Re: Consultation paper on the streamlining of the Quality Reporting Programme

Aged Care Crisis (ACC) is a community organisation that monitors the pulse of those experiencing aged care. Our web page is where the 'little voices' of those who see what is happening in aged care can be heard.

Our close contact with the individuals who must deal with the system's failures has made us a witness to the human consequences of the deterioration of our aged-care system and the escalating succession of scandals that has engulfed it.

ACC supports efficient bureaucratic processes - as long as the well-being and protection of vulnerable frail older people is kept paramount. We do know, for example, that aged-care staff - the nurses and carers who work on the floor - are often asked to complete extensive, and sometimes irrelevant, documentation when they would wish to be attending to those in their care.

However, our organisation is extremely concerned about any further diminution of the auditing and inspection processes of aged-care homes.

The neglect and abuse that is reported by the media on a weekly, if not daily basis, is clear evidence that the current system is failing both frail older people themselves and the general community, who expects more from those responsible for protecting the rights of its most vulnerable citizens. Strong, effective regulation and monitoring is essential.

Therefore, ACC would like to see the Quality Reporting Team addressing ways to overcome these systemic failures as a matter of urgency rather than expending efforts 'streamlining' the auditing.

For example, we would like to be assured that when an aged-care home has been audited or inspected and has been deemed to meet all required standards that the resulting report has veracity.

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With reference to point 2, dot point 2, 'Further two days following the exit interview to submit evidence'. Many service providers have a history of creating evidence documents. If the evidence is not there at the time of the visit, the service is not meeting the requirements under Part 6.3 (Record keeping) of the Act.

With reference to point 3, dot point 2 'Interim Quality Report', the above issue also relates to this criteria, 'for comment prior to the final decision being taken'. What is the point of an audit where the facility can argue their case and provide information that was not available at the time of the visit. If the auditors miss information, they are not trained adequately to consider all possible evidence. An audit is an audit, a snapshot of what they see at the time of their visit.
The appalling revelations of systemic mistreatment exposed by the ABC’s Lateline program and other media throughout this year, as well as regular disturbing reports to our own organisation, clearly show that this is currently not always the case.

We note that the latest Alzheimer’s Australia report echoes some of what we have been saying, especially in regards to community involvement and transparency.

Australia’s aged-care system is now almost fully open to the market economy where it is erroneously assumed that frail, aged people are merely customers who are free to pick and choose from commercial providers. Their very frailty, the trauma generally experienced at the time of choosing a home and the lack of readily available, accurate information often precludes making an informed decision.

Furthermore, the monitoring of homes is compromised by the conflict of interest that occurs when those who are meant to be the watchdog are part of the same body that has responsibility for ensuring the provision of care.

ACC has urged, in response to a series of inquires relating to aged care, to give the monitoring of aged care back to the community – where it truly belongs. We have suggested the formation of local community bodies with representatives on the regulatory system. Such groups would participate in gathering information, in oversight and advise on regulatory decisions. Most importantly, they would ensure increased transparency within the system.

In our submissions to the many aged-care inquires that have occurred over the past decade, we have urged politicians to address the political tensions that make it too risky for them to act in the public interest. They would then be able to confront the pressures generated by powerful vested interests and the problems created by dysfunctional markets.

In most cases this involves giving increased power and leverage to aged-care residents, their families and local communities. If this were done then much of the onerous regulation and red tape would become superfluous.

These issues are addressed in depth on our most recent admission, which is included in this document.

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2 Aged Care Accreditation in the spotlight (Lateline, 23 Aug 2013): http://www.abc.net.au/lateline/content/2013/s3832828.htm
Mistreated nursing home residents ‘better off in a concentration camp’: http://bit.ly/1dAEoOI


We also list below links to similar submissions where we have outlined the many problems in aged care and append a list of matters that we have addressed:

- Overview of inquiries\(^6\)
- Productivity Commission Inquiry: Caring for Older Australians (2011)\(^7\)
- Review of the Aged Care Complaints Investigation Scheme (October 2009) \(^8\)
- Review of the Residential Aged Care Accreditation Process for Residential Aged Care homes (July 2009) \(^9\)
- Inquiry into Aged Care Amendment (2008 Measures No. 2) Bill 2008 \(^10\)
- Aged Care Amendment (Security and Protection) Bill 2007 \(^11\)
- Inquiry into Older People and the Law (2006) \(^12\)
- Elder Abuse Prevention Project (2005)
- Inquiry into Aged Care (June 2004) \(^13\)

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Aged Care Crisis (ACC) welcomes the opportunity to provide comments on the Exposure Draft Quality Agency Principles 2013 and Quality Agency Reporting Principles 2013 setting out proposed subordinate legislation under the Aged Care Act 1997.

ACC is concerned about the very short time frame imposed on providing comments to the Exposure Draft Quality Agency Principles 2013, given the website was updated on 24 October 2013 with the 8 November deadline imposed. Nevertheless, ACC has moved swiftly in order to place our views on the record, and we welcome the publishing of this submission in whole.

ACC is a community organisation that feels the pulse of the community experiencing aged care and listens to their concerns. It’s where the ‘little voices’ of those who see what is happening in aged care can be heard. Our close contact with those who suffer from the system's failures has made ACC a witness to the human consequences of the steady deterioration of our aged-care system and the escalating succession of scandals that have engulfed it.

ACC has taken the time and effort to gather scattered information and compile it for critical examination. We have published articles from the coalface and created a forum where participants can tell of their experiences and comment critically. We produce a periodic newsletter.

Instead of confronting key issues, examining the evidence, drawing logical conclusions and addressing issues, successive reviews and inquiries have ignored the logic of the submissions and cherry picked items that have then been incorporated into policy and practice, adversely influencing the way in which the aged-care system operates.
An example of this is the way in which the *Review of the Aged Care Complaints Investigation Scheme (Walton Review)* ⁷ virtually destroyed the utility of the whole complaints system by embracing our recommendation to place more focus on local resolution.

The Walton Review critically ignored supporting information, the logic behind this and the essential linked recommendation that the complainant should be supported and advised by a trained local facilitator with investigative powers.

Not surprisingly this unequal barrier, in which there is a gross imbalance in power, and where victimisation is possible, has proved to be an effective barrier to lodging and investigating a complaint, as well as resolution, leaving the disaffected even more disillusioned⁸.

**We make the following general comments.**

- ACC asks that there be real transparency, accountability and disclosure in all aspects of aged care.

- The current Accreditation process is the primary reason why the system cannot improve. It is at the heart of the problems in aged care. Not only has it presided over a succession of frightening scandals and generally poor care, but its system of accreditation fails to empower users.

  The accreditation process does not measure care nor record the incidence of failures, and barely discriminates between providers. It generates pressures towards universal mediocrity. It does not reward those who strive for excellence. The limited applicability, yet loudly expounded, nature of its theoretical underpinning, the opacity surrounding its activities, the spin doctoring promoting it, even its very presence, have obstructed all efforts to make useful changes and challenged their legitimacy.

  It is not effective as a monitor of standards nor as a regulator. It should either be radically transformed or removed entirely. The problems with this agency are addressed in multiple previous submissions by ourselves and others⁹.

- Shortcomings in the current system of aged care are leading to widespread lack of confidence within the broader community.

- Frail older people across Australia are at risk because aged-care providers are not required to adhere to mandated minimum staff/resident ratios¹⁰.

- Consultation with independent consumer groups on all aspects of aged care should be paramount. For too long the voice of the aged-care consumer has been neglected.

- We draw attention to the current reliance on the market economy for the provision of care to a significant proportion of frail, older Australians. 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 humanitarian and personal empathic care out of the sector.

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¹⁰ [No staff for 10.5 hours per day: http://www.agedcarecrisis.com/yoursay/4611-no-staff-for-10-5-hours-per-day](http://www.agedcarecrisis.com/yoursay/4611-no-staff-for-10-5-hours-per-day)
The focus of our submissions have included most of the following general matters:

- that, because accreditation has become such an important regulatory activity, the central issue should be addressing the standards of care at the Home under evaluation, not the adherence to process for its own sake;
- that the accreditation process and the reports should accurately document the incidence and nature of failures in care;
- The presence of underlying conflicts of interest, which might undermine the integrity of the assessment;
- the requirement for burdensome documentation, so limiting staff's time providing care and distracting their attention from their primary care duties;
- the importance of timing accreditation and other site visits so that a review can be made of operations outside business hours, particularly at weekends and in the evenings when staffing levels are likely to slip;
- the protocols for notice for 'unannounced visits' should be clear and transparent as should be the findings;
- because of the risks of reprisals, staff, recipients of care, families and community should be advised of accreditation visits and be given an opportunity to speak with members of the team in confidence and importantly without the provider being aware that they are doing so, particularly if they fear that they or their family member will be victimised. Those who disclose information should receive the same protection as whistle blowers.
- because the accreditation reports are the only measure of standards of care available not only to residents and their families, but to those that advise them, when they make decisions, they should be structured to detect excellence and mediocrity as well as performance over time.

Reports should meet the needs of the community by:

- all accreditation and inspection reports should be published and available publicly so that residents and their representatives can make their own informed assessment;
- a rating system with a mean nearer to 50% and a Bells curve with not more that 10% of homes in the top 10% range;
- availability of current and previous reports and graphic analysis both of an individual providers’ performance over time, but comparing them with others;
- informed members drawn from local communities should be represented on audits and at all levels of the accreditation process so that they can advise families and residents. The agency should host educational meetings and work closely with the community. The agency should develop lines of communication with community visitors who have the legislative backing to monitor standards of care. Their assessments should be reflected in reports;
- accreditation team should acquire data on actual staffing on the floor including consistency in the availability of skills, numbers and rostering, and rate this against patient acuity. They should supply figures for both commenting on their adequacy. Staffing information should be conveyed in published reports;
- the accreditation team should review all complaints made in respect of the aged care home since last visit and report on this, as well as the appropriateness, effectiveness and success of any remediation taken;
reports to the community should be based on more regular monitoring and accurately reflect the standards of care given between accreditation visits rather than at them. Staff knowledge of processes and their performance in executing them is important for providers seeking to improve standards. It is not a measure of standards of care, and only peripherally important to the knowledge families and communities want and need about the care provided.

ACC and as individuals, have contributed to various inquiries, reviews and consultations - including the following:

- Overview of inquiries\(^{11}\)
- Productivity Commission Inquiry: Caring for Older Australians (2011)\(^{12}\)
- Review of the Aged Care Complaints Investigation Scheme (October 2009)\(^{13}\)
- Review of the Residential Aged Care Accreditation Process for Residential Aged Care homes (July 2009)\(^{14}\)
- Inquiry into Aged Care Amendment (2008 Measures No. 2) Bill 2008\(^{15}\)
- Aged Care Amendment (Security and Protection) Bill 2007\(^{16}\)
- Inquiry into Older People and the Law (2006)\(^{17}\)
- Elder Abuse Prevention Project (2005)
- Inquiry into Aged Care (June 2004)\(^{18}\)


1 Comments

The proposed legislation seems to have two primary purposes:

1. Name change
To change the name of the agency from Aged Care Standards and Accreditation Agency to Australian Aged Care Quality Agency (Quality Agency). The purpose of that change is unclear as its activities are otherwise largely unchanged. The substitution of the more emotive word “quality” for “standards” suggests spin doctoring.

2. Extend the scope of the Quality Agency
Transfer the responsibility of the quality review of home care services from the Department of Social Services to the Quality Agency from 1 July 2014 and make home care subject to the same sort of oversight that has characterised the residential care sector.

We note a number of other changes and omissions including:

1.1 Register of assessors: deleted
The removal of a requirement that the Quality Agency keep and publish a register of assessors (previous clause 2.97)\(^{19}\).

ACC is not aware of any plans to keep and publish a register elsewhere. If not, then ACC is concerned that this omission might increase the opacity of the system and make it even less transparent. It would prevent involved local citizens from checking that the assessors of services in their communities did not have a conflict of interest.

1.2 Quality Agency: greater regulatory powers
ACC believes that the critical role of education and the establishment of exemplar processes and practices within aged-care homes must be separate from the roles of oversight and regulation. A body independent from the industry would better accomplish the latter roles. This would address a number of other conflict of interest situations.

We note in sections 2.19, 2.20 and 2.21 that the CEO of the new agency is to be given greater powers to regulate and remove accreditation from aged-care providers, powers previously vested in the Department of Health and Ageing.

\(^{19}\) Aged Care Standards and Accreditation Agency: Registrar for assessors
We question the wisdom of this step as the current Accreditation Agency in its second submission to the Productivity Commission's Inquiry Caring for Older Australians, emphatically argued that the Department of Health and Ageing was (and the agency should not be) the principle regulator:

... Is the accreditation body a regulator? - No

Accreditation body purpose and functions
The legislation and the speeches by government at the commencement of the accreditation arrangements under the Aged Care Act made it clear that the Accreditation Agency is not a regulator ...

Draft response submission: Aged Care Standards and Accreditation Agency (March 2011)

The Accreditation Agency expressed its concern about the conflict of interest which a regulatory role created for them, and expressed the desire not to have such a role in any future system. Deliberately creating conflicts of interest is a recipe for problems and undermines the credibility of the new Quality Agency.

Logic dictates that the new agency should have been relieved of this burden and a new, more appropriate unconflicted system, built around community surveillance, substituted.

The Accreditation Agency's submission highlighted the danger of the duality of roles, which Aged Care Crisis concurs:

... The Accreditation Agency should, and does, report the outcomes of its quality of care assessments following accreditation and monitoring activity to the regulator (DoHA). It is the DoHA that has the complete picture of the home (i.e. quality of care and services, building, prudential position and key personnel) and is best placed to determine the appropriate regulatory response.

The Accreditation Agency’s responsibility is to support and encourage a quality improvement 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 the stakeholders. This does not align with an inspectorial/policing approach.

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A change to an enforcement and compliance monitoring arrangement as suggested in the PC Report (refer Figure 1) 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.

Draft response submission: Aged Care Standards and Accreditation Agency (March 2011)
1.3 Input considered for accreditation decisions

ACC is concerned that decisions made as to whether to accredit or re-accredit a service precludes information from sources other than current or past care recipient’s or their representatives, any agency report/s, information provided by the approved provider, or from the (Department) Secretary.

Staff, visiting medical personnel (eg, doctors, physicians, dentists or other medical personnel), or members of the community, are excluded from supplying information which might be extremely pertinent.

Giving those with knowledge, or with the time and interest to do research, the opportunity to provide additional information would minimise the risk that unsuitable providers might end up caring for frail and vulnerable people.

Subdivision C - Decision on application for re-accreditation

2.18 CEO must make decision on application

(1) Within 28 days after receiving the site audit report for the relevant service under subsection 2.17(3), the CEO of the Quality Agency must decide:

(a) to re-accredit the service; or

(b) not to re-accredit the service.

(2) However, the decision may be made by a later date agreed by the CEO and the approved provider.

(3) In making the decision, the CEO:

(a) must take into account:

(i) the site audit report for the service; and

(ii) any response given to the CEO by the approved provider under subsection 2.16(2); and

(iii) any relevant information given to the CEO, or to the assessment team that conducted the site audit, by a care recipient or former care recipient of the accredited service, or by a representative of a care recipient or former care recipient of the service; and

(iv) any relevant information about the approved provider given to the CEO by the Secretary; ...
1.4 Fear of retribution

Staff, families and members of the community should be invited to arrange confidential visits without the provider knowing that they are doing so if they fear retribution. Fears of reprisals deter staff and families, who fear the consequences for themselves or the recipient of care. Providers may well guess who provided information and those who speak out and any recipient of care involved should receive the same protection as whistle blowers.

1.5 Unannounced visits

We are concerned that the requirement that there be at least one unannounced visit each year is now absent.

While these visits are not reported publicly, as we believe they should be, we believe they are more important in maintaining standards across each year than announced accreditation visits.

Other changes with respect to unannounced visits (such as a removal of the reference that bans providers from objecting to an assessor doing an unannounced visit) seems to water down provisions relating to visits. Already unannounced visits are compromised by the fact that, in practice, some notice is generally given and that assessors only report on particular, pre-set issues.

For example, the new Principles state:

<table>
<thead>
<tr>
<th>2.33 Additional assessment contacts</th>
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<tr>
<td>Assessment contacts with the approved provider of an accredited service may be made, without notice, in addition to the assessment contacts notified to the approved provider under these principles.</td>
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</table>

The current Accreditation Grant Principles state:

<table>
<thead>
<tr>
<th>2.45 Assessment contacts</th>
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<tr>
<td>(2) The accreditation body is not required to give notice to the approved provider before an assessment contact takes place.</td>
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</table>

1.6 Assessment teams

It is critically important to ensure transparency and confidence in the system by making provision for the training and inclusion of local assessors who may accompany the assessment teams in their activities.

Part 4 of the Principles for the new Agency: We believe that if the new agency is to work effectively then assessors from local communities, particularly those who have had experience of the aged-care system, should be trained and appointed. This process should form part of a wider system of reforms and should commence as soon as possible.

The objective should be to have local assessors present at every accreditation visit. These matters have been covered in previous submissions and are summarised below.
1.7 Transparency: Information and reports on homes

We note that the new Quality Agency's publication of information and reports appears to uphold minimum levels of opacity in the release of information or reports.

Family members wanting to make informed decisions about a residential aged-care placement for their loved ones are often unable to do so. The vast majority of reports published are the cyclical, three year Accreditation site audits. These are the reports of planned visits, performed at a convenient time and after the homes may have spent months preparing for the audit.

Such reports tell us that the management of the aged-care home knows what it is supposed to do but gives little information about what happens on the other 1,093 days of the cycle. They may be nearly three years out of date for those seeking information about prospective homes.

Research shows that the average completed length of stay for permanent residents in 2010-2011 was under three years\(^2\). As a result, many residents will enter and exit a facility without ever taking part in an accreditation audit. In other words, the quality of care they receive will not be assessed while they are alive to benefit from any improvement made as a result of the assessment.

Information arising from other activities carried out by the Agency, such as support visits, contacts, and unannounced visits is not available. For example, if failures are identified during an unannounced site visit, these details are not publicly disclosed nor subject to public scrutiny.

In order for frail, aged people to achieve full protection, the community must be able to see what the company or provider is capable of when no one is watching - not just when they have been given time to prepare for an inspection and not simply after providing a response to an adverse finding in order to stay in business. It is critically important that there be regular informed ongoing surveillance within the community by trained individuals closely linked both to each accreditation visit and to groups advising and supporting recipients of care and their families.

1.7.1 Freedom from (any) information: A case study\(^{21}\)

Aged Care Crisis's (ACC) recent experience defies belief. It shows just how difficult it is to get information. ACC asked DOHA for the addresses of all facilities providing aged care. They needed the information to help those who approach them for guidance to find the facilities nearest to them in machine readable format. We did not anticipate that it would take an FOI, let alone appealed, to supply such basic information.

After some nagging by ACC, we received a response refusing the request on the grounds that addresses were "Protected Information" under the Aged Care Act 1997 (Act). ACC examined the Act and it was clear that this was not the case. DOHA did not respond to a request for clarification. A politician kindly offered to help ACC get the information but he too was refused. The addresses were only released after the politician appealed the decision.


\(^{21}\) http://www.agedcarecrisis.com/freedom-of-information
1.7.2 Desperately seeking information

A quick review and comparison of other western world counterparts in countries like the United States, Ireland, and the UK for example, all seem to be far more open and transparent with the way they collect and publish aged care data.

In all instances, open publishing of all reports, including unannounced inspections, complaints reports, for example, the Care Quality Commission in the U.K. places emphasis and focuses it's reports on consumer input: "What people who use the service experienced and told us".

All reports and information (including complaints information, along with provider's responses) are published.

The CQC openly publishes information in a machine readable format, allowing the public to download the data and analyse. They also have an active and responsive social media presence.

- The CQC website publishes all of their inspection reports – with substantial focus of the CQC reporting based on "What people who use the service experienced and told us" published in all of their online reports, as well as the inspector's independent assessment notes.

- The website also provides information such as a snapshot of the ownership or company structure and other services run by the same provider or company. CQC also publish the person or management responsible at the facility.

- Depending on the type of report (all are published), it also details the improvement actions and concerns about the facility (equivalent to the NRA's – Notices of Required Actions issued to Australian aged care providers).

- If a "Review" of a service is performed – what triggered the review is documented in the report, as well as how the review was carried out, including "What people who use the service experienced and told us" (eg, complaint, result of spot check, etc). These reports also detail the compliance actions and what the provider has been asked to fix.

All reports are made publicly available (including unannounced inspections), as well as the complaints information made at the facility level, the date the complaint was rectified, this also included the non-compliance information and/or regulatory activities and reports.

This is how a transparent system should work, making it easy for families to make informed decisions when canvassing care options.

Examples of how transparent other countries perform in similar areas of care responsibilities are published on our website:
http://www.agedcarecrisis.com/transparency-accountability-disclosure/desperately-seeking-information

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22 Care Quality Commission (CQC): CQC in the UK is the organisation that checks hospitals, care homes and care services that are meeting government standards: http://www.cqc.org.uk/#carehomes

23 Care Quality Commission: How we publish http://www.cqc.org.uk/organisations-we-regulate/registered-services/how-we-publish

24 Care Quality Commission: How to get and re-use CQC information & data: http://www.cqc.org.uk/cqcdata

25 Care Quality Commission - Twitter account: https://twitter.com/carequalitycomm

26 Example: Care home search result: (as at 7 Nov 2013) http://www.cqc.org.uk/directory/1-140448277
1.7.3 Missing: responses by providers

The *Aged Care Act 1997*\(^{27}\) stipulates that a home’s response to an adverse finding be made publicly available. In spite of this requirement, and contrary to the intent of the *Act*, responses can be made in a form, which is not actually available to the public. How a home responds to an adverse report is a critical part of understanding the practices and policies of that facility.

The publication of all relevant information is an essential part of achieving transparency. Privacy is an important consideration, but should not be used as an excuse or barrier to transparency and accountability – or as a way to hide a failure to protect those who are unable to protect themselves.

1.7.4 Timing and preparation for inspection visits

We draw attention to the fact that, to our knowledge, evening or weekend visits rarely occur – the very times where homes are known to have extremely low, even dangerous, staff resident ratios\(^{28}\). If visits at these times do actually occur, this information is not disclosed in published reports of the service.

It is also important that there be no restriction on the agency in regard to which visits are or are not unannounced. Furthermore contacts, which are simply communications and cannot be used as assessments, should be clearly distinguished from visits to the facility. The use of the term "assessment contact" should be clarified in section 2.30 on page 19 so that contacts that are not on site are not used for nor substituted for assessments.

1.8 Community involvement: Appointment of community assessors

Part 4 of the Principles for the new Agency: We believe that if the new agency is to work effectively then assessors from local communities should be trained and appointed. This process should form part of a wider system of reforms and should commence as soon as possible. The objective should be to have local assessors present at every accreditation visit. These matters have been covered in previous submissions and are summarised below.

Missing: consumer input: Research has shown that hospitals are safer and better when the consumer voice is heard. ACC asks why this does not occur in aged care and calls for more consumer input at all levels within the sector.

The accreditation process should be made much more consumer friendly – in particular by including consumer/carer advocates on every audit panel. Furthermore, managers of aged-care homes should ensure that there is an active resident/family member committee, which is fully supported and not patronised.

ACC draws attention to the Community Visitor Program managed by the Office of the Public Advocate (OPA) in Victoria\(^{29}\). Under this program, trained, volunteer members of the community make regular, unannounced visits to both government and privately funded residential accommodation facilities.

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28 No staff for 10.5 hours per day: [http://www.agedcarecrisis.com/yoursay/4611-no-staff-for-10-5-hours-per-day](http://www.agedcarecrisis.com/yoursay/4611-no-staff-for-10-5-hours-per-day)

Under the provisions of the relevant legislation, community visitors are permitted open access to all documentation regarding residents, as well as all parts of the home and free discussion with residents.

The value of these unannounced visits is well documented in the Community Visitor’s Annual reports\(^{30}\). We urge a closer scrutiny of this system of community visiting which provides a further degree of monitoring of an aged-care system that is critical to the well-being of us all.

### 1.9 Other changes:

ACC is also aware that the total accumulated assets and liabilities of ACSAA Limited will be appropriated by the Commonwealth and not transferred to the new Quality Agency. In addition, reports indicate that the work of accreditation will revert to the public service. The Quality Agency will be an Australian Public Service agency that will engage staff under the *Public Service Act 1999* and be subject to the *Financial Management and Accountability Act 1997*. It will no longer be an independent agency.

It is far from clear to us:

- what the impact of these changes will be;
- the degree of independence that the new Quality Agency will have from the political process; and
- whether the changes will open the new agency to Freedom of Information access or whether they will increase the opacity and lack of transparency.

We believe that a lack of transparency is a critical failure of the current agency. We ask that this issue be considered.

We believe that these changes highlight the need for there to be independent, community elected representatives on the new Quality Agencies CEO Advisory Committee.

We note the provisions for appointment of the CEO’s Advisory Council in part 4 clauses 29 to 32 of the explanatory Document for the “Australian Aged Care Quality Agency Principles 2013”. We believe that this section should, at some stage, be modified to include at least two members elected from and by the community, when the necessary structures for a community organisation are in place. The conflict created by the increased regulatory role of the new agency (see item 4 above) reinforces the need for this change. We will address this issue later in the submission.

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2 Fundamental reforms

2.1 An opportunity
The creation of a new agency provides an opportunity to make real changes and to confront the elephants in the room; ones that sit silently behind every committee inquiring into aged care and legislation. It is an opportunity to create a system, which provides real customer support and empowerment, one which can and will address many key problems and protect the communities interests.

2.2 Overall concept
We propose changes to the system that would create real reform by replacing the top down model with a bottom up model, one where it will be obvious to each community whether the changes are working or need modification. One where flexibility would be ensured as proposals, and pressure for modifications and improvements would come from the coalface, where any problems are quickly identified, and not the boardroom.

2.3 Restoring confidence
Changing the agencies name will do little to restore the agencies lost credibility. The way to restore lost confidence is to be totally transparent and this will only be credible when the community is directly involved with the agency in accreditation, oversight and monitoring of standards.

2.4 Brief overview of changes
We outline here only the sort of changes that we believe are critical for the aged-care sector and indicate where they could be included in the legislation. We believe the need for real change is desperate and clear. The logic of our arguments and proposals is irrefutable. They are not new and more detail is available in past submissions.

Local community groups: Our reforms proposes that the focus of aged-care activity be moved into local communities and that the role of central bodies should be to facilitate train and support the services provided locally. We propose the creation of a network of local community supported aged-care groups, each group appointed by other groups within the community. These support groups would supervise the activity of trained people from the community who would be jointly appointed and jointly responsible to the local group and to the central coordinators and supervisors.

The groups’ role: This community group’s role would embrace the full range of aged-care activities and would include real world advice and support based on direct knowledge and experience of the aged care providers operating in the community. Their role as supporters and their role in regulation would give them the leverage needed to act as an effective real world proxy aged care customer for the members of community.

Types of activities: The group would coordinate and supervise all local aged care services including ongoing and regular oversight of care and adherence to accreditation standards. It would facilitate and support mediation and complaints handling and would immediately investigate any concerns that families have. It would be the on site arm of the complaints system.
It would coordinate the visitors system and its local knowledge would enable it to educate inform, support and advise families and prospective recipients of care. It would be well placed to negotiate fair compensation when someone has suffered unreasonably because of neglect, abuse or unacceptable breeches in care, and check later that agreed remediation has occurred. If the provider fails to respond appropriately the facilitator would be able to advise on legal resources to consult - and use the resources available to pursue punitive penalties that would be a deterrent.

**Central structure:** Local groups would elect representatives to a central organisation, which would lobby for the aged care community. It would appoint representatives to the CEO's advisory committee and work with the central aged care regulators.

### 2.5 Accreditation and the proposed changes

The creation of a new agency, and the legislation to do so, is an opportunity to take the first logical step by **including provisions in this legislation for the new Quality Agency to train and then appoint members from the local community to the accreditation panel.** They should aim to have a local accredditor present for each and every accreditation visit and decision. These appointees should be appointed by the community group, and, where possible, be drawn from the panel of visitors linked to the local community group.

**The visitors:** These would be people from the community with the training and legislative powers to monitor and report on activities in the aged care sector in each community and they would do so in the long intervals between accreditation visits. Such visitor systems already exist in other sectors in Australia, where vulnerable people are at risk. The current aged care visitors system should not be confused with our concept. It is different to that in Victoria, does not have the powers or skills, and could not carry out these activities.

These visitors would report to the local group and the community but be trained to observe confidentiality requirements when doing so. They would be in a position to monitor the providers own auditing of care and, in particular, their auditing of failures in care. This would enable the new Quality Agency assessments to move from its current reliance on assessment of process to an assessment of real outcomes and standards of care.

These visitors would know exactly what was happening in the community and be in a position to brief the agency and ask for a formal accreditation visit when required.

There is of course much more that could be accomplished in these changes and there are many options. We refer you to previous submissions and would be happy to elaborate and to cooperate in fleshing out plans for these changes.
3 In-home care

ACC supports the increased provision of 'home-based' services for frail, aged people. One of the major issues is the current lack of supervision to ensure that the care provided is of an adequate standard.

Furthermore, the practice of an original contractor sub-contracting care to another group whose staff may not have the required training places some frail aged at risk and is of great concern\(^{31}\).

3.1 Subcontracting or outsourcing care

We understand that, in most cases, the care is not actually provided by the recipient of the funds\(^{32}\). Instead it is subcontracted to another group that employs staff to provide the care. They in turn take their profit from the $15,000 remaining before employing those individuals who actually do the work and who are often paid at very low rates.

\[\text{Charges by agencies for administration and case management are soaking up over 60\% of allocated budget each month. I have since found out that there is no ceiling on what provider's can charge. Others I know have had as much as 67\% snapped up.}\]

\textit{Feedback to Aged Care Crisis: October 2013}

ACC urges the Commissioners to review Dr Wynne’s submission\(^{33}\) where a range of suggestions were made which would bring a real balance of consumer direction and input into aged care.

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4 The elephants in the room

We believe that there are three elephants in the room that have impacted negatively on western society and no sector has suffered more heavily in Australia than aged care. No progress will be made until they are confronted. These elephants are:

1. **Widespread market failure** due to an imbalance of power between provider/seller and customer/client/recipient of services

2. **The power of vested interests**, particularly those groups whose wealth and power is dependant on maintaining the power imbalance that result in failed markets

3. **The emasculation of effective political processes** by political expediency and self-interest to the extent that no party dare act in the public interest without fear of attack from vested interests supported by opportunistic political opponents.

We have expanded on and explained the role these elephants play in society in Appendix A of this submission.

4.1 Elephants and caring services

The caring sectors are particularly vulnerable, and vulnerable citizens suffer most when markets fail because of an imbalance in power. The community expects the caring sector to be governed by the same ethical principles - morality, humanitarian motives and the primacy of the person or persons needing care - that once underpinned care, and they believe still should. These are no match for the strong pressures generated by the drive for profit and the fear of failing to meet promised financial targets.

It is relevant that in the marketisation of health care in Australia, particularly in hospitals, another group of citizens with market power, the medical specialists, whose interests were also threatened, stepped in to protect vulnerable citizens. They acted to bankrupt those who overstepped the mark and acted as a proxy customer. It is likely that they will continue to protect sick citizens, while their interests are in doing so and while they are able to maintain their ethical traditions and values.

4.2 Elephants and aged care

The failing aged person and their families lack almost all of the attributes required of an effective customer. It is obvious that the market in ageing decrepitude was at high risk of failing and it has done so. Care takes from profit and the pressures are consequently towards the cheapest that can be provided so ensuring general mediocrity. There are no groups with market power in a position to play out the role of customer on their behalf.

The structure, assessment methods, opacity and unwillingness of the current accreditation agency to really engage with community groups make it impossible for any group to function effectively as a proxy customer. We are deeply troubled by the absence of any evidence of a change in this for the new agency.
The sector has been characterised by disclosures of neglect and abuse of frail citizens. Highlights in the succession of revelations have been the Riverside scandal in 2003, the rape scandals of 2006 and the appalling revelations of mistreatment exposed by Lateline early this year.

But this is only the tip of the iceberg. The plight of the aged has been hidden because they have been sequestered behind closed doors in institutions and shielded from view by the illusion of "caring experts" and the credibility they claim. There is a massive imbalance of power between confident and polished providers on the one hand and anxious family on the other.

It is not only the family and the community who are disempowered and prevented from exposing mistreatment. There are few sectors where messengers or staff whistle blowers have been so viciously attacked, discredited or mistreated and received so little support. The victimisation and terrible consequences for those who speak out to expose a failure to meet societies basic expectations ensures that these failures remain hidden.

There is also an impact on those who provide care. Non-compliance with pressures for profit has adverse consequences for incomes, careers and for individuals' perception of self. It impacts on who individuals believe they are and what they are doing in this world. The ethic and culture of the entire sector is affected so that not-for-profit entities often behave similarly. The vast amount of rhetoric directed to improving standards and placing the recipient as the primary focus has little impact on the elephants and the stark impersonal reality of their worlds.

4.3 Regulatory agencies

Regulatory agencies, buried in their own theoretical worlds, and in pursuit of their own objectives and their own careers have been wilfully blind to what is happening and have put their heads in the sand. The two agencies most at fault are the Aged Care Standards and Accreditation Agency and the Aged Care Complaints Scheme, both of which provide an illusion of legitimacy, which those who refuse to look and act can use to rationalise their position, and confront the evidence pouring in from the community.

ACC believes that the Government, including the Complaint System and the Accreditation Agency have failed Australians. They have failed Australians because they are deeply conflicted and are consequently unable to act for and provide the onsite customer support needed.

The Accreditation Agency admitted their conflict and the difficulties this created for their roles as regulator and as patient supporters. They asked the Productivity Commission's Inquiry Caring for Older Australians, to relieve them of these responsibilities, which were peripheral to their primary role in supporting providers. Sadly, instead of filling this role of proxy customer or of facilitating it, their

36 Many nursing homes provide inadequate care:
   http://www.abc.net.au/lateline/content/2013/s3824967.htm
   Aged care accreditation in the spotlight:
   http://www.abc.net.au/lateline/content/2013/s3832828.htm
   A family demands to know why their father died of malnutrition:
   http://www.abc.net.au/lateline/content/2013/s3871658.htm
37 Nursing home in alleged cover-up of resident's drowning
practices, policies and lack of transparency have prevented others from filling that role. They have contributed to ignorance and powerlessness. These issues have been repeatedly addressed in past submissions from our group.

4.4 Responding to this situation

It is clear that the failures are similar if not identical in nature to those that have occurred in many other vulnerable sectors where the necessary customer conditions for a market to work do not exists.

The irony of the situation and symptomatic of the deceptive rhetoric used by regulators to delude themselves and the public is the extent to which the descriptive term "quality", with its positive associations is used. It is used in the title of organisations and in the descriptions of activities that oversee standards of care and are intended to maintain the quality of life of people in need. Nowhere is this more apparent than in those sectors that have failed our citizens.

The documentation surrounding the agency and their rhetoric is one of the most striking examples. Using the word 'quality' as a catch phase for this agency is a mockery of what often happens. In the Exposure Draft "Quality Agency Principles 2013" the word "quality" is used 236 times and the word "standard" only 64 times.

This legal document relating to an agency charged with maintaining and improving standards reads like an advertorial for that agency.

4.5 Conclusions

ACC have closely followed developments in the sector and the evidence of a failed system is not really contestable. The explanation of what has happened is logical and self-evident.

It is clear that we need an on the ground, independent local support system, with all of the attributes of an effective customer. Such a support system should work with and act as a customer for aged citizens and their families in the community. Such a community system should extend back into regulatory structures, where the grassroots community should be represented and have real power. Accreditation and complaint handling are the two structures where such representation is most needed.

ACC’s primary interest in the proposed legislation is the unique opportunity it provides for confronting these issues and setting in place structures that have some prospect of reforming the aged care system so that it serves aged citizens and does not harm them.
5 Appendix A

5.1 The Elephants in the Room

While there are a multitude of factors contributing to problems in aged care, there are elephants in the room, elephants that we believe must be confronted if any progress is to be made and if the parlous state of our aged care system is to be addressed effectively.

The largest elephant is one that underpins many of the problems we see and prevents effective resolution of others. This elephant raises challenges to prevailing ideological beliefs in the infallibility of unregulated markets. As a consequence there has been unremitting wilful blindness and a failure to confront evidence and logical arguments.

1. Market Failure

This elephant in the room is market failure. A necessary condition for a market to work is that there be a body of knowledgeable customers, who have transparent access to information, the power to reject what the market offers, insist they gets what they want, and who can when they act together bankrupt those who fail to do so.

It is hardly surprising that mediocre services, poor care, neglect, fraud, exploitation, and a succession of scandals have characterised those sectors of society where this necessary condition has not been met. These include banking, share market trading, financial advice, etc.

But the market can be made to work when effective customers do not exist if there are independent and concerned groups in the community prepared to support and help their vulnerable peers. They can only do so if they have the capacity to be effective customers themselves with all of these attributes including the capacity to put a provider out of business when this is required. Such groups should be able to organise themselves effectively into a support system, working with, advising and acting for the recipient of the product or service.

It seems remarkable that in western democratic societies, where market failures resulting from incompetent customers are so common, this has not happened. Those who so ardently advocate for markets, including our politicians, have not sought to establish and support such groups. Reviews and inquiries have been studiously and wilfully blind to these suggestions in our submissions, and have not even mentioned this option in their reports. But there are more elephants in the room that explain why this happens.

2. The power of vested interests

The second elephant in the room is the power of wealthy vested interests that capitalise on the vulnerability of weak markets and whose financial success is threatened by a real market. Their wealth, their ability to use the media to create misleading perceptions and stir up the public, and the dependence of political parties on donations from the wealthy and self interested gives them unprecedented power and control over government policies and practices.

The precarious financial position of the press and their financial dependence on advertisements from wealthy businesses renders them vulnerable. They gain brownie points from the advertisers they depend on and boost their profits when they join in and promote the beat ups that protect market interests and threaten motivated politician's hold on power.
Markets have underpinned the success of Western civilisation, but until the middle of the last century they were balanced by a healthy constraining cynicism about their values and their compliance with community norms. Change, including spin doctoring, unbridled rhetoric and the decline in the analytic focus of the media have steadily impacted on this to the extent that a blind unchallenged ideology has ignored even the fundamental precepts that underpin markets. A good example is the response of the powerful mining interests to the proposed mining tax, and their success in enticing one party to gain political mileage by supporting them; and in doing so generating nonsensical political catchphrases to advance their election prospects.

In the 21st century the situation has deteriorated to the extent that the dominance of uncritical market thinking is now destroying community values and feeding on (ie. cannibalizing) the weaker and more vulnerable members of society. What is happening in aged care should be a wakeup call resulting in critical analysis and logical action. What we are seeing is any thing but - only a flock of ostriches with their heads in the sand.

3. The political process

The third elephant in the room is the dysfunctional nature of the political process. Political self-interest and political opportunism has so dominated public interest that it is now impossible for any political party to pass important legislation without risk of losing the next election. The appalling behaviour of politicians over the last 6 years builds on a steady deterioration during the last decade of the 20th century, escalating during the 21st.

Like most thinking Australians ACC is deeply disillusioned by the political process. Australians do not vote for parties but against them. Most Australians would probably vote for any other credible party in preference to the current two if there was such a party. Disillusioned citizens have disengaged. To their shame, instead of reforming the system and behaving responsibly, politicians have capitalised on this by attacking the credibility of opponents and relying on emotive catchphrases rather than reasoned discussion of alternatives to muzzle debate and promote their political prospects. They too have abandoned the values and norms which society expects them to adhere to. No party is innocent in this regard.

5.2 A threatened society

Competitive markets are impersonal social mechanisms that, in essence, depend for their success on the balance between two conflicting interests, both driven by the self-interest of participants. It functions equally well in democratic and totalitarian societies. Competition between these competing interests means that both will seek to advance their positions. They will try to control and if that fails have the support of rulers whether they be totalitarian or democratic.

When one group succeeds, legislators create situations that favour them. Instead of legislation to maintain or restore balance they ensure that the balance is lost and markets fail. One or both of the competing interest groups suffers.

The world is threatened not only by global warming and overpopulation. Social order is threatened, and western democracy is under attack, from radical fundamentalism of several types, many of which embraces terrorism as its weapon.
At this critical time western democracy is being weakened and undermined by an imbalance in the market forces on which its society's wellbeing and strength depends. Not only has the balance of forces in many markets been lost, but some sections are eroding democracy's value systems and cannibalising society by preying on its weaker members.

It is sad that at a time when the western democratic world needs real leadership and a flourishing democratic process, the political process in countries like ours is immobilised and the citizens who should be debating these issues are disillusioned and disengaged.

Worse still the structures of government and society seek to exclude citizens from involvement in the structures of society and in serving their peers. The opacity and lack of transparency in all government activities, disempowers society and prevents members from being involved and contributing.

5.3 The challenge and the opportunities

As Churchill famously said democracy is not a stable system but it is the best we have. Its foundations are inherently weak containing the seeds of failure. Its unattainable ideals are repeatedly threatened. It succeeds to the extent that society and the political process embraces, identifies with, strives to reach those ideals and challenges each threat to them.

Nowhere are the effects and consequences of having these elephants in the room more apparent than in aged care, and nowhere has the wilful blindness to their presence had a greater impact on vulnerable citizens than in aged care. The sector has failed society miserably.

Aged care presents a unique opportunity for politicians to reform their ways and unite in a bipartisan effort. The election is over and political grandstanding has lost its gloss. Aged care provides an opportunity to take the first steps to confront the elephants in the room, address the problems they create and rejuvenate, not only aged care, but our democracy and our society.

These Principles provide a unique opportunity to invite citizens into the process, engage them, and so take the first small steps towards rejuvenating our democracy and leading western democracy back from the brink. The Accreditation system has failed citizens and this is consequent on the structural failures consequent on these elephants.

Involving citizens by placing the community and its citizens at the centre of government and its regulatory processes and giving them power there lies at the heart of the democratic ideal. Aged care desperately needs them there. ACC challenges politicians to seize the moment, grasp the nettle and restructure these Principles as the first step in bringing citizens into government structures and giving them power there.
6 Appendix B: Links

Below are a series of links to articles, which illustrate the significance of the issues raised in this submission.

- Nursing home deaths spark concerns over aged care complaints system (ABC, 7 Nov 2013)

- OPINION: Courts strong avenue for battling neglect (Newcastle Herald, 28 Oct 2013)

- Sydney family sues Parramatta nursing home after grandfather’s death (ABC, 18 Oct 2013)

- Court told how a nursing home went to extraordinary lengths to hide the truth about the death of someone’s mum (Herald Sun, 6 Oct 2013)

- Freedom from information: A case study (ACC, 14 Sep 2013)
  http://www.agedcarecrisis.com/freedom-of-information

- Call to set up independent aged-care watchdog (The Age, 25 Aug 2013)

- Care crusade (The Age, 25 Aug 2013)

- Aged Care Accreditation in the spotlight (Lateline, 23 Aug 2013)
  http://www.abc.net.au/lateline/content/2013/s3832828.htm

- No staff for 10.5 hours per day
  http://www.agedcarecrisis.com/yoursay/4611-no-staff-for-10-5-hours-per-day

- Oh no! Not another aged care inquiry – but this time it might really matter: (Dr Wynne)
  www.corpmedinfo.com/agereport.html

- Australia’s ageing aged care system (ABC Radio National - Peter Mares): 29 May 2009

- Nursing Home Transparency: www.agedcarecrisis.com/nursinghomes/transparency

- Ageing Bonanza: www.agedcarecrisis.com/nursinghomes/ageing-bonanza (Dr J.M. Wynne)

- Regulating nursing homes: The challenge of regulating care for older people in Australia
  (John Braithwaite, BMJ 2001):

- Behind open doors – A Construct of Nursing Practice in an Australian Residential Aged Care Facility:
  [PhD -Anita De Bellis, Lecturer, Flinders University, South Australia]:

  www.abc.net.au/7.30/content/2006/s1592672.htm

- Consumer participation in accreditation - Resource Guide (Consumer Focus Collaboration)
