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Accreditation Review and Risk Analysis Section

Department of Health and Ageing

MDP 68

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Re: Review of the residential aged care accreditation process

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.

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 are identified:

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

It is suggested that the key to redesigning 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 discussion paper opens debate by detailing some of the areas in which accreditation has been criticized. The options they canvas will do little more than tinker with the problems. They will not disappear.

The submission examines the discussion 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 "*Discussion paper : Review of the accreditation process for residential aged care homes*". The complaints about the system mentioned there reflect the anxiety and unhappiness of those in the community who have examined the aged care system, and 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 accreditation agency. 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. Such an outside position may fail in detail but often 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.

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.

With the best of intentions humans behave humanly by finding ways and justifications for succeeding in whatever situation they find themselves. They now find themselves in a marketplace. For those who have embraced the system it all makes sense. They see the 1997 changes as needed reform.

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 as 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 religious 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.

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.

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.

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 which 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 have 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 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 and they are not playing it.

(Because of the important role that language has played I have added an [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.

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 accreditation system

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.

3.9.1 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.

3.9.2 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?

3.9.3 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

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 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 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 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 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.

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 it has not 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 suggested to them.

The section will keep an overall record of all complaints made to the representative and the outcomes. The extent and nature of complaints will be on the public record and in the representatives' reports.

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 role 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 resident 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.

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 accreditation?

The discussion paper lists some of the objectives of the accreditation process and then identifies a number of issues where it has been criticized. The proposal put forward here promises to meet the objectives, outlined in item 18, more successfully than the current system. Many of the criticisms will be resolved and a number of other issues will fall away.

8.1 Conflict of interest in the accreditation role (items 83 to 87)

8.1.1 Experience elsewhere

The objectivity of oversight and accreditation processes have been a burning sore in the USA and more recently in Australia. Corporate lobbying of politicians who have received campaign donations, and who also control the employment of regulators and their career prospects is one burning issue. Another is assessors who are or have been friends or colleagues of those in the sector, or past or likely future employees in the nursing homes. Critics blame this for a multitude of failures in process. Past assessors, have well paid jobs waiting for them in the industry.

It has been claimed that this network of friendly contacts is so effectively developed that few unannounced audits in US nursing homes are unexpected. It is almost inevitable that assessors in the sort of system we have will be drawn from the industry. The discussion paper indicates that the agency advertises in industry magazines to recruit assessors (item 46). The agency does not indicate how many come from the industry.

There are also conceptual and interaction tensions in doing both training and assessing. This does happen in schools, universities and in the most closely related field child care. There are real and important differences as soon as a strong profit focus is introduced in the face of “consumer” vulnerability or innocence. This is well illustrated by the multiple failures in the USA, particularly those related to large credible and influential hospital corporations such as Tenet Healthcare (http://www.corpmedinfo.com/entry_to_Tenet.html) and Columbia/HCA (http://www.corpmedinfo.com/access_columbia_hca.html).

Universities have been selling courses competitively internationally to attract paying students. They are already being accused of favouring private students who have paid “for their degrees”. In school and child care all parents have been there themselves. They are also closely involved and knowledgeable in this area themselves. It is not comparable to aged care.

8.1.2 Benefits of separating the two roles

Separating education and support from the oversight role of the agency solves all of these problems and potentially reduces costs. I have no problem in accepting that motivated nursing homes find the education and the nursing processes helpful, that they are, and that they improve care. The worry is when motivation is lacking or challenged by other imperatives.

By concentrating on support the section can do it well. There can be no objection to this section drawing heavily on industry resources and enlisting industry support. The emphasis on processes is appropriate and will be informed by data generated by the representatives. Quite clearly the oversight sector should not draw on industry resources and the proposal advanced excludes them. The issues about nominated assessors raised in items 37 and 38 fall away)

8.1.3 Self Assessments

The discussion reviews the self-assessment submitted by nursing homes before the accreditation – both in regard to its usefulness and the burden in developing it. (items 23, 26 and 27) As the representatives will have cooperated with nurse managers in drawing up reports, the data needed for such assessments will be readily available to both nursing homes and assessors, so making it less burdensome for both. The information on which continuous improvement depends will be available for use and for assessment. Usefulness will be improved and the burden reduced.

It may well be more profitable for such self-assessment to be targeted to specific sectors coincident with educational visits, and these in turn be generated by the findings of the representatives and their discussions with management. It is also an opportunity for homes to put their point of view and have it debated. They may have alternative ways of addressing problems.

Reports on continuing education and compliance with processes by homes could be provided annually. These changes will meet the concerns of the Aged Care Association Australia while meeting the government's commitment to compliance and continuous improvement.

As the representatives will already have collected much of the information, desk audits, if they are still necessary, will be greatly simplified. (items 23 and 33)

8.2 Role of education by the accreditation body (items 9, 20 and 81 to 88)

This is a useful activity and the involvement of a section of the agency in this is in my view essential. It should not be discontinued but some cost and resources might be moved to the industry. (item 88)

There is a risk that without departmental involvement the focus will move to avoiding detection and frustrating the oversight process. Education will become instruction in the art of misleading and of hiding problems, rather than addressing them. This can become a formula for marketplace success. Entrepreneurs, who have had experience in the audit process and ingratiated themselves to big business while doing so, might run thriving businesses.

8.3 The oversight role of the agency

The oversight process should be closely aligned with the handling of complaints. Complaints often point to areas where oversight is needed. Combining these might be logical but it will raise far too many hackles and fuel distrust further if a government department took control. It is best left for now.

There are multiple issues about the oversight process raised in the discussion paper. If the proposal can be successfully introduced it is much more likely to meet the objective of maintaining overall standards than the current system.

Having people regularly on site in regular communication with the agency will facilitate and improve effectiveness in carrying out all of the core functions outlined by the 1997 and 1999 acts (item 4).

One of the major problems of the current process is its intermittent and transitory nature giving snap shot information that could be totally unrepresentative. This is a situation where Murphy's Law will apply in that everything will be wrong on that day, sometimes damning a very good nursing home. It is unfair to the homes.

By making the process ongoing and local we get representative information that is accurate and fair to all parties.

Much is written about Accreditation standards and Quality indicators and about developing benchmarks. (eg. item 17) Little of this is evident in the publicly available accreditation reports which are focussed on process areas rather than outcome measurements.

It is essential that residents physical and mental acuity, care and quality of life be quantified with objective measures when possible, but supplemented by the subjective views of participants and observers. On site representatives talking to residents, meeting family and talking to volunteers will be well placed to do so. (item 7)

Clinical audit is a critical function of the nursing home so that this is educational and benchmarking, as well as stratifying. As indicated nurses and geriatricians should be consulted and strategies devised to integrate what is required for monitoring and managing care into nursing homes' documentation. The representatives will assist them with this. Management and community can unite in finding ways to improve.

By having a regular on site presence the proposals will "*minimise the prospects of non-compliance*". By picking up early signs of non-compliance the proposed structure will "*ensure non-compliance is identified early and remedied in a reasonable timeframe*" (item 19) it will do so more expeditiously than the current system

Because the community will be at the heart of the system and will be aware of what is happening and what is being done this will "*provide assurance and maintain public confidence in residential aged care through an open and transparent system*". (item 19) The current system is not transparent and falls a long way short.

The proposal will "*ensure that the accreditation body has an accurate view of the status of individual residential aged care homes and of the aged care industry*" in a much better way than at present. (item 19) This will be ongoing and regular, not intermittent and fragmentary.

By providing accurate on site information to all parties it will be possible to institute "*continuing improvement in quality of care and quality of life for residents*". (item 19) It is difficult to know how this has been done in the past without objective data. Because oversight is ongoing it will be far more successful in "*Validating compliance*" (item 20)

Currently the accreditation does not have access to "*electronic information*". (items 35 and 36) Clearly this should change. The representatives will be working with staff to accurately record and collect information. This can only be done electronically so full access to information will be essential.

Many including The Australian National Audit Office (ANAO) have questioned the impact of accreditation on the quality of care and the quality of life of residents. (items 6 to 9). Critics are less than enthused by the findings of outside commercial entities paid to evaluate. Would the commercial entity have received further government contracts had its evaluation been damning?

If the accreditation agency was collecting clinical information then this could have been readily and transparently evaluated from that information. This question should be less of a problem under the proposal because what will be evaluated will be the short and long term impact of educational processes and this will be genuinely transparent. The observations and measurements made will be reviewed and refined in an ongoing manner to be sure that they are both useful and practical.

8.4 Consumer focus and a resident centred approach (items 20 and 58-64)

While syntactically correct there is really no such thing as a "consumer" of aged care in the sense in which it is usually used. The term is a generalization reflecting how far we have strayed in using words to conceal the unique and personally emotive features of aged care. Aging is a debilitating terminal

condition with which all living things are afflicted. We claim uniqueness among species and call this our humanity. This leads us to empathize and care for each other when we are in need. It is not about consumerism.

The representatives and the volunteers will both be dealing and talking to the frail residents and their families, then sitting on the same committees. The representatives will be closely monitoring the residents' quality of life and the factors that impact on them. This will put the frail residents at the centre of everything that happens in the nursing homes. The regular contact of residents and volunteers with staff, and even management will diffuse the values, norms and patterns of behaviour that underpin this focus to all staff.

The problems of interviewing residents or their families during the brief accreditation will fall away. Representatives will be doing so in an ongoing manner and at times when residents and friends are visiting and can act as both interpreters and contributors. The need to interview outside the audit will largely fall away.

While the Consumers' Health Forum of Australia might take issue with my linguistic hair splitting, they should welcome the proposal, which meets their objectives. Residents and family will all know that they have a representative to turn to on a regular basis. Many of the issues and suggestions made in this regard would fall away.

8.5 Unannounced visits and spot checks vs announced audits (items 9, 48 to 57 and 69 to 72)

This is a critical problem and what is being done is unsatisfactory. Extensive debate about announced and unannounced visits will fall away. Instead there will be a regular presence with regular oversight and monitoring. Success will depend on the representatives' commitment and skills, as well as support from the community, not on the rigor of transitory visits. Educational visits will be arranged and targeted to identify deficiencies for maximum benefit.

It will only be necessary for the oversight section to do surprise visits on rare occasions when there is a crisis when the local community structure has collapsed, or perhaps when a nursing home is to be closed. For most purposes a visit by the representatives' supervisor would be adequate. When the supervisor would simply be accompanying the representative to vet and confirm findings and activities this will be unannounced. When issues are to be taken up with management then an appointment will be made or will follow.

Educational efforts will be closely monitored by the representatives when there have been failures in care. This should be useful for management. The proposal addresses many of the problems that nursing homes have. Not only will most be removed, but also the representatives will be contributing to the successful operation of the home.

Because residents will be on site regularly they will be aware of what is happening. As a consequence monitoring, education and remediation will become far more targeted and so more efficient, more effective and hopefully ultimately less costly.

8.6 The administrative burden, stress levels, morale and impact on care (items 10, 20, 28 to 34)

The administrative effort, the time spent, the stresses and the disillusionment of staff as a consequence are a never ending problem bitterly complained of by all parties. They lament the diversion of staff and the adverse consequences for care and for the quality of life for residents.

If accreditation is of real value for care then the proposal in the discussion paper to abandon some portions of the accreditation process, to reduce this burden, will simply make it less effective and less credible.

The proposal advanced here removes most of the burden and the stress because the representatives will be helping the staff collect and collate the information they need to run the nursing home and improve care. They will become part of the furniture. They will not only be extracting this but they will be talking and observing, feeding their findings back to the nursing home, while protecting staff and family from unfair reprisals.

Monitoring, training, accreditation, assessment, oversight and the resolution of complaints would become a part of the week by week routine of working in a nursing home.

The problem of not having documentation readily available when needed for review will fall away (item 34)

8.7 Community involvement

Criticisms about a lack of community involvement go to the heart of the problems with the current accreditation and complaints system. The criticisms are met by placing the local community at the heart of the accreditation and complaints resolution processes. They will appoint, supervise and support those monitoring care in the nursing homes. They will have direct access to nursing home managers in their regions.

8.8 Open and transparent systems (item 18 & 20)

As explained earlier the claims to transparency in the current system simply do not stand up to analysis. Tinkering with the details will not change this. A whole new mind set is needed.

In the proposal the problem should evaporate because the local community will play a key role in collecting information. They will be regularly briefed. The information will be collated and then presented to community organizations for discussion. Collected data will be compared and discussed in an Australia wide forum. Outliers will immediately be apparent and the reasons why they have become an outlier whether good or bad debated. Reasons for the failure of remediation will be debated and acted on.

8.9 Decision making and the reporting of accreditation decisions (item 23, 75 to 78, and 89 to 91)

Because accreditation would be an ongoing process, decisions about unsatisfactory performance and continuing operations would be based on the nature and extent of complaints, the oversight findings, and the inability or unwillingness of a nursing home to respond to educational efforts. DOHA will be kept fully briefed about substandard homes. Normally overall performance, continued Medicare funding and the need for forced sale or closure will be reviewed annually. When an acute situation exposing residents to risk develops then immediate action will be required.

Because data will be collected in an ongoing manner and this information made publicly available there should be no delays in detecting problems and rapidly sorting them out.

Natural justice dictates that a nursing home be able to indicate its rejection of the findings or offer an explanation. It should be also be recorded when findings or penalties are appealed, and when the outcomes are known.

The burden of recurrent applications every 3 years would be removed as accreditation would be automatically reviewed each year after examining the performance record of the nursing homes, the managers and the owners. Renewal would be automatic or qualified. Homes and operators with an intractable record might be cautioned, sanctioned, ordered to sell or compulsorily closed. Recurrent offenders would be handled more effectively. (item 23)

8.10 Informing residents and families (items 64 to 66)

The representatives will be dealing directly with the residents committee and will be briefing them. When there are adverse findings or sanctions they will facilitate the process of informing residents and the interaction between management and residents.

8.11 Confidentiality of sources - residents and staff (items 67 and 68)

The representatives and sometimes the chairman will provide a conduit through which residents families and nurses can convey their concerns and be assured of confidentiality.

8.12 Inconsistent or flawed assessments , training of assessors (items 12, 39, 40-47 and 70-72)

Representatives will be trained by DOHA who will be looking at performance and providing ongoing training and remediation.

Data will be collected continuously by the representatives. Supervisors will check the way they are collecting and rating data when they visit. Complaints and educational activities will be compared with representatives' findings. It should become apparent when things don't fit well. When this happens, when representatives differ significantly among themselves or when a home becomes an outlier, the supervisor will be checking and will undertake a site visit.

When educators come to remediate, it will be readily apparent when assessments by representatives have been inappropriate and this information can be fed back into the loop.

The standards used, their sensitivity, their utility, and the ease of recording and quantifying will be the subject of ongoing research and evaluation between community, representatives, agency and possibly providers at annual meetings. (item 12)

8.13 Capacity Constraints (item 20)

The discussion paper indicates that there are financial and capacity constraints. In the proposal made there will be cost gains and cost losses.

The educational "accreditation" costs will be markedly reduced. An assessment of the way processes operate and the outcomes will already have been performed. After verifying this, the educational process will be targeted and more specific. Owners and operators can reasonably be expected to contribute to this.

In regard to oversight, the number of central accreditation oversight assessors will also fall away rapidly and will be replaced by a smaller number of experienced supervisors. The process will become much more personal and the supervisors will get to know the representatives and the chairpersons they work with. Site visits will be by supervisors mentoring the representatives.

Similar adjustments and reductions will be made in the complaints system.

Because the proposed changes will be progressively introduced over time there are unlikely to be job losses because of normal attrition. Many will change roles.

I have insufficient experience of the sector to attempt to quantify the cost of the representatives required. I don't know if it will be significantly greater. I note that many of the other suggestions made also have significant cost implications. Because there will be greater efficiencies in data collection, oversight and remediation there may be an efficiency dividend and unquantified cost benefits in other areas where the governments approach is currently met by more cumbersome processes. (items 18 and 72)

Clearly in some geographic areas much less oversight, complaints resolution, and remediation will be required. In others much more may be necessary. The need for these may vary widely from time to time or need to be increased in response to changed ownership, management or local personnel. The oversight and complaints sectors will need to keep funds in reserve so that they can pay for extra hours or employ more representatives. Community committees will be in a position to recognise this need and ask for more support.

It may well be that in some areas representatives might be assisted by volunteers in some of the non-confidential assessments they do. Committed communities and families might be motivated to raise funds to support overworked representatives by paying for more time.

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 and 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.

Many of the words in the discussion paper reflect this. 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.

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 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.

Proposed Lines of Communication

