2017 senate submission focusing on:

1. A flawed system: The negative impact of the competitive pressures and the drive for financial efficiency on the staffing so essential for care. The problem is that resources are rationed to boost or maintain profit and growth rather than give needed care. When disempowered customers and a disengaged community are confronted by aggressively competitive but powerful businessmen, market failure is almost inevitable leading to disillusionment and unhappiness among staff and families.

74 Aged Care Crisis - main submission: http://bit.ly/2A4Uu6x
Part 5: The journey - submissions made by Aged Care Crisis

We have developed a system that is constantly driven towards mediocrity and failures in care. This is in spite of the efforts of those who are strongly motivated. Some have tried and, when they dared, spoken out. With these forces at work good care depends on the effectiveness of regulation.

A system that depends on regulation if it is to work is not fit for purpose and when that regulation is ineffective then failure is almost inevitable.

2. **Ineffective regulation**: A fundamentally flawed regulatory system designed by the industry and its supporters has been hopelessly inadequate and poorly designed. It depends on an industry friendly accreditation process and a complaints system far removed from the bedside. Both have failed repeatedly over the years. Changes have been ineffective because the thinking behind them is flawed.

3. **Power imbalances**: The power imbalances between management and staff, and between both groups and residents.

In regard to the remaining terms of reference there is less information. We consider that the following factors are likely to be important:

c. concerns regarding standards of care reported to aged care providers and government agencies by staff and contract workers, medical officers, volunteers, family members and other healthcare or aged care providers receiving transferred patients, and the adequacy of responses and feedback arrangements;

**Hospitals and other referral sources**: We have some direct experience of a measure of ageism in hospitals. The focus is on the young and when the benefit of lives saved is measured in years of future life then in a stressed system rationing operates.

When the elderly are admitted without sufficient clinical and other background information it can be difficult for the hospital to determine what happened and whether it was negligent. There is a natural reluctance to start making trouble for others. They leave it to the families who can be too frightened to act.

While it is not directly related to the terms of reference an interesting paper by Kendall and Reid explores the problems for the elderly in our acute hospital system from an ethical and equity perspective. It examines some of the difficulties created by the neoliberal agenda that impact negatively on their care, when care is used in a broad sense of person-centred, relationships, dignity, control and choice. They look at the difficulties this creates for patients who are being transferred to nursing homes and their loss of autonomy during the entire process.

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78 Kendall S and Reid E. Person-centred acute hospital care for older people transitioning to residential aged care - whose needs are being met? Ethics and social welfare, 2016: [http://dx.doi.org/10.1080/17496535.2016.1266371](http://dx.doi.org/10.1080/17496535.2016.1266371)
Part 5: The journey - submissions made by Aged Care Crisis

d.  the adequacy of medication handling practices and drug administration methods specific to aged care delivered at Oakden;

e.  the adequacy of injury prevention, monitoring and reporting mechanisms and the need for mandatory reporting and data collection for serious injury and mortality incidents;

d and e  Medication issues as well as injury prevention: These are issues that are closely tied to poor staffing. Nurses are simply unable to meet the needs of residents in spite of extreme effort. The failure to record or report them may be due to loyalty or to the fear of losing employment. Families appreciate this and know that their complaints will get those they depend on and who have tried so hard into trouble.

f.  the division of responsibility and accountability between residents (and their families), agency and permanent staff, aged care providers, and the state and the federal governments for reporting on and acting on adverse incidents;

f.  Divisions of responsibility: We have a fragmented system, driven by powerful forces that have nothing to do with care. At the heart of the service is a conflict between market forces and care which few are prepared to confront. This makes effective discourse to address the issues impossible. There are major differences in power, in knowledge and in confidence. There is little transparency and no shared data. It is not a system where people are able to work together efficiently and comfortably. Without data, power and a measure of control staff and families feel disempowered. They struggle to be heard. Even with the best of intentions they struggle to contribute. What we propose puts a community organisation in the driving seat. It is active integration here that will hold the different providers to account and ensure they work together.

The thrust of the submission

The submission draws attention to system issues and explores them in Appendices. The body of the submission addresses the staffing problem and the issue of data before moving on to an in depth analysis of the history and problems of regulation in Australia broadly and them specifically looking at accreditation, complaints, government regulation and the exclusion of advocacy and the visitors scheme. It describes Braithwaite’s study of and strong criticisms of Australian aged care regulation in 2007 and shows that these criticisms still apply and that his warnings were ignored. It proposes and describes a Community based approach to resolving the many problems identified.
5.2 Introduction: The terms of reference for the Standing Committee on Health, Aged Care and Sport inquiry into the Quality of Care in Residential Aged Care Facilities in Australia.

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;

There is no data about the care given. That suboptimal care is widespread is revealed by the comments of poor care from staff and families. This is confirmed by the revelation of that staffing levels and skills are so deficient that good care is not possible in many facilities.

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;

While regulatory success is rising the staffing data and the increasing acuity show that care is actually deteriorating. The agency’s own data reveals its ineffectiveness. It is concluded that the regulation has been effective in protecting government and industry from embarrassment, in brand generation and in countering critics of the system.

government policy

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.

Without data no firm conclusions can be reached but without a family to protect them they are at greater risk in a predatory market system

The thrust of the submission

The submission documents the extensive criticism of the system by staff and families then uses staffing and Quality Agency data to confirm that poor care is widespread and that the regulatory system is ineffective. Criticism by staff confirms this. It describes the lack of clinical knowledge at the management and policy levels of the system including its regulators, and the consequent failure to address clinical considerations and the welfare of the consumers.

The submission explores the reasons data is not collected and the way financial data is collected instead. While financial success has become a token for good care it is associated with poor care. It explores the role that the neoliberal discourse on which policies are based plays in this and its inapplicability in the sector. Many warnings were ignored. We recommend a community based approach to addressing the problems revealed

The submission expands on these issues in appendices and also performs an in depth analysis of the social and psychological processes that make us vulnerable to belief systems that are harmful and the strategies we use to shield ourselves from these harmful consequences.
A system designed to fail

Aged Care Crisis (ACC) is very critical of the geographically centralised highly bureaucratised and process driven way in which aged care is managed and provided.

It is an extreme example of the flaws in the neoliberal managerial approach. A major consequence of this is the fragmentation of the entire process leading to multiple silos each of which is able to address only a limited part of the system so that the whole is lost in the minutiae. Bizarrely, financing the system is separated from the assessment of the care, which is being paid for.

The effectiveness of this care is not measured by a system that claims efficiency as a primary virtue. As a consequence, the drive for efficiency focuses on finance and the consequences for care go unnoticed.

Each central financing, managing or multiple regulating silo can be manipulated by political or other interests more easily than the whole. It is easy for interest groups to divide and conquer. It leads to a process driven system that is impersonal, lacks humanity, is easily manipulated, can be rorted, and where people fall through the cracks. Silliness from one silo is not countered by the experience of others and the common sense of the whole.

Those to whom the service is provided are far away and despite tokenistic ‘consultations’ have little real input. The whole process is undermined by a lack of accurate data, lack of transparency, personalities, and the power disparities between the silos involved and the community served.

Responding to the problems in the system

Aged Care Crisis has been pressing for changes that would integrate these multiple processes so that they complement, reinforce and when needed, constrain one another. It argues that this integration should be local and close to the care being provided and be closely tied to the collection of data. This is essential if the process is to be pinned to the real world and not allowed to escape into fantasy and the illusions created by political ideology.

By addressing the power and information imbalance and by making the various groups including an empowered community interdependent we create a context where they have to engage in discourse around the issues of care. This approach ensures that ill-suited beliefs and policies are challenged debated and resolved. All are forced to examine their own beliefs and when needed construct more appropriate alternatives. This approach is based on insights from the Sociology of Knowledge, a discipline that studies the way ideas and understandings are developed within society.

Pressing for a solution

ACC has been making submissions to the many different reviews, consultations, summits and inquiries, each addressing one of the silos, pressing across all of them for an integrated system. The problem is that each of these processes has terms of reference that prevent them from addressing the whole.

We hope that this these two inquiries will have the breadth to look more broadly at the aged care system and make recommendations that address this underlying problem. To this end we describe our efforts below and link to a number of representative submissions. We hope that an understanding of what has happened in the past will prevent your committee from making the same mistakes and will give them the courage to think differently.
Part 5: The journey - submissions made by Aged Care Crisis

We are looking at a broad approach and the suggestions we make are intended as examples of what might be done. They are not prescriptive nor are we claiming this as a cure all. It will have its own problems but it will be better equipped to deal with them.

The intention is to create an aged care system which is responsive and flexible and on which a more effective system can be built. Our focus is on social responsibility and responsible citizenship and our criticism of politics is that it has abandoned both. Our suggestions are submitted as options for debate.

5.3 Background of proposals for change

5.3.1 Community group dynamics
Aged Care Crisis (ACC) has been in existence for nearly two decades now, but some of those who later became members had already been involved in studying health and aged care and had been writing about it. We have observed a pattern of response to failures in health and aged care in ourselves. We have watched subsequent community organisations follow the same general pattern. They go down this path for varying distances before giving up.

The first step is often precipitated by a painful personal experience, followed by the realisation that similar failures are widespread. This in turn is followed by a desire to protect others in the future.

The next step is usually to identify that the regulatory system is not working when they encounter difficulty, even resistance, when trying to use it. Groups then form to progress the issues.

The first and sometimes the only gut response has been to call for more stringent regulation without considering the underlying reasons for the failures in care and the failure of regulators to address them. This is as far as many go before giving up.

Community movements do form and exert strong pressure on government for more regulation or for a specific change. Even when successful, they fail to address the underlying problems, which manifest again elsewhere with more failures in 5 to 10 years.

5.3.2 Confronting system dysfunction
Failed systems are based on paradigms or discourses which those involved come to believe in. It is particularly difficult for those, who have adopted paradigms or ideological beliefs and then used them to build their own successful lives, to accept that these beliefs are not universal truths and that they are not universally applicable to every sector of our complex societies.

Logic and belief: Without any training in logic they fail to understand the importance of category errors and that the theoretical ideas we generate and that work for us are bounded by “necessary conditions”. They will not operate successfully in sectors where these conditions are not met. Because they have worked in an area where they have experience they expect them to work everywhere.

Because politicians embrace paradigms or discourses, which become policy, they are particularly prone to apply these indiscriminately and to be resistant to accepting that these policies are not based on universal truths and are not universally applicable.

Individuals: This is readily apparent when those who live within the neoliberal market paradigm encounter failures in a system either through personal experience or through public advocacy. We regularly see them on television or social media calling for changes that would make health and aged care more market-like, claiming the market would fix the problems.
**Part 5: The journey - submissions made by Aged Care Crisis**

**A tautology:** As Robert Kuttner indicated in 2001⁷⁹ this is a tautology grounded in the belief in markets. If the market will fix everything then failure can only be because it is not sufficiently market-like. Making it a more perfect market is used to fix the failing market. Obviously when the market itself is the problem making it more market-like will simply compound the problems and make them worse.

Even the limited evidence available reveals that this is the story of health and aged care in the USA and of aged care in Australia. The *Aged Care Roadmap* currently being marketed to the public like candy is a classic demonstration of the process that Kuttner described.

It takes long experience and analysis before most who see problems are ready to confront the prevailing beliefs and the dogma of our societies and even longer before society itself does so. Those who have had past experience of ideologies more readily see what is happening and start looking for a way of addressing the problems and finding something better.

Ideas and criticisms that challenge dogma are often not seen as credible and are ignored until society is overwhelmed by tragedy. The critic is discredited in order to evade the arguments.

One of us went through the process described here in the 1990s and by 2000 was writing about the conflicting paradigms in the sector and suggesting a way forward⁸⁰. The importance of wide debate and of embracing the community was recognised – even elements of what is now called participatory democracy can be seen in this.

In a criticism of the accreditation process⁸¹ in 2006 following the rape and other scandals in which the Agency had failed, he wrote:

> "... It should be obvious by now that I favour the development and exploration of a community driven and focused paradigm within which to cautiously develop a new community system for vulnerable services - one in which people can ‘realise themselves’ and act out their lives in a more diverse and humanitarian manner ...""

He wrote about the importance of congruence between the values and norms of the community and the regulations that give form and structure to these values in social systems that work for citizens.

In the same year he wrote:⁸²

> "... My own view is that whatever system we have, communities should play a pivotal role in running and overseeing the operation of nursing homes in their community. Neither politicians nor market moguls can be trusted to deliver the care the community expects.

The community needs to place itself in a position where it has the muscle to ensure that funding is fair in the light of what the country can afford and what the community is prepared to contribute.

It also needs to be in a position where it not only knows but sees what is happening in the local nursing homes so that it can balance funding and care. **Organisational structures in the community are needed to accomplish this ...**"

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5.4 Submissions made by Aged Care Crisis and its members

Either individually or as a body, Aged Care Crisis has made in excess of 40 submissions to various aged care related inquiries, consultations and reviews since 2004. These can be downloaded from our publications page where there are also links to the final reports of the processes\(^83\). These reflect our own move away from political solutions and government regulation towards pressing for a context in aged care where empowered community discourse can drive the sort of paradigms that will lead to needed change and effective policy.

We write about and provide links to some of these submissions because they illustrate the repeated failure of the system over many years. We identified the same failures in the system and in its regulation 12 years ago as we write about today.

Since then our analysis and our recommendations have changed becoming deeper and more analytical. We now focus on the reasons why, even when repeatedly faced by failures, the system has been unable to confront its failures and been so resistant to the changes that are required.

In spite of the exposures at Oakden and multiple other facilities recently the family of believers is still controlling the inquiries and then meeting to regroup and implement the flawed Aged Care Roadmap. We gave an example of this in Appendix 5 of our 2017 submission to the senate Inquiry.

In this submission we use our past submissions to emphasise and explain the failure of multiple inquiries and reviews, and the unwillingness of industry and politicians to address fundamental issues in policy.

5.4.1 Early submissions: 2004 to 2008

During this period ACC became aware of the many problems and made submissions describing them and making suggestions for change. At this stage we still expected government or some other group to do something about this.

2005: Senate Inquiry into Quality and Equity in Aged Care

This was a senate inquiry in response to a bland self-congratulatory government report “Future Ageing”. It received large numbers of critical submissions\(^84\). It drew attention to the parlous state of nursing in aged care and the adverse effect this was having on care. It emphasised the shortage of doctors and other health care workers in the sector.

Geriatricians felt marginalised and discouraged. The inquiry was very critical about the accreditation process and the (then) Accreditation Agency. It quoted a nursing association claim that the process was a farce.

The Committee questioned the effectiveness of accreditation and made many criticisms of the process, concluding that it was not effective. It was very critical of the complaints mechanism finding multiple deficiencies. It documented the fear of intimidation felt by those who complained and recommended whistleblower legislation to protect them.

\(^{83}\) Publications Aged Care Crisis Aged Care Crisis [https://www.agedcarecrisis.com/publications](https://www.agedcarecrisis.com/publications)

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This was a landmark review because it identified the many problems that still exist today. Instead of addressing the issues, the government of the day attacked the report. They claimed that they were already addressing all of the issues.

The core problems were ignored and nothing effective was done by this government nor by the Labor government that replaced them in 2007. This would have meant confronting core beliefs and policies that by then both parties had accepted.

ACC Submission: This was one of the first submissions made by ACC. It addressed the problems in the workforce and the inadequacies of staffing, accreditation, complaints, young people in nursing homes, home care programs, the problems for the elderly in hospitals and the difficulties in transferring between hospitals and nursing homes.

An appendix consisted of large numbers of quotes from feedback obtained from staff and families describing exactly what was happening in aged care. It made many recommendations in the naive belief that someone in power would find a way to do something about it, but that is how we thought at that time.

Link: Submission to Senate Inquiry into Quality and Equity in Aged Care 2005

2005: Elder Abuse Prevention Project in Victoria

ACC made a submission to this consultation process. It asserted that neglect of the aged was a form of elder abuse. It made some general recommendations about education, awareness and the strengthening of the response to elder abuse. It examined abuse within the aged care sector, describing the impact of poor staffing and the failure of the complaints and accreditation processes to address issues effectively. Once again, an appendix with extracts from the extensive feedback received at this time describes what was happening in the sector.

Our comments at that time in 2005, refer to exactly the same problems that still exist today – more than a decade later:

Why we exist

Our group seeks the urgent reform of many aspects of aged care. In particular:

• we ask that critical issues relating to the shortage, low morale and inadequate training of aged-care staff be addressed;
• we stress the need for a transparent and rigorous monitoring process which protects the safety and dignity of elderly, frail, and vulnerable people, who mostly cannot speak for themselves;
• we urge that consumers (residents, family members and carers) of the system have ready and complete access to information about the system, and the facility, to which they have entrusted the care of their loved one;
• we stress the need for a transparent and totally independent complaints collection and management process.

And further on in regard to the mediation of complaints:

**Mediation**

ACC notes the support expressed for mediation processes within the Consultation Paper. We, however, have grave concerns relating to mediation as a means of resolving issues between frail older people and other parties. The inequities in the power balance between the two negotiating parties are generally substantial.

It is difficult to see how such inequities could be overcome in order for meaningful mediation to occur. For example, the resources and power of an aged-care provider would normally be far greater than that of a frail, aged-care facility resident.

Others have said the same things on many occasions yet the system seems to be deaf to anything it would rather not hear. Twelve years later those who look and see what is happening see no improvement and in many instances deterioration as market pressures grow.

Aged Care Crisis has now moved on to studying why the system has been so resistant to evidence and logic. It now urges debate and advocates for a way out of the intractability of this problem.

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**2006/07: Inquiry into Older People and the Law by the House Standing Committee on Legal and Constitutional Affairs**

ACC members made two submissions to this inquiry, describing the problems here and making recommendations urging legislative change and protection for whistleblowers. Once again the problems were illustrated by quotes from the extensive feedback we were receiving.

Members from ACC gave evidence to this committee in 2007 indicating their concern:

> “... that the rights and entitlements of those vulnerable individuals who require those services should not be displaced, diluted or, indeed, seen as a secondary consideration to the primary demands and interests of the corporate sector and their shareholders …”

- We indicated that regulations do not “provide enough protection for those frail older people at the end of life.”
- In regard to staffing we indicated that “flexibility with staffing- - - is a dangerous policy and can lead to gross neglect of some residents” urging that “a safe, basic, minimum staff-resident ratio be set” because “The main place that you can cut costs is with staffing”. It was “the low level of staffing which concerns us most. This is a sector that requires good people to give good care”.
- In regard to regulation “the sanction system, we believe, is not working as well as it might”.
- Another new system for complaints had just been introduced and we hoped for change. We stressed the “reluctance by residents and families to use a complaints process” and described a resident who when she felt she “was being gagged she did not continue with the complaint”.
- We noted that “Residents and families often fear retribution”. Others “also find that the processes are too complex and some of the residents die before there is any resolution”.

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Part 5: The journey - submissions made by Aged Care Crisis

- We indicated that “there is a real need for a quick response. The complaints system that existed was anything but that”.

We addressed issues surrounding “the abuse of enduring powers of attorney and those sort of things”. These are still unresolved matters that the 2016/17 ALRC Inquiry into Elder Abuse has once again been examining.

The only thing that has changed in the 10 years since then is that the government has responded by making it more competitive and market like and this has made the system very much worse in all of the matters that we raised then.

Link: Submission to Inquiry into Older People and the Law  http://bit.ly/2Dly2rW

2007: Inquiry into Private Equity investment in Australia by the Standing Committee on Economics

This submission made 10 years ago draws attention to problems that had already developed in the health and aged care markets and the potential of private equity investment to make this much worse. It wrote about the consequences for communities and called for them to be consulted and involved. The arguments made by this and another submission by an academic from UTS, both warning of the consequences, were rejected by the committee but were prophetic. The first Private Equity scandals in aged care were exposed in the USA within 6 months and problems subsequently developed over the next 10 years in the UK and then in Australia88.

Link: Submission to Inquiry into Private Equity investment in Australia, Dr J M Wynne  http://bit.ly/2FdAYLm

2008: Inquiry into Aged Care Amendment Bill - October 2008

Two submissions were made to this senate review of proposed legislation. In these submissions we indicated deficiencies in the system and questioned whether this Bill would adequately address these issues.

Our focus was beginning to shift towards the importance of consumer groups and we recommended consultations with independent consumer groups and expressed our concern at the increased reliance on the market economy and the negative impact this had on staffing. We wrote about the need for transparency and for mandated staff/resident ratios.

We were concerned that probity was no longer required in aged care. We wrote about the strong influence that owners had on the services provided. We were concerned that ownership had been excluded from the approved provider process and that criminals could now buy and own aged care facilities provided the managers (“key personnel”) they appointed did not have a criminal history. One of our submissions was now pressing for greater community involvement and suggested moving both accreditation and complaints management into the community.

Dr J M Wynne  http://bit.ly/2oS1NKb

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5.4.2 Submissions: 2009 to 2017

By 2009 we were increasingly aware that expecting central government to take effective action was unrealistic. Not only were they trapped by their broad policies but also the structure of the system made this almost impossible. We started advocating and arguing for a community based and controlled aged care system and making suggestions about the sort of system that might work.

5.4.2.1 Regulatory and system problems

Submissions were made by ACC and individuals, into reviews of the accreditation process and then the complaints process both in 2009; and then to the 2010 Productivity Commission Inquiry “Caring for Older Australians”, which formed the basis of the so called “Living Longer Living Better” reforms.

In these submissions the problems were restated and proposals made to integrate these ineffective fragmented regulatory processes through local community based structures close to and in regular contact with aged care facilities.

A further submission was made in 2013 to a consultation paper on the streamlining of the Quality Reporting Programme. Most of these submissions addressed core problems and pressed for system changes that embraced the community.

2010/11: Productivity Commission’s Inquiry into aged care

In these submissions the problems were restated and proposals made to integrate these ineffective fragmented regulatory processes through local community based structures close to and in regular contact with aged care facilities.

- **Sub 433 from ACC** calls for transparency and accountability and then deals with problems in accreditation, complaints handling, fear of retribution, private equity, probity, accommodation bonds, staffing ,home care and retirement villages. It is still calling for government to act but supports more community participation.
  

- **Sub 368 personal submission by MW:** This submission does a detailed analysis if the history of aged care explaining where it went wrong. It proposes “giving local communities leverage by involving them” in many of the aged care management and regulatory activities and sets out a model for doing this.
  

- **subdr520 from ACC** Response to the draft report making the point that these recommendations would not improve the quality of care, It included the copy of a letter ACC sent arguing that by not gaining access to and using the recent 2009 review of the accreditation agency carried out by DOHA it was failing to address its terms of reference. We are aware that many critical submissions were made to this 2009 review. None were published and the report if any was buried – as if it had never happened.
  

- **subdr568.pdf from MW** Response to draft report. This indicates that consumer’s hopes have been dashed because this is a report on behalf of the providers and not customers and the necessary conditions for a market to work have not been met. The draft report made no attempt to give the vulnerable customer market power. The submission aims to be a “devils advocate by challenging the Commissioners’ thinking” and explaining the consequences.
  
Part 5: The journey - submissions made by Aged Care Crisis


A further submission was made in 2013 to a consultation paper on the streamlining of the *Quality Reporting Programme*. Most of these submissions addressed core problems and pressed for system changes that embraced the community.

**2013/14: Inquiry into Care and management of younger and older Australians living with dementia and psychiatric symptoms of dementia (BPSD)**

ACC made a submission addressing the conflicting roles of the Quality Agency and the problematic structure of the Complaints system. We stressed that our earlier proposals for supporting complainants at a local level had been ignored and that this would have addressed many of the problems.

We reiterated what we had previously said about staffing. Staffing is totally unregulated and the staffing and so the care provided depends on the beneficence of the business managers employed by the providers. Even if the customer understood the importance of this it would not help them because that information is not published by nursing homes.

> “... We draw attention to the current reliance on the market economy for the provision of care to a significant proportion of older Australians including those with dementia. This increasing dependence is creating serious problems within the sector. In particular, the pressures associated with cost cutting are driving many of those staff who seek to provide skilled, humanitarian and personal empathic care out of the sector.

> The current level of ownership of aged care facilities by private equity groups, their short term focus on profitability, and the distance of their decision making processes from the coalface is a matter of grave concern ...”

We stressed again that the care of vulnerable people is a community responsibility and expressed our concerns around the suitability of the regulatory framework.

In referring to the complaints system we said:

> “Not surprisingly, this unequal barrier—in which there is a gross imbalance in power, where victimisation is possible—has proved to be an effective barrier to lodging a complaint as well as resolution, leaving the disaffected even more disillusioned”.

In regard to accreditation and it’s ability to protect residents from abuse and poor practices, we indicated that:

> “The current accreditation system does not adequately measure the delivery of care to frail Australians in our aged-care homes. The agency concentrates on processes rather than on measurable adverse events. These often remain hidden”.

**Source:** transcript of our interview with the senate committee [http://bit.ly/1UxtdQj](http://bit.ly/1UxtdQj)

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89 Submission Community Affairs References Committee - 14/02/2014: Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia [http://bit.ly/2CZYqcT](http://bit.ly/2CZYqcT)
Part 5: The journey - submissions made by Aged Care Crisis

Then (then) CEO of Alzheimer’s Australia (Ita Buttrose) was so concerned around poor practices in aged care that Alzheimer’s Australia commissioned a report “The Use of Restraint and Psychotropic Medication in People with Dementia”90, which was released the week after the Inquiry report was tabled in parliament.

A later CEO of Alzheimer’s Australia, Carol Bennett, indicated in 2015 that:

“Every research study around the world has demonstrated that where you do put in place quality measures and they are comparable, you drive system performance and that is what we need to do here.”

In a radio interview91 Bennet indicated that quality of care was one of the biggest gaping holes because we don’t have “a single measure of quality” and without accurate data about care you cannot have choices. She could not understand why this was so. Researcher Dr Richard Baldwin (UTS) supported her comments.

Only a year later in 2015 and the Government were planning to further reduce accreditation standards from 44 to 8 under the label of the “Single Aged Care Quality Framework”. They simply ignored anything that challenged what they were determined to do.

Link: Submission to Care and management of younger and older Australians living with dementia and psychiatric symptoms of dementia http://bit.ly/2CZYqcT

2015: Community care

In responding to a 2015 discussion paper “Increasing Choice in Home Care”, which was really an exercise promoting Consumer Directed Care (CDC), ACC made it clear that it was not opposed to the idea of CDC or the exercise of choice. We criticised the inappropriateness of the www.myagedcare.gov.au system and the manner in which it was being implemented – as well as the market centric approach hiding behind the illusion of ‘choice’ and ‘control’. We stressed the importance of putting the community rather than the market at the centre of the services being provided and so ensuring that ‘choice’ did not become a cover for exploitation.

We have been very concerned about the absence of effective regulation controlling owners of nursing homes or providers of services. They control the business. In 1997 a probity system based on ownership was replaced by an approved provider one which took no account of ownership. A totally unsuitable company can buy an existing approved provider and so have the right to offer services to any community.

In our submission we suggested regulatory changes to empower the community. “To address the issue and protect vulnerable consumers, the local community should have the power to decide whether they consider a provider suitable to operate in their locality”. Probity would become important again.

Link: ACC submission: Increasing Choice in Home Care: http://bit.ly/2mhs0Ac

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90 The Use of Restraint and Psychotropic Medication in People with Dementia (26 Mar 2014) http://bit.ly/2Eu1yLa
91 Better data needed to compare aged care ABC Radio pm 24 Nov 2015 http://www.abc.net.au/pm/content/2015/s435621.htm
**2015: Advocacy**

This was a behind closed doors process contracted out to a consultant company who used an online feedback format that restricted input and did not publish the submissions. We completed the online form and then sent an additional document. We indicated that advocates were well placed to see what was happening in the sector yet they rarely (if ever) exposed failures and were never mentioned in complaints including the horror stories published in the media. It was only later that we read Braithwaite’s research describing the way they had been prevented from becoming involved and from speaking out.

We suggested that advocacy services should be integrated with complaints, data collection, regulatory oversight and accreditation within a local community structure. All these services would be far more effective if they were integrated and worked together.


**2016: Single Aged Care Quality Framework**

In 2016 the Quality Agency mounted a public relations exercise about quality before coming up with a proposal to reduce accreditation from 44 standards to only 8. While benefits and effectiveness were proclaimed, it was clearly based on the neoliberal free-market discourse advocating less regulation.

We felt it was a response to pressure from the industry and free-market politicians pressing for less regulation and a reduced regulatory burden. While it sounded good it collected even less useful information than the present system. Submissions were sought.

ACC responded to two online questionnaires strongly opposing the new proposals, which it thought would be even less effective⁹². At the same time it remained critical of the existing system and pressed for changes that would empower the community as the first line regulator and rebuild the oversight process within civil society.


**2015 - 2017: Elder Abuse Inquiries (NSW and ALRC)**

Submissions were made to the NSW Inquiry in 2015/16 and to the Australian Law Reform Commission 2016/17 Inquiry.

**2015-2016: NSW Inquiry into Elder Abuse**

**Links:** No. 110 Aged Care Crisis: [http://bit.ly/1UbuEW8](http://bit.ly/1UbuEW8)  

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Part 5: The journey - submissions made by Aged Care Crisis

2016-2017: ALRC Inquiry into Elder Abuse

(a) Submission responding to ALRC Issues Paper (IP47):
This submission addresses the nature of elder abuse in aged care facilities and in local communities, and the reasons why it has become such a problem. It advocates for the integration of the legislative processes with local community organisations that we suggest should be monitoring and managing the oversight of aged care in communities.

This submission describes the multiple failures in aged care, the extent to which residents have been abused and neglected as well as the ineffectiveness of the Quality Agency, the Complaints system and the Advocacy service. It gives an overview of the sort of local community based structure that we believe is the only effective way to make this market become socially responsible and as effective as possible within available resources.

Links: Aged Care Crisis - Submission to Issues Paper (IP47):

(b) Submission responding to ALRC Discussion Paper (DP83)
In their Discussion Paper, the ALRC argued for an empowered visitors scheme, particularly for the community. This would feed into the existing aged care regulatory structure. While we welcomed most of their analysis and the problems they identified, we stressed that this existing aged care regulatory system on which implementation depends has been singularly ineffective and obstructive. Making the control of elder abuse subservient in this way would frustrate the effectiveness of this proposal.

We reiterated that abuse was occurring within communities and that preventing abuse meant addressing the issues that gave rise to it within the social fabric of our communities and our nursing homes. Centralised regulation was most effective when it was informed by and responsible to an interested and actively involved community.

Links: Aged Care Crisis - Submission to Discussion Paper (DP83):
2016/17: Competition in Human Services - Productivity Commission: Introducing Competition and Informed User Choice into Human Services

We made submissions to several stages of this Inquiry first pointing out the many risks of what they were asked to do illustrating this with an analysis of policy and practice, and multiple examples but particularly from aged care.

In response to the first draft report we pointed out that while the problems were recognised in the report their significance was not. Their proposals depended not on their internal coherence but on external control including accurate data and government regulation. The government was incapable of exerting the control required, and there were major difficulties in collecting the sort of data on which this depended.

In commenting on the draft final report we submitted that inquiries should begin with and address problems. They should not start with ideological solutions and then go looking for somewhere to impose them.

The draft report spent time stressing the importance of community involvement for success in providing services to aboriginal communities – the community owning the service. We expressed our concern that this was being denied to the rest of us in several human services in the face of evidence that it was being used successfully elsewhere.

We stressed that human services belonged to the discourse of care rather than that of the neoliberal marketplace. We pointed out that palliative care, which the inquiry considered would benefit from these reforms occurred largely in communities and aged care facilities where there were already intractable staffing problems. As in aged care, the recommendations would result in a greater focus on profitability at the expense of the additional skilled staffing they accepted was required.

Links: Aged Care Crisis - Submission to Productivity Commission, Human Services:  
Aged Care Workforce issues

Staffing issues and the need for minimum staffing levels have been a constant theme in our submissions. We made a submission to the NSW Inquiry into state Registered Nurse requirements\(^95\). We strongly opposed the move by industry and government to allow fewer registered nurses.

**2016: Senate Aged Care Workforce Inquiry**

We started by analysing why past inquiries so seldom confronted and addressed issues and why effective changes such as minimum staffing requirements and staffing transparency were not made. The lack of data about staffing was particularly worrying. We suggested that an effective and involved community with the power of an effective customer would not tolerate current staffing levels if they knew and understood. We examined the social forces at work.

When we discovered that financial institutions were collecting staffing data we managed to secure these staffing figures. We were finally in a position to address staffing issues in the light of the extensive research that has been done internationally. We made a late supplementary submission.

**ACC 2\(^{nd}\) Supplementary Submission:** A recent CEO of LASA now working for the financial group StewartBrown (SB) published data that was wrongly labelled “Direct Care” and sent this to senators shortly before a meeting of the inquiry. This added almost an hour of extra direct nursing care to the care actually received by residents. A senior officer at ACSA repeated the claims.

Our submission exposed this error, suggesting that it might be deliberately deceptive. In retrospect we think it more likely that this simply reflects the extent to which those who manage and advise the industry and government are hopelessly out of touch with what actually happens when caring for frail people. Those involved had been advisors to government and politicians and had represented the industry on central government bodies.

SB is the organisation that sets the staffing benchmarks which provider groups use when making staffing decisions. We can only wonder at the utility of these benchmarks and the quality of the advice governments receive when those giving advice and setting benchmarks were so ignorant.

The remainder of the submission compares staffing in the USA and Australia showing how poorly our facilities are staffed particularly in regard to trained staff where Australia has half the numbers of trained staff and provides on average an hour less care (25%) to each resident each day.

International data showing how closely both staffing and failures in care are linked to the owner's focus on profits is compared with the limited Australian data suggesting that we are no different in this regard. This is something that the industry and the Quality Agency deny, even when their own figures show it.

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**Part 5: The journey - submissions made by Aged Care Crisis**

**The Aged Care Legislative Review 2016/17**

The legislation introducing the Living Longer Living Better (LLLB) aged care reforms required that the system be reviewed in 2016 and that the community be consulted.

**Our response:** The submission proforma seeking feedback was tightly constrained to limit criticism by asking questions which focused on structural issues and did not lend themselves to system analysis and criticism. We did our best and wrote about the issues in greater depth in the final question in the online web form which allowed independent comment.

[Link: Response to Aged Care Legislative Review](http://bit.ly/2qSly8v)

**Community consultations:** The legislation was followed by community consultations with Mr Tune who was chairman of the Aged Care Sector Committee, which had designed the Aged Care Roadmap. In a room with multiple community members wanting to address the personal problems they had experienced there was little room to discuss system issues in depth and this was not encouraged.

Individuals who attended were permitted to make a personal submission within 5 days and some did. Members of ACC attended three of the community workshops and after the last, one of us wrote to Mr Tune addressing these issues.

This letter addressed the issue of social responsibility and the manner in which the neoliberal discourse had abandoned it. It examined broader issues in society and their relevance to what was happening in aged care. It explored the reasons for regulatory failure locally and globally. It looked more closely at the discourse of care using Professor Fine’s work. The letter then advocates for a community based approach in order to address the many issues raised.


**5.5 Final comments**

**5.5.1 The importance of staffing**

We reiterate that the problems in care and in its regulation are not unique to Australia. This suggests that the underlying patterns of thought and policies common to these countries are inappropriate.

A major reason for substandard care is poor staffing skills and numbers. This is in large part due to a failure to clearly define nursing requirements based on acuity and then to regulate staffing levels effectively. Without this, competitive pressures will impact staffing levels and we will see further deterioration in staffing.
Part 5: The journey - submissions made by Aged Care Crisis

Even nonprofits are now reducing staffing levels to meet StewartBrown’s commercially based guidelines\(^{96}\).

“The cuts to staffing levels were underpinned by an Aged Care Financial Performance Survey written by consultants Stewart Brown in 2016.

The report is a survey of approximately 700, predominately charitable aged care homes across Australia, and ranks them in accordance with the acuity of the residents present, as determined by the Aged Care Funding Instrument.

Mr Bell said SCCQ had set their staffing levels “based on the midpoint of all those homes for each category of staff, for the resident acuity level for 100% occupancy”.

“This means that following the realignment, we will have staffing levels consistent with the mid-point of the charitable sector of the industry, which is generally higher than in the corporate sector,” Mr Bell said.”


For profits providers like BUPA are using unqualified staff to do skilled work so placing residents at risk\(^{97}\).

The association of poor staffing with missed care has been documented in health and aged care globally and locally. A large study in 300 hospitals in 9 countries\(^{98}\) has shown the impact this has on mortality following surgery. The study has shown that low trained nurse staffing levels and skills are associated with higher mortality. The paper reveals that this is linked to missed care. Each 10 per cent increase in the amount of care left undone was associated with a 16 per cent increase in the likelihood of a patient dying following common surgery.

We are not aware of any work examining the association of staffing with mortality and morbidity in aged care. In a sector where illnesses are complex, diagnoses more difficult and support more intense the dearth of medical and nursing skills must lead to delays in diagnosis. The poor staffing levels suggest that missed care is common and an increased mortality very likely.

The problem becomes clear when we compare Australian nursing levels with international levels. The figures below compare the figures collected from 15000 nursing homes registered with the Centre for Medicare and Medicaid Services\(^{99}\) in the USA with the figures collected by StewartBrown from 800 facilities in Australia\(^{100}\).
Figures for chart, below:

<table>
<thead>
<tr>
<th></th>
<th>USA: CMS Recommended Minimum</th>
<th>AU: SB Recommended Benchmarks</th>
<th>USA: US Average</th>
<th>AU: SB Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registered Nurses</td>
<td>0.75</td>
<td>0.36</td>
<td>0.8</td>
<td>0.37</td>
</tr>
<tr>
<td>Enrolled Nurses (equivalent)</td>
<td>0.55</td>
<td>0.34</td>
<td>0.8</td>
<td>0.33</td>
</tr>
<tr>
<td>Nurse Aids (equivalent, eg PCAs)</td>
<td>2.8</td>
<td>2.22</td>
<td>2.4</td>
<td>2.08</td>
</tr>
<tr>
<td><strong>Total nursing time:</strong></td>
<td><strong>4.1</strong></td>
<td><strong>2.9</strong></td>
<td><strong>4.0</strong></td>
<td><strong>2.8</strong></td>
</tr>
</tbody>
</table>

*TOTAL rounded to 1 decimal point.

5.5.2 The importance of regulation

There are three aspects of regulation. The first is the regulations themselves. These set the limits of legitimate conduct and these limits reflect the community’s expectations. The second is the monitoring and oversight of conduct and the social pressures that sanction and contain unacceptable conduct. Finally there is the punitive aspect which penalises and stigmatises unacceptable conduct. All these are important.

In Australia the regulations themselves reflect the neoliberal ideology and the needs of the market rather than the expectations of the community. An ideology that seeks to reduce regulation leaves regulation to the market in the belief that it will behave responsibly. The poor staffing in aged care is just one example of the consequences. The use of restrictive practices is another area where regulation provides no guidance of acceptability.
The Office of the Public Advocate in Queensland wrote about the excessive use of restriction saying that:

“the aged care sector remains unregulated with the Aged Care Act 1997 (Cth), the primary legislation governing aged care in Australia, containing no provisions that address or regulate the use of restrictive practices. The unregulated use of restrictive practices in aged care settings in Australia, without legal justification or excuse, is unlawful and amounts to elder abuse”.

Source: Legal frameworks for the use of restrictive practices in residential aged care: an analysis of Australian and international jurisdictions - Office of the Public Advocate (Qld), 15 June 2017
http://apo.org.au/node/104001

The monitoring and oversight of conduct is carried out infrequently by an excess of process driven conflicted central agencies which are distant from the bedside. This distance from the community and the customer makes it impossible for members of civil society to interact and exert the pressures needed to constrain aberrant conduct. Excess use of restriction, both physical and chemical, is not stigmatised in effective face-to-face interaction.

In the absence of effective oversight, data collection and the documentation of failures in care, effective prosecution of offenders becomes problematic and at risk of legal challenge. This compounds a multitude of regulatory problems discouraging effective prosecution of offenders. We addressed these in our August 2017 submission to the senate.

Aged Care Crisis is advocating for an integrative approach to regulation and this must be focused locally to be effective. Formal regulation must respond flexibly in supporting and augmenting society and its members. The concepts and understanding that they develop as they gain knowledge and insight can be reflected in regulation and so be attained.

Note: a list of all our submissions and of the final inquiry and review reports is available on our website.101