

31 July 2009

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Re: Review of the Aged Care Complaints Investigation Scheme

Attached please find my submission to this review. Hopefully the very different ideas that some of us have been debating, and the sort of processes that would result will stimulate discussion that moves beyond patching the present system.

A very similar submission has already been submitted to the review of the accreditation agency. The problems in the accreditation agency and in the complaints scheme are similar and interrelated. The solution I am advocating involves both and would address many of the problems both have. I will therefore not remove all of the sections dealing with the accreditation process. How they might fall together will be more apparent.

I will however expand on the complaints scheme and explain how it could operate better and meet its objectives while at the same time bringing some resolution to those who suffer the anxiety, pain and anguish that comes from concern about mistreatment of a loved one, whether it be real, or based on a misunderstanding.

Signed: _____

J Michael Wynne

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1 Summary

This submission comes from an outside and very different perspective to that which currently prevails in the sector.

It uses this perspective to critically examine what has happened to the nursing home sector over the last 12 years and to identify what appear to be key and very fundamental problems not only in the whole sector but particularly in the accreditation and complaint handling processes. It is clear that there is insufficient information and that the accreditation and complaints processes are not working for the community.

Four key problems for the Complaints Scheme are identified:

1. The disenfranchisement and disempowerment of the community
2. A lack of on site empathic person to person communication
3. An excessive emphasis on process rather than resolution for the parties
4. An almost total lack of transparency

It is suggested that the key to redesigning both accreditation and complaint handling is to place the community at the centre of both processes and give them responsibility.

To show that this is a real and a practical possibility and not a pie in the sky cop out, I have outlined a possible model in some detail. It is not intended to be final or definitive but to open discussion. There are problems and to be successful the community must embrace it and become involved. For this reason its implementation will require careful and staged introduction and close monitoring.

The consultation paper opens debate by detailing some of the areas in which the complaints system has been criticized. Simply addressing individual items will do little more than tinker with the problems which are systemic. They will not disappear.

This submission examines the consultation paper and shows that, with a model like that proposed, objectives will be better met, processes will be simpler and more effective, and it will be far less burdensome than either the current system or any of the modifications proposed. Many of the issues will simply drop away.

Because the way we use language has played an important part in what has happened in the past, and because it will play an important role in any fundamental changes made, I have included an appendix in which this is explored.

2 Introduction

I have examined the document titled "*Consultation Paper : Aged Care Complaints Investigation Scheme*". It describes the process whereby decisions are made but gives very little information about how the matters are dealt with and in particular how the complainants are dealt with. As always the devil seems to be in the details, and in particular the way in which the word "may" is interpreted. Many complain that witnesses are not interviewed, offered evidence is not examined and that communication is delayed and impersonal.

It is here that the problems lie. If no solace is provided, and if the parties are left aggrieved and hurt because there is no resolution for them, then it matters little if "natural justice" is provided. The current process is excessively legalistic. In my view all of those cases aired on the recent Four Corners programme could and should have been resolved in a way that salved the hurt they had suffered.

There have been many complaints about the aged care system and these reflect the anxiety and unhappiness of those in the community who have examined the aged care system, lodged complaints or tried to get meaningful information from it. There is a sense of disenfranchisement, distrust, disbelief and suspicion as a consequence of the lack of transparency and the unsuitable and often meaningless nature of the information that is publicly available. The recurrent scandals, and the way in which the press pick these up as newsworthy, is a measure of the distrust.

In this submission I will summarise why I believe this is so and explain the consequences. I will then outline the sort of changes that I believe are necessary if we are to move forward. I will then look at how this will apply to the complaints scheme. I will indicate how, if these changes can be made, this will accomplish the objectives far more effectively, and most of the contentious issues will fall away.

I come to this from a lifetime providing care to citizens including the aged, but I come to nursing home care as an outsider looking analytically at the information available. I have had experience in dealing with patients unhappy about what has happened in hospitals or about the medical care they received. What has been critical in these situations is not whether something was done wrongly, but the nature of the communication and what was done about the complaint whether justified or not at the time. I have also been present as an observer when a community group met with the department to consider unresolved complaints. It was clear that the scheme was severely deficient in this regard.

An outside position may lack in detail but may still provides important insights that are not readily apparent to those directly involved. They may even be strongly denied by them.

Many who have had close contact believe that like other major Western countries nursing home care falls far short of what it should be. They question the exaggerated claims that are made about it.

This submission tries to bring a rather different perspective that will throw a new light on many of the problems. There are some background issues that underpin the suggested changes.

3 Background

The *Aged Care Act of 1997* was a sentinel event that reflected the political imposition of patterns of marketplace thinking that were already intruding into aged care. The act turned community focussed not for profit nursing home care into a competitive market and brought into it the values and norms of the marketplace. While community values still get lip service, they have been progressively replaced by market thinking by management. Marketplace parameters become overriding when decisions must be made. Legal considerations dominate when mishaps occur and when there are complaints.

3.1 Motivation and management

Organizations and individuals providing care now enter the sector for very different reasons to the past. These are often primarily economic. Government have seen the primacy of self-interest as the solution to their difficulties in funding and have encouraged it. Whether the changes introduced in 1997 were necessary or simply the inappropriate application of ideology can be debated but this debate is now irrelevant. The consequences are not.

The managers of market listed and private equity corporations have a “fiduciary duty” to put the financial interests of their shareholders first, i.e. before that of the welfare of their residents. While this may be modified by a personal or even corporate sense of social responsibility, the patterns of thinking that have developed in the marketplace are deeply entrenched in management and are given expression in the way they manage and in the way they motivate staff. The dissonance created for existing staff, who entered the sector for very different reasons, is profound. This causes discontent and impacts on care. Responses to complaints from staff and management are likely to be defensive rather than engaging. This gives offence and arouses suspicion.

The not for profit religious groups still dominate the sector and we would not expect this criticism to apply to them, but it has impacted on them. While there may well have been concern about their financial management in 1997, the change in 1997 went much further than reforming financial management. It drove the churches to bring in trained market managers from the business world to run their operations. These managers brought their thinking, their training and their ways of motivating staff with them. So while the changes are less profound for these groups they are not insignificant.

3.2 Care and profit

That a strong market focus is linked to less staff and poorer care has been demonstrated repeatedly in the USA. This reflects the competition of care and profit for the same dollars. The sort of information to demonstrate anything like this is simply not available in Australia.

The limited information that has been collected and collated by the Aged Care Crisis Team in Australia suggests that if a correction is made for regional differences then for profit nursing homes are 4 times more likely to fail to meet all 44 accreditation standards than church run nursing homes. This requires further validation and an in depth study.

3.3 Secularisation and charity

The increased secularisation of our community has meant fewer committed participants in religious “good works”. Churches have had little choice but to employ others to operate their hospitals and nursing homes. While many Australians still profess to be church members, the active participation of our community in religiously organised community activities has fallen -- particularly among younger members. The complexity and level of managerialism in hospitals and nursing homes contributes to their disengagement.

Secular groups now play a greater role in charitable activities in the community. They do not operate hospitals or nursing homes. If we are to build community and foster a civil society that will support nursing homes then I suggest we need to support and involve them.

This changed society must be considered when planning. While we must learn from it we cannot go back to an imagined and idealised past.

3.4 History of the community's involvement in aged care

The care the aged receive has been, is, and, I suggest, must remain the ultimate responsibility of family, friends and the local community. The health and aged care systems have grown from their involvement and from the leadership provided by the churches.

The community have in the past turned to their own members and to the churches when they have been dissatisfied with care. They have contributed to resolution. The importance of contributing to the correction of a problem and to making improvements cannot be underestimated as a means of resolution.

Complexity and cost have combined to make it necessary for the community to seek funding from and then later delegate some of the care provided to government.

A government, reluctant to shoulder the capital costs and the burden of ageing, has enticed the market into the sector and paid them enough to invest in the care of elderly citizens.

There is an expectation that these delegated entities will provide care within the community's value systems and be accountable to them. When things go wrong there is a feeling of responsibility, and perhaps some guilt in the community. It helps when they feel that they have contributed constructively to change.

3.5 Cynicism and distrust

The emergence of cynical terms like "wrinkle ranching", "profit body", and "people farming" suggest that the implications of the changes in 1997 are being recognized. There is a sense of betrayal. A buyer beware mentality is emerging.

The very nature of nursing home care when bundled as a commodity is such that the product will of necessity be flawed – outcomes will ultimately be unsuccessful. In such an emotive area many "customers" will inevitably be aggrieved, angry and questioning of the product purchased. As a commodity, aged care has future unhappiness with the product built into it. Additional care is needed to address their hardly unexpected suspicions.

Financial and staffing constraints operate in a sector that is open ended so rationing is necessary. Market strategies promote and promise in order to sell so creating expectations that the system is unable to meet. Rationing requires community involvement, understanding and the sharing of responsibility.

3.6 Language and Cognition

The Canadian thinker John Ralston Saul has pointed out that language is not only the tool we use to understand reality, it is also the way we obscure reality and make ourselves unconscious of it. These insights build on a long line of philosophical thought. By changing the words we change the way we think and understand.

The changes introduced in 1997 brought with them not only a different pattern of thinking but a new range of words. The new lexicon and the ideas they support position nursing home care within a broader framework or “industry”. In doing so they removed its uniqueness, and masked the reasons for treating it differently.

The new lexicon enables a wealth of rationalisations for the providers of care. It anaesthetises those near the coal face to the heart wrenching emotionalism and tragedy of the last years of life. The sensibilities of the community are dulled, and they lose their sense of responsibility. The uniqueness, the emotion and the pain are wrapped in insulating words and packaged. Family become customers sold a product, rather than interested and involved participants.

As the handling of complaints has become formalised and legalised, a lexicon to accommodate complaints, complaints mechanisms and appeal processes has similarly come to separate the angry and painfully aggrieved from resolving their pain and from ensuring that others are spared. People know that others are not perfect. Ill considered outright denials fuel suspicions.

As ageing is “normalised” and “de-medicalised” with words there has been a flight of doctors from nursing homes. This is a population with a far higher incidence of complex illnesses, one where diagnoses and critical decisions are difficult to make. The sparse nurses simply do not have the time or the training, and nurse aids are out of their depth. This lack of diagnosis and appropriate action in the face of clinical deterioration is a common complaint. Doctors have an important role both in providing care and in dealing with patient’s complaints. They have the authority and standing to both act in the nursing homes when things are wrong, and to explain what is happening to family. They are not playing it.

(Because of the important role that language has played I have added an appendix: [Appendix: From Semantics to doctors](#) to this submission where the issue is explored further.)

3.7 The Complaints and Accreditation Systems

The community have been disenfranchised, disempowered and deprived of information. The accreditation and complaints system are responsible for this.

3.7.1 Complaints

Members of the community making complaints have become supplicants to an arbitrary and largely impersonal and legalistic process concerned with rights more than resolution. They are often left bruised and unhappy about decisions that seem incomprehensible and unjust to them.

This is what you would expect from an agency distant from the homes that during the 2007-8 year was asked to address 11,323 complaints made by people it did not know and often did not meet.

The recent ABC Four Corners program illustrates this well. In my view every one of those complaints could have been negotiated and resolved satisfactorily by the provider and the local community, if they had used an empathic and understanding personal approach. All parties could have been spared anguish and cost.

3.7.2 Accreditation

The limited information made available to the public by the accreditation agency is of little value. It is largely meaningless to the public. The information is inadequate for any meaningful research. This points to the agency's origin as a product of ideology, rather than a considered process of reform.

Arguably, both the accreditation agency and the complaints system were set up by the government in 1997 to counter criticisms that financial pressures in the market would compromise the quality of care. It was a political response to neutralize criticism - forced to operate and to show that it was successful. Unhappiness with the complaints system resulted in a revised system in 2007. It is apparent that critical issues were not addressed.

3.7.3 Consequences

Both processes have been modified and strengthened repeatedly in response to pressures from the community after recurrent scandals in the sector. At no stage have the underlying problems or the disenfranchisement of the community been addressed.

As a consequence the accreditation system has become ever more onerous for nursing home staff, and the community ever more disenchanted with the information provided and the way complaints are addressed.

Both systems need major restructuring. The problems are similar and the solutions interrelated.

3.8 Standards of care and the validity of complaints

There are conflicting messages coming out about the quality of care in nursing homes and about the resolution of complaints. The exaggerated claims from politicians and the industry must be set against the concerns expressed by the nurses, by the press and by those members of the public who have adverse experiences. These differences are very probably a reflection of the differing "conceptual worlds" each has inhabited since 1997. That the latter is the more accurate viewpoint is suggested by experience elsewhere. It is also suggested by the emergence of community groups critical of the provision of aged care and advocating for change.

In the accreditation program Australia has followed the USA where there can no longer be any doubts about the serious problems that exist. Our accreditation system is modelled on theirs. Both have been subject to repeated failures. The US JCAHCO continues to make exaggerated claims and present itself as a model for others. It does so in the face of its many failures – a characteristic of the modern competitive marketplace. (see http://www.corpmedinfo.com/hospital_accreditation.html)

The actual standards of care in Australia's nursing homes and the validity of the current resolution of complaints are not critical to my argument here. What is critical is that we do not have the information to make valid decisions in regard to either, and that neither is working for the community.

While both DOHA and the agency may have brought in outside agencies to review their practices, this has not resonated with the community or satisfied them. It has not been positioned within frames of understanding and fields of relevance that they relate to.

What must be done if accreditation, oversight and complaints are to work is to fully engage the community in the process and to produce valid information that will mean something to them.

3.9 Critical problems for the complaints scheme

Critical underlying problems in the current complaints scheme include

1. The disenfranchisement and disempowerment of the community
2. A lack of on site empathic person to person communication
3. An excessive emphasis on process rather than resolution for the parties
4. An almost total lack of transparency

3.9.1 Personal Experience

Personal experience often presents a one sided argument but I think mine illustrate the many problems well. I have been involved in resolving unhappiness about hospitals, unhappiness about the treatment I have given myself, and when there have been complaints about other doctors. I have taken up issues in the hospitals in which I have worked. I have also, as a relative, complained about the treatment given to a family member in a hospital and to authorities. In the later instance I met a brick wall and became suspicious. What I uncovered ultimately cost the large multinational many millions of dollars. It was forced to sell up and leave Australia.

Critically important in resolving any complaint is a sympathetic and understanding hearing, preferably by someone the complainant knows and already trusts. The most common cause of litigation and unhappiness is a lack of person to person interaction and simple people skills. The most serious errors that can be made are an outright denial, an attempt to demean or belittle, an attempt to claim superior knowledge, to embroil the family in a drawn out process, or not to properly address issues when they are real. Problems can be addressed and improvements made promptly, with gratitude and grace, and without admitting fault. Briefing on process and, where possible, direct involvement in resolving the issues provide a sense of involvement and fulfilment for the complainant. It is clear that this is not happening in aged care.

It was once routine for a doctor to take up issues directly with the ward sister or medical superintendent and together they would sort out the problem, talk to the nurse responsible etc. I vividly recall when the system in my hospital was changed to structure it, and a formal process instituted. When there was a complication in one of my patients due to bad nursing, I was told by the ward sister that she had been told that complaints like this now had to be put in writing as complaints were being dealt with officially. I did so. What would and should have taken 24 hours took months. After nagging on my part I got a non-information response clearly written by a lawyer. Had the patient's complication not responded, and had the patient elected to sue the hospital for damages I was sufficiently off side to give evidence, describing my inability to have the matter addressed. Ensuring that patients were as safe as possible was my responsibility and I was given no assurance of this.

In the case where I complained as a relative (not in Australia) after a family member died, remediation required the hospital to deal with the way one group of its referring doctors practised and to arrange for some assistance and training in organising an intensive care unit. It was a very profitable hospital and this would not have cost much. I was in a position to assist and was willing to do so and cooperate. When I met a brick wall I became suspicious and started making my own enquiries. I learned much they would not have liked me to know. I considered this a risk to others and I decided to act.

The Medical Council suspended two doctors from practice. The hospital paid many thousands of dollars in legal costs and damages. When I followed up the local matters, I had heard about, I obtained detailed information about a subsequent US \$1 billion scandal and criminal convictions involving patient exploitation and mistreatment by the parent company in the USA. I made this information available in Australia. The company, lost many millions of dollars more in Australia as opportunities were closed off. Things became so unpalatable that they were forced to sell up and leave the country.

Instead of learning from their mistakes and addressing the issues this company remained in denial. It promoted some of the staff involved in similar practices, but not directly accused, into senior positions in the USA. It is not surprising that some years later it was involved in a second scandal that cost it about US \$2 billion in settlements. The administrator of the hospital where I had complained was one of those brought home and promoted. He had personally negotiated lucrative contracts with doctors in the USA. These were probably similar to the unethical ones I had heard about years earlier. Two doctors were encouraged into carrying out over 500 unnecessary coronary artery open surgical bypass operations with some deaths. This was a significant contribution to the US \$2 billion payment.
(see http://www.corpmedinfo.com/entry_to_Tenet.html)

This is clearly an extreme example but it was the second largest company in the USA. A single mistake could seldom have been so costly. It illustrates particularly well what can and does happen when commercial or other interests intrude into, and frustrate the normal human to human interaction that underpins, constructive debate and improvement.

Had these hospitals and their senior staff been forced to interact with doctors and community before making decisions many of the rationalisations that resulted in self delusion and these unfortunate actions, would have been stripped away. Unlike most in Australia, US doctors have been dis-empowered by restrictive contracts. Those who spoke out about what was happening were hounded and their careers destroyed. Powerful commercial entities are in a credible position and become so filled with self-importance that they disregard critics as irrelevant or out of touch.

In Australia Mayne Health did exactly this, in about 2000, a new Mr Fixit rode rough shod over doctors' arguments. The specialists in the hospitals had retained power and exerted it forcefully to protect their patients. Mayne paid a heavy price and eventually sold all its hospitals. A situation similar to the USA seems to be developing in some sections of General Practice in Australia. Doctors are being trapped in contracts. These restrict their capacity to negotiate for their patients. They lack the power to constrain corporate practice owners when management policies intrude adversely into care.

A similar situation exists in nursing homes in Australia today and there is much to suggest that care has suffered as a consequence. The professionals in the nursing homes are the nurses. As employees they lack the power to act. They do not speak out lest they lose their jobs. The proposal I am making very specifically puts the community in possession of the knowledge and the negotiating power needed to successfully challenge owners when what they propose is not in the best interests of the residents and the community. The community's representatives will also give an ear to the nurses.

3.9.2 The aged care complaints system

I was asked by a local community group to attend a meeting with senior members of the Complaints Investigation Scheme (CIS) in Brisbane. The group had acted to assist families with complaints. They were very unhappy about the outcomes and had spoken out publicly. What became clear was that the investigations were primarily concerned with the processes to be followed rather than the human experiences and frustrations of the parties involved. Complainants were often not interviewed and the evidence that they had carefully collected not inspected. They were often notified of decisions in writing. Although the meeting was amicable and the department professed a real intent to review some of the cases I understand that the matters dragged on and outcomes were far from satisfactory. In my view this was because they were frozen in processes and simply did not have the capacity to respond appropriately to the situations.

I was told by the group that an investigator, speaking on the phone, had responded to a question asking why he had failed to interview a nurse, who was a key witness. He had responded that the nurse had been fired (or was it resigned?) after a dispute with management and so lacked credibility.

It is this sort of attitude that destroys the credibility of the scheme and any confidence in it. Complainants have no means of knowing whether their complaints have been fairly investigated or not. Past experience with the all too common failure of systems that lack transparency fuels our distrust and anger.

3.9.3 A failure to meet even basic requirements

In the provision of empathic person to person communication, and in pursuing resolution for the parties rather than process the scheme fails miserably.

DOHA may see the scheme's primary role as documenting whether there have been failures in care, whether action should be taken against the home or whether follow up visits of any sort are required. A process of careful documentation may be required for this. These are important but secondary considerations, and are not necessarily the reasons the family member made the complaint. In most instances they seek to protect a loved one or to spare others what they perceive as similar mistreatment. Sometimes they simply want it sympathetically acknowledged that there was a failure. The process does not help them in this.

Those who actually complain represent only a small sample of the many with concerns. By their very nature, and the nature of the business and legal systems, the majority of complaints will be impossible to resolve one way or the other. They will be denied, become acrimonious, and few witnesses will come forward. Family members who have witnessed events and then plucked up the courage to speak out are furious when the person responsible simply denies what happened, is supported by management and is believed. The more rapidly a complaint is dealt with, the less acrimony there is. There is less opportunity for attitudes to harden.

Decisions about care and about follow up visits require far more perceptive monitoring of what is happening, and an ongoing presence. Informal contact with others likely to have had similar experiences helps enormously in building a picture.

3.9.4 A total lack of transparency

Nothing infuriates and fuels distrust more than secrecy and distant bureaucracy. No one knows what has been done to investigate their complaints, what the explanations given were or how many similar or related complaints have been made against the nursing home or its owner's other homes. They have no assurance that their observations will have been taken seriously, and even if denied will result in closer surveillance and increased penalties if the home is later found to have similarly denied proven instances. For them the entire process has been conducted by strangers.

3.10 Critical problems for the accreditation system

This section is retained in this submission to show how closely related complaints and surveillance are and how their problems can both be resolved in the same way.

Critical underlying problems in the current accreditation system include

1. The disenfranchisement and disempowerment of the community
2. Conflicting roles for the agency.
3. A failure to collect useful information
4. An almost total lack of transparency

To a significant extent problems 3 and 4 can be seen to be a consequence of the original objective to counter criticism as well as to problems 1 and 2. Most of the problems critics identify, including those referred to in the departments discussion paper are a consequence of all four.

Persevering with the present structure for accreditation as is suggested by the discussion paper is not going to resolve the criticisms.

3.10.1 Conflicting roles

As the discussion paper points out the agency is charged with supporting and assisting nursing homes to put in place processes that will result in good care. At the same time they are charged with policing the standards of care and are ultimately responsible for the information that results in penalties being applied.

Although not unrelated the roles of teacher on the one hand, and overseer and policeman on the other are contradictory and should be separated. They create tensions at multiple points. Most have been cited as the reasons for failure of oversight in the USA. Their presence fuels distrust.

The financial pressures in a market are very different to those in a school, university or even a child care centre. Either the agency should be split or there should be two arms. The oversight role should be more closely aligned with the complaints system.

Particularly concerning is the recently publicised information that almost half (5 of 12) members of the agency's board are drawn from the industry. While appropriate for a body that supports and trains the industry, it is totally out of place for an oversight body whose findings can and do put nursing homes out of business. To remain credible this must be stopped. It confirms that this agency was set up to support and assist the industry, and not to police it. That has been glaringly apparent to outside observers.

3.10.2 Collecting information

The agency's focus has been dominated by its support activities and by introducing and supporting processes that will provide good care. The accreditation assessments consequently focus on process rather than outcomes. Oversight and punishment have been tacked onto that.

There is insufficient information to determine whether the processes are achieving their objective and any information available is not readily apparent to the community. There is no information about the acuity of residents' needs, and little if any assessable data about the incidence of complications, adverse events, medication errors and other failures in care or the quality of life of residents.

Either the nursing homes do not audit their services by collecting this information, the information is so unreliable that it is not worth using or the agency does not want to collect it. This must change if it is to become credible.

The community need to know what sort of care the local nursing home is providing, care which their family members will receive and which they will one day be subjected to. They are less interested in process. Without assessable information documenting care it is impossible to compare services, do any useful research, or engage in assessable "continuous improvement".

No one can provide perfect care. That almost all homes achieve a rating of 44 out of 44 is an illustration of its current lack of utility, and its lack of value for family and community as well as for both continuous improvement and scientific assessment. Veteran US health care legislator Pete Stark has criticized accreditation in the USA as little more than a marketing tool. Is this different?

3.10.3 Transparency

Of the over 8000 visits and/or reports made to a little under 3000 nursing homes by the agency and by DOHA in the 2007-8 year only the 513 accreditation reports are publicly available. The vast majority, 426, of these accreditation visits were done 3 yearly at the request of the nursing home, at a convenient time, after the homes may have spent months preparing. They tell us that the nursing home knows what it is supposed to do but gives no information about what happens on the other 1,093 days of the cycle. Useful for those motivated to care, they are of no value to a community, anxious about those who lack motivation.

During this period only 87 of the accreditation audits were initiated by the agency for other reasons. In 38 a date was arranged and the home had time to prepare. Only 49 were unannounced and give any information about what happens on a day by day basis. It is also unfair to the homes as Murphy's Law will apply, visits coming on days when everything goes wrong and half the nurses are sick.

Not only is the information of little relevance to the community, but so little is released that no conclusions can be drawn.

Legislation stipulates that a home's response to adverse finding be publicly available. In spite of this responses can be made in a form not publicly available. The agency seems to encourage this. Not a single response was available during 2007-2008.

For whatever reason there are often delays in reports becoming public. Adverse reports are removed as soon as a new report showing compliance is produced. Neither the track record of the nursing home, nor that of its owner can be ascertained.

This is a travesty, and makes a mockery of claims to transparency and accountability.

4 Addressing the failures in accreditation and complaints

I have participated in ongoing discussions with community groups in Victoria and Queensland over the last year. Both are critical of the system we have. We all realize that it is not enough to simply criticize. If we want change we need to press for the sort of changes we want, changes that will give us the sort of information we need to make useful contributions into the future. While some of the details of what I will suggest may be my own, the general thrust of the suggestions and most of the proposals come from the discussions with and the experience of these groups.

Key reforms required include

1. Splitting the accreditation agency
2. Re-enfranchising and re-empowering the local community by placing them at the centre of the oversight and complaints processes. They must be in a position where they can support complainants, as well as mediate and negotiate outcomes with nursing homes and their owners.
3. Collecting the sort of information that is useful to the community, that will indicate when problems are developing long before we have a crisis, and that will form the basis for accreditation, ongoing debate and research.

Australia has not experienced the same problems in its corporate for profit hospitals as has plagued the USA. I believe that this is largely because the specialists who work in these hospitals have, unlike the USA, maintained their independence. Their careers their rewards and their professional standing are allied with the interests of their patients. They control the admission of the patients from which the hospitals make money and have demonstrated that they can and will bankrupt any group that introduces practices that impact adversely on care.

This forces the owners to confront their own rationalizations and give credence to professional and community value systems. Because the doctors and the accreditation process are generally congruent the latter makes a useful contribution. While the power doctors hold, frustrates the market and its supporters and can be criticized, in this instance it has protected Australians.

To be successful any changes must bring the community and the medical profession back into nursing homes. They should have sufficient leverage to ensure that the views and the value systems they espouse are serviced.

4.1 Historical Background to the proposal

I am going to suggest that the deficiencies in the accreditation and complaints processes can be best addressed by moving the focus of both into the local communities.

These ideas are not novel. I do not have details but I believe that the Hawke government considered a plan to monitor nursing home care by using trained and empowered members of the community during the 1980's. Instead oversight of nursing homes was handed to state departments. The federal accreditation process replaced this in 1997 and 1999.

The concept however was not lost. There are what are called "visitor" programs that I am aware of in Victoria, NSW and Queensland. These are very different to the visitors used by the commonwealth in nursing homes.

Provisions in state legislation ensure that these visitors have the powers to examine confidential documents including medical records, as well as interview staff, relatives and management. These

“visitors” are trained. They monitor the care provided to those who are impaired and unable to care or act for themselves because of physical or mental impairment. They do so in an ongoing manner by visiting regularly and usually unannounced.

In Victoria the visitors are independent volunteers but in Queensland they are government employees. In both instances they report back and are responsible to the government department. In these states the visitors do not visit nursing homes.

4.2 Position

The pattern of thinking underlying these proposals acknowledges that in a capitalist market society, the market has been and still is a very successful mechanism for serving the community – as has been the church in the past. Both are however a component of that community. Both must accommodate to the values, norms and requirements of a balanced community when serving them. To ensure this, the involvement of the broad community is essential

The history of religious extremism both past and present attests to what happens when belief systems escape. The current economic crisis is another good example of the consequence of society relaxing its oversight of the market and handing over control. No belief system is universally applicable or magically self-correcting.

This thinking further asserts that the care of the aged and infirm is unique in that it is a humane empathic interactive activity provided at a time of personal emotional crisis. It is in essence, a responsibility of friends, family and community. It cannot be subjected to the dictates of an impersonal mechanism.

Those who of necessity carry out that function are doing it on behalf of the community, represent them, and function within the parameters the community sets. The community is involved and is entitled to be informed and to take such steps, as it needs to satisfy itself that its expectations are met.

5 Outline of suggested changes

This proposal builds on suggestions I made in a submission to the Community Affairs Reference Committee's review of the proposed 2008 amendments to the *Aged Care Act 1997*.

(http://www.aph.gov.au/senate/committee/clac_ctte/aged_care_amend_2008_measures_no2/submissions/sub16.pdf)

In the proposed restructuring of oversight and complaints mechanisms, selected community representatives (visitors) will be trained, supervised, mentored and paid by the federal aged care department. They will comprise the front line in addressing complaints, in monitoring standards and in collecting information for the oversight section of the agency and the complaints section of DOHA. They will be drawn from the local community, be appointed by them, be supported by them, be responsible to them and report back to them in broad terms that do not breach confidential patient information. Their appointment will be subject to the approval of DOHA as well as the oversight section of the agency. They will have a personal supervisor in each. Both will receive detailed reports.

A local community committee will play an important role. The roles of the representatives will be wider than handling complaints and oversight. They will act as independent facilitators and mediators, oiling interaction between community, residents, relatives, resident committees, complaints system and both sections of the accreditation agency

Such an arrangement will put the local community at the centre of the provision of aged care to their members. DOHA will oversee this and will monitor its effectiveness and intervene when it is required. The community will be in a position to formulate opinions and convey these to DOHA or to the manager or owner of nursing homes. There will be consultation.

What is important in any revised system is that the broad objective of re-engaging and empowering the community be met and that they play a key role.

To indicate how such a system would work and how it will address the deficiencies in the current system, I will describe one possible scenario in detail by looking at the roles of the parties. I want to show that it can be done, that it is a practical alternative, and how it would work; then to look at possible problems. This is not intended to be definitive or final.

6 A different model for accreditation and complaints

6.1 Structuring the community

DOHA would identify local communities that had one or more nursing homes and/or hostels but probably not more than 200 residents. The community should also have charitable and/or other community groups that take an interest in and play a role in the community.

These community groups would be asked to appoint a representative community committee of at least 4 but preferably more members. They need not be members of the community groups but should not be specifically connected to or have a financial or other interest in nursing homes. There should be no conflict of interest.

The community representation on this committee might need to be tailored to the local situation. In some regions small groups under a larger central committee might work better. It is anticipated that where possible at least one of the committee members would have nursing or medical experience, and another would have past experience as a carer.

This committee would find at least 2 suitable people within the local community to appoint as the community's representatives. These might be part time or full time depending on the work load. Education and some medical, nursing or carer experience would be desirable whenever possible. The final appointment would be subject to ratification by DOHA and the agency. Under extreme circumstances DOHA may appoint representatives without the approval of the committee but only subject to the approval of the aged care commissioner.

6.2 Initiating role of authorities

DOHA and the oversight section of the agency would

1. Define general employment requirements and guidelines for the selection of representatives. This would not bar the committee from adding some to suit the local situation.
2. Train the representatives for their role in the collection of data, oversight and complaints resolution. While the manner in which nursing and other care processes are carried out will be monitored, the focus will be on outcomes, standards of care and on quality of life. Technology will be used to support this. The emphasis of the complaints section would be on resolution and correction of failings and not only on fault finding or exoneration.
3. Set up reporting processes for the representatives and provide representatives in each area with a mentor and supervisor from both the complaints sector and the oversight service. They will maintain contact, consult with and supervise the representatives.
4. DOHA and the agency will be supplied with data by the representatives. They will collate and analyse this then make it public. They will track both the performance of the nursing homes over time, as well as that of management groups and or owners. They will report on this. They will track complaints and their resolution.
5. Supervisors will visit regions when required. They will verify the work done by representatives and meet with the community and with management. They may elect to mount a formal investigation themselves or may do so in response to a request from the representative or the committee.

6. Organize an annual national conference/meeting for local committees and community representatives. This will provide opportunities for networking. Sessions will be directed to sharing experience, discussing problems, reviewing the data collected and collated by DOHA and the agency, and for the presentation of relevant research. Research will be actively encouraged. The conference will elect a National Committee to act for and represent the interests of the community committees in national debate, in dealing with DOHA, the agency, politicians, industry, and other community groups.

6.3 The Accreditation Agency

A top priority will be the separation of the two conflicting functions of the agency, either as a separate entity or as two individual arms. I have recently learned that 5 of the 12 board members come from the industry. If board members from the industry are to continue in office then it is essential that the oversight section be split off as a separate entity and the new oversight section become much more closely aligned with the complaints scheme.

6.3.1 Supporting arm

One arm would operate as a support and educational service. It will work closely with the providers in a cooperative effort to improve processes and standards. Their primary function would be support. It will draw on the resources of the industry as there would be no conflict of interest.

Its primary focus will be training and remediation, ensuring that homes understand what is required. They will have access to information from the oversight and complaints sectors and will initiate support activities in response to this information or when requested by either. They will visit homes periodically to check on processes and discuss with the representatives, but these visits would usually be targeted. They will be largely educational for staff and representatives, so that they both know what is expected.

It is anticipated that this support will often be requested by the nursing home after discussions with the representatives and/or the community committee. Failure to do so when help is needed would be frowned on by all parties.

Except for new homes accreditation reviews in their current form would no longer be required. This section would report each year on the support activities that have been required for each home, by whom they were requested and, how these were embraced. Successful remediation would be among the factors contributing to continuing accreditation.

The prime purpose of this section would be to ensure that the homes knew what was required and that the processes were being adhered to. They would consult with the representatives in this regard when visiting for training or for any other purpose.

The presence of the representatives will go a long way to simplifying this facet of the accreditation process, by monitoring compliance, and making it less disruptive.

The final decision on continuing accreditation and Medicare funding would be based on the oversight record and the complaints record, as well as the accreditation findings. It would be made by the oversight section in consultation with DOHA.

6.3.2 The oversight arm

I have referred to some of the activities in the section on initiating the process. Staff would not be drawn from the providers, from those employed by them or those likely to be employed by them. Fewer staff would be required than at present. Their primary role would be in supporting and working with the representatives, the community chairpersons, and in resolving their problems.

They will be responsible for the measurements that will be made and for the oversight protocols to be followed.

They will collect the data, and be responsible for processing, utilization and publication. Information from the support section and from the complaints units will be incorporated in their reports. The track record of homes, companies, owners and sectors should be tracked so that changes in any direction are readily detected and early intervention taken.

The supervisors from this arm will do site visits to support representatives and to monitor what is happening. They will mount a full review when required. This is likely to be when reports indicate that the well being of residents might be at risk, when there are too many complaints, when the home is not addressing them, when remedial support has not been requested by the home, or when remediation by the support arm has not been effective. Such full reviews are likely to lead to penalties, withdrawal of accreditation, a forced sale or closure.

When tracking indicates that a home has become an outlier and is falling behind, all sections will mobilize resources to reverse the process. Situations where some signal event or the action of some whistle blower exposes a can of worms should be avoidable.

When the sort of recurrent tragedy, seen over the last few years occurs then the responsibility will also be because of community inaction or lethargy. They are responsible for appointing and supporting the representatives and this is something they will have to resolve and remedy. The responsibility is theirs and they will have to confront the families.

6.4 The Complaints Scheme

The Representatives will be pivotal in hearing out the complainant, which is what most require. The representatives will provide the empathic person to person contact and the negotiating skills that have been so sadly lacking. They will facilitate communication with management and may be asked or even elect to be present when complainant and management meet.

The supervisor will support and advise the representative and the representative will report to and consult with the supervisor.

The representative will have the power to investigate the complaint and negotiate the issue with management. The representative will monitor and report to the complainant on the findings made, ensuring that steps are taken to prevent a reoccurrence.

The representative will interview parties and collect information making copies to ensure the integrity of notes. Where a breach in care has occurred, it must be acknowledged and steps taken to address the matter. When a breach has not occurred the representative, who would by now have established a relationship with the complainant will explain this in person.

When a breach cannot be proven (eg. contradictory claims by both sides neither of which can be confirmed), it should be carefully explained to both parties that the matter cannot be resolved but has been noted and the situation will now be closely monitored.

A full complaint investigation by the complaints unit can be requested by the complainant, the representative, the community committee, an accused nurse, the nursing home, or by the supervisor. Hopefully this will not often be necessary.

The content of interviews and the findings of the representatives will be protected and not released in criminal or civil actions except with the permission of the persons and parties involved. The representative

can only be required to give evidence on things personally witnessed. The representative will not be required to divulge any information given in confidence.

Because the emphasis is on resolution and remediation the details of each case should be accorded similar privileges to hospital audits, but when the findings are used to initiate remediation or sanctions then this information and the reason for it should be available.

If it is in the interests of a complainant that they seek legal advice then this can be indicated to them but should not be actively encouraged.

The section will keep an overall record of all complaints made to the representative and the outcomes. The extent and nature of complaints as well as the facility with which they are addressed will be on the public record and in the representatives' reports.

The complaints scheme will have a joint responsibility with the accreditation system when the number and nature of the complaints indicates that a systemic problem is likely, that problems are not being addressed or that they are recurrent. The representative will in such a situation have been instructed to collect hard data preparatory to a formal visit by the complaints unit, the oversight unit or both. Such visits are likely to lead to punitive as well as remedial action.

This regulatory role will be a secondary one undertaken when the community representatives and the community themselves are unable to address the issues and drive remediation, or are frustrated in their efforts.

6.5 The Community Nursing Home Committee

The Community Nursing Home Committee selected by the community organizations should aim to have a representation that includes some nursing, medical or carer skills, as well as representatives of interested volunteer groups. It should have two functions, oversight and liaison with nursing homes, and the fostering of links between community, nursing home and residents. Members of the committee will be volunteers and not receive remuneration.

The chairperson or else a specified delegate will play a key role in working with the representatives when they are appointed. The representatives will become members of this committee and will be eligible to hold office as secretary or treasurer but not chairperson.

The expertise developed by this committee and the communication between the chairperson and nursing homes will place pressure on substandard care on the one hand and make the community more understanding of the difficulties in providing care and managing the ravages of slowly dying. They will understand the financial and staffing problems. The community will be better equipped and more informed when dealing with providers and politicians, and they act in the interests of the aged. They will play a positive role in motivating and acknowledging service to the aged, and good nursing care.

The committee will elect a chairperson and other office bearers. They will meet at least 4 times a year.

It is anticipated that the chairperson (but another could be delegated) will be the key person working with, supervising and supporting the representatives and helping them in their dealings with residents, families, the residents' committees and management.

6.5.1 Nursing home supervisory function

It is anticipated that the chairperson and perhaps one other will be key players in supporting and smoothing the process. They will make themselves known to management, as well as the nursing homes' residents'

committee. They will meet with both periodically either at meetings or separately as required. They will provide local support to the residents.

Clearly relationships between the appointed representatives and management are likely to break down when serious deficiencies and contentious issues arise. It is anticipated that, when contentious issues arise, the chairperson with the support of the committee will accompany the representatives when they meet management and support them.

There will be times when the representatives will come under pressure from nurses or managers. This is why there should never be less than two representatives responsible for visiting a nursing home and their visits should overlap frequently. The chairperson and the representatives will be mutually supportive and provide sounding boards for one another so that decisions are considered and balanced.

6.5.2 Making the nursing homes part of the community

With the increasing complexity of nursing care, the pressure on staff, the risks of cross infection, the risks of accidents from clumsy volunteers, and the risks of litigation, family and volunteers have become an impediment in a busy nursing home and are not always welcomed. They in turn feel awkward and out of place.

With the commoditization of aged care, families see themselves as using a specialized service much as they would use a plumber, and feel the same embarrassment when they must reveal their own clumsy attempts with pipes. They disengage.

That there is too often a breakdown in relationships between staff and family is clear from the many complaints by residents who discover that their parent has a pressure sore or some other problem which they were quite unaware of – or as often that its severity and gravity was not disclosed. The use of agency staff, or foreign imports from other cultures is not the only explanation for this. One of the characteristics of a home is open and continuing communication. This is the residents' home.

The aged become separated from their community, their family and friends. They become isolated, lonely and no longer tied to family and community life. Life rapidly loses meaning.

The elderly may struggle to maintain one on one communication making it awkward for both parties. However they do need to be part of the family and the community, be listening and contribute when they can. Regular group functions and activities inside or outside the nursing home where family and friends including children, as well as volunteers meet up to talk about other family, past events, photographs, and the affairs of the day bring the elderly back into the circle of life. The sort of activities and types of interaction will differ from culture to culture. Volunteers can help by bringing old friends unable to come alone to visit.

A key function of the committee would be to foster such activities with family and volunteers, and negotiate with the nursing home to ensure that volunteers are welcomed and made to feel useful and valued. Some might be trained to provide some assistance (eg feeding). A balance between unacceptable risk and activities that improve the quality of life must be reached and the law should provide some protection for volunteers making a contribution.

6.5.3 Reporting

The representatives will report to the committee each time it meets. The chairperson working with the assistance of the representatives and those coordinating quality of life activities will report back to their respective appointing organizations and to other sections of the community. This will be done through an informative annual report describing these activities and indicating in broad terms the positive and negative findings in regard to each nursing home, the actions taken and the effectiveness with which the nursing

home has dealt with any problems identified. This will be a public document and will be copied to groups in the community as well as to DOHA and the agency.

6.6 The Community Representatives

The representatives, together with the chairperson will be critical to success. Particularly important will be their people skills and their ability to facilitate interaction. As a general rule two or preferably three representatives will work together and be in a position to support one another. For this reason they are likely to be part time. This is important, as there may be a tendency to criticize and demonise representatives. Support will be essential.

It is likely that at least one of the representatives would have had nursing experience and training, and another experience as a carer. Although having a current relative in one of the nursing homes would disqualify them, past experience would be an asset.

While nursing homes would be able to express their objection to particular candidates, they would have to give reasons and would not have the power of veto.

It is anticipated that representatives would work unobtrusively, becoming familiar faces and on good terms with staff, residents and relatives, sharing confidences and being trusted. The atmosphere should be one of openness acknowledging that failures occur, recording them and not being punitive. If staffing is a problem then this is something to be negotiated by the chairperson. The thrust should be to identify where problems occur and look at ways of improving, readily turning to the accreditation support section for help and keeping the residents' own committee in the loop.

The representatives will always introduce themselves to new staff and greet them. They will introduce themselves to new residents explaining their role as a representative of the community, offering to discuss difficulties and getting written consent for access to medical and nursing notes. Nursing staff would be expected to encourage this. If permission is withheld the representative will not routinely access personal notes but if it is necessary to secure the integrity of data or to address failures in care then they will have the power to overrule the request. In this situation the relative, the chairman and the DOHA supervisor should be informed that the decision was taken and why.

6.6.1 Auditing

This is where the representatives will play an active and contributory role. Nursing homes cannot function financially or plan effectively without careful financial auditing. A similarly vigorous process is required for clinical auditing and clinical management. The accreditation process makes much of the presence of continuous improvement. Yet there is no evidence in their reports to indicate that the data on which continuous improvement depends, and against which it is evaluated has been collected.

The week to week routine of the representatives will focus on working with the nurses in the collection and collation of data. It is anticipated that representatives would participate in sessions in which nurses and nursing aids are instructed in the grading of patient acuity, the severity of complications and other aspects of monitoring. They will have explained their role to staff and the way in which they will assist.

The representatives will play an active roll here examining notes and collecting the information together – in effect working with and assisting nurses and management. Because they are there and involved they will be in a position to verify the integrity of the notes (eg. times medication actually given) in a friendly and open way. The representative with nursing experience would visit when dressings are done and might look in on that to check on progress and be sure that it was appropriate and that relatives were being kept in the loop.

The number of trained nursing staff and nursing assistants on duty will be recorded as will the rate of staff turnover and the use of agency staff.

The representatives will be around sufficiently frequently to see whether residents are being properly fed, whether they are left for long periods in gusty corridors, whether their toileting needs are met, how soon call lights are answered and the quality of activities in which they engage.

They will be in a position to quietly monitor the nature of the interaction between staff and residents, the nature of communication with residents, the involvement of the residents' medical practitioners in care, and the zest for life of the residents. They will get to know residents, families and staff. They will be open to their concerns and suggestions, responding to these or passing them on as appropriate.

The representatives may remind staff but will not harass them when failures occur, nor will the representatives walk around with a clip board and check list. They will use these when they return home. They may draw senior nursing staff or managers attention to problems that threaten care.

The representatives will meet monthly to collate their findings. One or more, sometimes, accompanied by the chairperson, will also meet monthly with the nursing supervisor to constructively discuss the findings and learn of the difficulties that the home is experiencing in providing care. They will include these in their documentation.

It is anticipated that managerial rationalizations and inappropriate frames of understanding will become apparent and will soon disappear. The representatives will report in general terms to meetings of the community committee, as well as to the residents representative committee, on their findings and their discussions with management. Their collated data will be forwarded to their supervisors.

The concept is to foster a constructive debate between community and management in an endeavour to best serve the residents.

6.6.2 Complaint management

An important role of the representatives will be to act as a conduit for complaints and suggestions from residents, families and also nurses. Both sometimes fear reprisals from management, particularly when they speak out about failures in care. When management is receptive then representatives will facilitate the complaint process encouraging contact and discussion with management, participating if there is any anxiety. The representatives will monitor any attempt at reprisals or muzzling and report on this, ensuring that there are consequences. The chairperson is likely to become involved if this happens.

Where there are concerns about victimization of residents, or staff are worried that this might occur, then the representative will deal with this confidentially and the source will not be disclosed to either DOHA or the chairperson without the complainants consent.

In the event of a complaint the representative will be responsible for the integrity of data and will copy or note the content of records. She will talk to the parties and will note their accounts of what happened. While DOHA and the agency will have access to these statements when making decisions such statements will be confidential and privileged and will not be produced in any legal dispute without the approval of the witness.

The chairperson will not have access unless the witness grants it although he or she may be aware that there are differing accounts. The legal consequence is that unless the witness agrees to their being used, such statements cannot be used to support litigation, penalization or in an appeal against the removal of accreditation. Someone's admission of culpability to the representative cannot be used in prosecuting that person.

When a complaint can't be resolved by the representative or any party is dissatisfied then a formal investigation by DOHA can be asked for by any of the parties. The representative will act as the contact person for the complainant and explain the reasons for the decisions and the limitations of the process.

Any of the parties might turn this into a legal dispute but in that case some statements and documents may not be admissible in evidence. DOHA will monitor developments and may intervene acting through the supervisor. The extent to which the chairperson of the committee can be involved will depend on the wishes of the parties.

The representative will brief the complaints supervisor and will supply a full report of these activities using a prescribed format. The information will be collated into a publicly acceptable format and supplied to the community committee and included in overall reports. A key issue will be the willingness of the home to examine complaints objectively and respond constructively to them.

While the prime role of the representatives when acting in regard to complaints will be resolving the issue and ensuring remediation when required, they will also be responsible for the recording of information and preservation of data, should it be needed for remediation, action by oversight bodies, or legal action by any of the parties.

6.6.3 Resident Nursing Home Committees

One of the roles of the representative will be to enlist competent residents and family members to form a resident's committee. This will be by election when possible but in some instances it may have to be by general agreement. Unless the residents request otherwise a representative will attend such meetings and may be asked to chair them. The representative would normally also attend general meetings of residents and meetings with management. Their primary role would be to oil the process but not control it. It may be appropriate for a representative from the volunteer section of the community committee, or from the guardianship or public trustee to be a member of the committee or to attend meetings. The residents may wish to seek advice from a medical practitioner or other expert.

6.6.4 Other disputes

Representatives will be receptive to information from staff and management. When there are disputes between staff and management in regard to care, staffing or the way the home is run then either party may ask the representative and the chairman to attend and if the parties so desire one may chair the meeting.

6.6.5 Staff morale

Of necessity this submission deals with oversight and problems in care. It is however important to understand that as important is the role of representatives and the community committee in praising staff, welcoming success and highlighting successes. Educational initiatives should be followed by positive responses to success. Care is driven by humanitarian motivation, and there is no stronger incentive than the satisfaction that comes when the community recognizes this and expresses its appreciation. Not only is this good for staff morale but as it diffuses out into the community it is good for business.

6.6.6 Guardianship

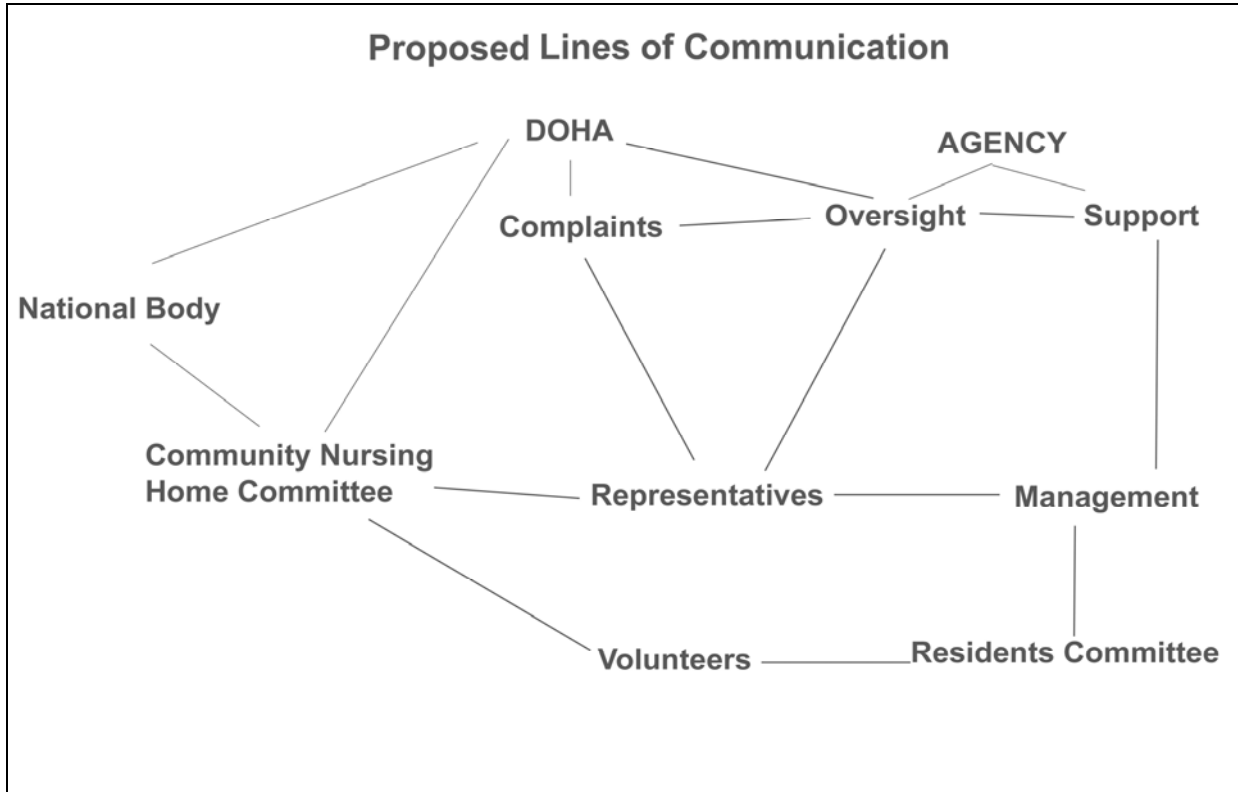
Some have accused nursing homes of seeking guardianship for residents simply to silence critics or resolve family disputes. To prevent this happening such requests should only be made after consultation with the representatives dealing with the disputes, and with the approval of the chairperson.

6.6.7 Legal considerations

The role of all parties will require legislative backing. The powers required by the representatives will need legislative support, and they will be required to embrace the same confidentiality codes that bind other

health professionals. The extent to which material given in confidence is made legally privileged in the same way as clinical audit in hospitals must be defined.

Legislating these powers should not be problematic. Legislation in Victoria, Queensland and NSW already provides many of these powers to their visitors.



7 Introducing changes

What happened in 1997 and subsequently must be a lesson. No set of presuppositions or model of care should be enshrined in stone and go unchallenged when things go wrong.

The presuppositions made are a starting point to give direction and may need modification and change as may major or minor aspects of any program. Any changes must be tempered and guided by solid information and experience.

There will be downsides and unintended consequences. These must be met and confronted. There should be no place for the wild claims made after the 2006 rape scandal.

Introduction should be progressive starting in receptive localities and moving on to others. Some localities may be unable to rise to the occasion and modifications may be needed for them.

7.1 Difficulties and the community

Academics such as Robert Putnam and our own Eva Cox have documented the decline in social capital and a degradation of the “civil society” that fosters it. Cox has stressed the importance of community activities that engage people interactively in activities that benefit the community. These build social capital.

Current community activities have increasingly concentrated on self gratification and enjoyment rather than service. In doing so the personal rewards that come from serving are no longer understood. The values, norms and motivations that come from serving the community atrophy and are lost. Arguably our affluent community’s detachment from activities such as the care of the aged has contributed to this.

It can be argued that it will be difficult to reintroduce an empathic service mentality into the community and this may well be so. The response is that if we don’t do so our society will continue to lose important community values and will be much poorer for it. The only way to reverse this is to engage people in those activities that will foster our humanity.

7.2 Having courage

What is very clear is that the vast majority of wealthy western countries have followed similar strategies in providing aged care. They all have serious problems and all face an ageing bulge. There is community unhappiness.

Australia has been a follower and not an innovator in aged care. It now has the maturity to engage with different ideas and try them out.

8 How will this resolve problems in the complaints scheme?

The explanation of the way this proposal will resolve or make irrelevant almost all of the issues raised by the accreditation discussion paper is in the submission sent to the agency. I have not included that here but it can be obtained from them.

The problems I have described in the complaints scheme would be readily resolved by the proposal made here.

8.1 The disenfranchisement and disempowerment of the community

The community would be at the centre of the process and complaints would be handled by a representative of the community overseen by the DOHA. Subject to the approval of the complainant the chairman of the local community and possibly the committee would be involved in mediating the complaint. They would be empowered and when necessary could negotiate on behalf of the complainant.

8.2 A lack of on site empathic person to person communication

The representatives would be selected for their interpersonal skills. They would soon be known and trusted by the residents and their families. They would be well placed to lend a sympathetic ear, evaluate the nature of the complaints, assist residents' families and mediate a satisfactory outcome, one which saw the issue resolved and remediation undertaken if necessary. They would have the power and the backing to act if this was required. They would also be well placed to explain when anxieties are not well founded or when expectations are higher than resources allow.

Part 4 item 2 and Part 5 Item 2 of the consultation paper refers to the situations where the scheme has been most deficient. With this proposal communication between all parties would be facilitated in an empathic manner. This would be done by someone all parties know and have come to trust. Because they will be readily available and trusted anonymous complainants will feel far more comfortable coming forward knowing that their anonymity will be protected even from government. At the present time I am aware that nurse complainants, at least, fear for their jobs and their futures. Families fear that their loved one will suffer if they complain. Neither trust government and many will not disclose their identity to the CIS. I am well aware of what has happened in the USA, particularly, and feel that bureaucratic failure in this regard is so common as to justify their concerns.

Part 4 Item 8 is another area where the scheme has been severely deficient. Because the representative is both at the centre of the investigative process, if not the decision maker, there will be ongoing briefing so that the complainant will be kept in the loop and made to feel that their concerns are contributing to the aged care debate. They will be briefed in person about the outcome of any formal investigation. Because the collection of information will be on site, resolution would be expedited.

Part 5 Item 1. The proposal would vastly improve communication by giving the CIS a local representative known to the parties involved.

Part 5 Item 3. The CIS can do much better in meeting the needs of all parties by having someone local trained and skilled in resolving issues promptly and effectively.

8.3 An excessive emphasis on process rather than resolution for the parties

The primary focus of the representatives will be dealing with the residents and their families when they are unhappy in order to see fair play. While they will keep records and ensure that deficiencies are addressed

their primary focus will be the well being of residents and their families. They will mediate between families and management. At the same time they will collect information and make it available to their supervisors. The decision to proceed to a formal evaluation will generally be based on a pattern of events with a failure of prompt remediation. It will be closely allied with the oversight section of the accreditation agency.

Notwithstanding any of this, any of the parties, including the community and the nursing home may, if they are unhappy with the outcome, still seek a formal investigation and appeal decisions up the system. Due process would then take its course but information provided in confidence in order to seek resolution would not be considered. Natural justice as outlined in Part 4 item 1 of the consultation paper would not only be done, but would be explained personally and honestly to the parties and so be seen to have been done.

8.4 An almost total lack of transparency

This criticism would fall away as the representatives would report in broad terms to the local committee, who would frequently have been involved and so be aware of some of the details. They would in turn further de-identify information in their annual public reports to the charity organizations involved as well as to other community groups.

The complaints history of each home, each operator, each owner and each sector would be collated and discussed at an annual meeting. The community, both at a local level and at a national level would be well informed and be in a position to debate the issues and contribute to improvements. Material would be available on which informative research projects could be based,

8.5 Adequacy of training of representatives

Part 4 Item 3. The representatives will be trained initially by DOHA and they will work closely under a supervisor with whom they will discuss issues and who will visit to monitor and advise. They will also be working with another representative so that they monitor and reinforce each other. The chairman of the local community will exert a similar supervisory and supportive role.

8.6 Clinical and Investigative Expertise

Part 4 Item 4. It is anticipated that the representative will establish a working relationship with local medical practitioners and be in a position (with the patients approval) to seek opinion and support. In addition it is clear that DOHA would have expert geriatric and other clinical support that could be called on by the GP's involved or the representatives. The representative would have the full investigative experience and resources of DOHA to call upon.

8.7 Risk assessment framework used for the escalation of complaints

Part 4 Item 5. I don't fully understand the issue. The representatives would be well placed to discuss with each other, the chairperson, the family and the supervisor in deciding to call for a formal complaint and investigation. The seriousness of the problem, its recurrent nature, and the threat it poses to others would clearly be considerations.

8.8 Adequacy of information collected

Part 4 Item 6. Because the representatives would be involved from an early stage, and be collecting information, its adequacy and accuracy will be considerably improved. However because the primary focus

would be resolution, some statements made could not be used in a formal investigation without the agreement of the person making the statements.

8.9 The relationship between the CIS and other groups

Part 4 Item 7. The relationship between the CIS and the oversight section of the accreditation agency would become much closer and the distance between the educational/accreditation arm of the agency would widen but they would still be constructively engaged. A strong argument can be made for combining the complaints scheme and the oversight role of the agency under one organization.

Since sending in my submission to the accreditation agency I have learned that almost half (5 of 12) of its board are appointed directly from the nursing home industry. This is totally unsatisfactory in a body responsible for oversight – a case of the fox guarding the chickens. There can be no objection to such representatives on a body concerned with education and accreditation but clearly this cannot be credible in a body concerned with oversight and penalty. It fuels the argument to break the agency into two and align one half with the complaints unit.

Both the complaints scheme and the oversight section of the agency would form closer ties with the community both locally and at a national level. They would be expected to justify their actions and meet criticism of their thinking in the same way as would the nursing homes. My assessment from my experience is that this would be beneficial for the scheme.

8.10 Evidence based initiatives from similar investigatory bodies

Part 4 Item 9. As indicated earlier “Visitor Schemes” operate in other sectors where residents are impaired in Victoria, NSW and Queensland. They are trained and monitor the services provided. They do not operate in nursing homes. These visitors enjoy many of the powers envisaged for nursing home community representatives. In some states these visitors are voluntary and there are some difficulties in recruitment. In others they are state employees and controlled by the state, In all they report to and are responsible to the state. In none do they report to or have direct responsibility to the community and its representatives. The sort of data the question asks is not readily available but I understand that the voluntary system in Victoria has worked well. As far as I am aware none collect the sort of data on which research can be based.

9 Appendix: From Semantics to doctors

A submission like this is an unlikely place for a discussion on words and meanings. They have played a critical role in developments over the last 12 years. If we are to make real changes then we will need to challenge some that have served us poorly, find new words and new meanings, and unpack older words and meanings that are now seen to be appropriate. That is why I have included an appendix.

As indicated in the earlier section “Language and Cognition”, the “reforms” introduced in 1997 introduced a whole new range of words and concepts. These enabled a more impersonal and analytical approach. Parallels could be drawn with other activities and services. Aged care could be positioned in a broader context and its particular attributes ignored. At the same time a number of terms that were more accurate in describing the predicament of the aged had acquired connotations that were seen as depersonalising, medicalising, paternalistic or to reflect ageism. They were dropped.

9.1 Distorting real situations

One consequence of these changes has been the (probably unconscious) use of linguistic strategies to remove the legitimacy of the community model. Words with associative meanings that bring out the unique and important humanitarian characteristics of the sector have been replaced with words without specific associations other than those common in commercial enterprises. The unique emotional content intrinsic to the sector has been removed.

Emotional content and humanitarianism has been replaced by broad promotional feel good phrases suitable for public relations. Aged care has been turned into a commodity that sits comfortably within the market paradigm.

Nursing homes become residential facilities, nursing and medical care becomes a service, and patients become residents.

The good English word “quality” has been overused and misused, when there were better alternatives, because of its positive associated meanings. Any document liberally peppered with “quality” and other positive sounding words favoured by public relation efforts raises the suspicions of cynics about its veracity and of the motives behind it. Broad words such as customer and consumer similarly remove defining characteristics. More and more TV savvy members of the community are becoming cynics and distrustful of what they perceive as marketing. Red flags go up.

The use of words in this way results in category errors, so that strategies that may be generally applicable to some broad categories are applied to subcategories where the necessary conditions (uniqueness) makes them inapplicable. Aged care has suffered.

9.2 Embracing ideas and words

The problem is not only that the words and ideas expressed project a false image but that participants in the care process are more prone than anyone else to embrace the words, the ideas and the positive implications. The feel good impact on self realization is very seductive.

This distorts their perceptions and the way they behave. They often simply do not see what is happening. They are more shocked than anyone else when the house of cards collapses, and they are blamed for what they had come to believe was desirable. My experience in meeting with the CIS causes me to suspect that this may be so.

9.3 Becoming real

The vast majority of the occupants of nursing homes do require “nursing” and often highly skilled nursing. The nursing home becomes their “home” and not a facility. If they are to have a life with sufficient meaning to justify existence then it is critical that they experience it as a “home” with all the emotional bonds that develop there.

Like any other citizens these “occupants” require “services”, but they differ in being frail and vulnerable and in requiring “care”. The vast majority of “residents” have illnesses and require ongoing medical care so are “patients”. In our society the word “patient” now has association with medical paternalism, but without a word that adequately reflects the vulnerability and dependence of the elderly its abandonment has serious consequences.

9.4 Linguistic anaesthesia

This juggling with words is well intentioned and an attempt not to stigmatise the elderly and display our ageism. They might approve themselves. Canadian John Ralston Saul has stressed that language is the way that we grasp the real world. He decries the trend to use words to distort and hide the real world in order to escape it, to support ideology, or to distort it for any other purpose. He gives many examples. He calls this being unconscious and that is what has happened to our community in regard to aged care.

The linguistic gymnastics serve to insulate politicians, bureaucrats, businessmen, and even those providing care in nursing homes from the real needs and anguish of the frail elderly. Empathic care and quality of life become the victims.

The same processes sanitize and dehumanise the real lives and problems of the aged for the community by positioning them within comfortable concepts and clothing them in neutral words. The way in which commonly used euphemisms serve to hide the real horror of dying is now well recognized but this insight is not applied to ageing. The community ceases to act as a caring, compassionate and supporting entity - avoiding the discomfort that would ensue.

9.5 Demedicalising

Demedicalising the ageing process has accentuated the flight of doctors from nursing homes and undervalued their important role there. It is more tedious for them, more time consuming, they are not seen as needed by staff or community and receive little credit or reward.

The elderly are among the most taxing and difficult medical problems yet this is now left to nurses. Some nurses who may have received complex training and the ability to handle complex nursing problems may believe, like the current minister for health, that they can act as doctors. The training is quite different. The consequence is only too apparent in nursing homes.

9.6 Where are the doctors?

In the myriad press reports about failures in care, whether it be paraffin baths, gastroenteritis, gangrenous legs, wrong medication, or missed injuries there is never any mention of the doctors who should have been there. They are responsible for diagnosis and care, as well as raising the roof when they are not called in time and when their patients do not get the care that they need. These patients have illnesses and it is their responsibility.

A World Health Organisation Directive imposes an ethical duty on doctors to act when they are aware of situations that place the lives and well being of citizens at risk. It is exceptional for any of the press reports of adverse events and inappropriate responses to document the involvement of doctors or hold them responsible.

I doubt that many of the over 11000 complaints made to DOHA during the 2007/8 year came from doctors or were supported by them. They were not there and no one thought that they should have been there.

One of the commonest complaints made by relatives is about a failure to recognize an obvious to them deterioration in the elderly persons condition and call in a doctor or send them to hospital. They have to call ambulances themselves. It does not occur to them to ask where the doctors are because they are conditioned and have never seen them. This mindset is also reflected in the accreditation reports.

All of this occurs in a society where we speak of preventive care and urge citizens to have doctors and to visit them regularly. Nursing home residents, the most in need of care are left out.

9.7 Decision making

Important decisions about the cessation of treatment and administration of palliation, which might hasten death, when there is no hope of a meaningful recovery, can only be made by a doctor who because they have been in regular attendance is familiar with the persons medical history and condition. This must be directly negotiated with staff and with the family who will need support. It is clear that this is not happening. When patients are referred to hospital from a nursing home, information from the referring doctor about their prior medical state is critical in making decisions. Dumping some one in an ambulance and sending them off is suboptimal.

These situations will be important for representatives. To be reliable indicators, complications that are terminal events should be treated differently. This also applies when complications occur because prevention and even treatment measures would cause more stress than benefit and have been abandoned or modified.

9.8 Relevance for the proposed model

One of the benefits of placing the community at the centre of nursing home care will be the reintroduction of emotional content, empathy and real words into the lexicon used to discuss and deal with aged care. These will reflect the sectors uniqueness rather than its more general attributes. The breadth and nuances of language allow us to define our world and our lives in ever more sophisticated ways and so grasp its unique features. We can respond in better ways.

Hopefully another consequence will be recognition of the important role that independent doctors can play in the care of nursing homes and in ensuring that problems in care are detected promptly and addressed. Doctors in regular attendance are potentially both powerful allies and important resources for the representatives who would cultivate them.