29 December 2017

The Hon Ken Wyatt AM, MP
Minister for Aged Care & Indigenous Health
Member for Hasluck
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Dear Ken,

Re: Clarification of pressure injuries prevalance in aged care and new developments

We write to clarify the confusion surrounding the prevalance of pressure injuries in aged care as well as to take the opportunity in thanking you for some other, unrelated developments in aged care. Members of our group have been busy evaluating recent reports that have become available, meeting with industry figures and more recently attended the Aged Care Workforce Summit Taskforce to which we made a response.

In the past industry have been condemnatory and dismissive and this is an unusual development. We suspect that this willingness to meet critical community groups is a consequence of your own approach to the issues in aged care and is due to your influence. That is greatly appreciated.

Given our past experience, we worry that industry may be more interested in showing that we have agreement and in curbing adverse publicity than in addressing our concerns and making changes. We believe that an attempt to claim agreement in a communication to the Minister and others, rather than outline the areas of disagreement that we should be working with them on, may have been an example of this. Aged Care Crisis and several other invitees refused to be associated with this and objected strongly.

We welcome the opportunity to continue engaging constructively in considering the evidence for both failure and benefit. If we are to make progress then we must address the differences in perspective and not pretend we all agree.

We would like to contribute to the development of policies that are evidence based and not highly selective in the material they consider. We are currently looking critically at the Carnell Review report and are concerned by the selective way in which important material that was critical of regulation was not acknowledged or confronted in reviewing its failures.

Transparency: We have obtained copies of the minutes of an Aged Care Sector Committee meeting released under freedom of information and note that your representative at the meeting made a valiant attempt to have the results of all the unpublished reports from the Quality Agency (which would include the contact/desk assessment reports, as well as the unannounced visits) released.

This was vetoed by the committee on the basis that these reports were too complex for the community. It was felt that *"these reports were more technical and, without explanation, may not provide useful information for consumers or their families"*. A consumer representative who often speaks for government and industry claimed that "Consumer Experience Reports" would be adequate.

We found this paternalistic and insulting and felt that it showed contempt for the community and a failure to recognise that families who don't have knowledge, need support in this marketplace if they are to exert their right to choose. Complexity should be addressed by accompanying outlines of significant points.

Community groups, the growing numbers of commercial operators offering to guide their customers when choosing homes, doctors and nurses – all those who support residents and their families need this information. Those who study the sector, whether academics or community groups, and those in the community who are consulted by government when making policy, need this sort of information if they are going to contribute constructively.

We raised this issue with Sean Rooney, the CEO of LASA when we met with him recently and we urge the Minister to press harder. The principle of disclosure is important even if, as even Carnell has had to acknowledge, the information gathered by accreditation is a poor measure of performance.

The value of consumer opinions: We are concerned by the reliance, which the government and the Quality Agency are placing on consumer opinions such as the *Consumer Experience Reports*. While important in this context, they must be supported and verified by solid verifiable data and the Agency is ill equipped and reluctant to collect this.

People without knowledge will look to those around them when forming an opinion. When those around them are enthusiastic or believe in what they are doing then this is reflected in their responses. Every medical researcher is well aware of this and many older researchers have experienced this directly by falling into this trap. Researchers interest and enthusiasm cannot be concealed and patients will minimise their experiences and ignore the problems that they are experiencing. This is why only double blind studies have validity in health care research and why benefit is so difficult to prove when this is not possible.

We are aware of examples in the corporate sector where vast numbers of vulnerable people who believed that they were receiving high quality medical care were harmed. Those providing the care were enthusiastic about what they were doing because it was so profitable. What was happening was exposed by total outsiders who were able to look in from outside, in one instance a policeman and in another a priest.

This is what worries us about aged care and Carnell's claims that our aged care service is generally good. As there is no data on which to base this, it can only come from opinion within the industry and those related to it. We have no doubt that the industry believes in what it is doing, but there is more than enough smoke coming out of it to worry outsiders.

The Ministers position: We appreciate that as Minister you may be struggling with a portfolio and a series of problems you did not create. In one of our submissions to the Walton Review of the Complaints scheme in 2009 we expressed the view that:

> "... 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 neutralise criticism - forced to operate and to show that it was successful..."

The government was under intense pressure and strong criticism at the time and its popularity was in decline. Eminent academic authority on regulation John Braithwiate has expressed similar reservations about the use of accreditation as a regular.

Our system is built on this imperative to be successful and escape criticism. This is why the lack of data about aged care is so worrying and why the problems are more likely to be systemic. Our system is the legacy of flawed policy in the past, which it is difficult for you as Minister to renounce or change. It is not your fault that there is so little accurate data to support the claims that are made in response to criticism. The lack of data about pressure injuries is a graphic illustration of the problem.

Clarification of pressure injuries prevalance in aged care

We thank your Senior Adviser, Paula Gelo, for providing the source of information (on 27 October) quoted by the 2006 RACGP to support the suggestion that the '*prevalence of pressure injuries in aged care homes is low and even between 3.4 and 5.4%*[1]*'*. This part of our letter is in response to that.

Baseline figures: The figures quoted by the RACGP referred to were referenced from a 2001 paper *"Pressure ulcers: the case for improving prevention and management in Australian health care settings"*[2]. This in turn took the figures from reports in 1996[3] and 1997[4].

This was prior to the pressure put on staffing by the marketisation of aged care in 1997 and the abandonment of more effective regulation in favour of accreditation. It is a useful baseline for evaluating the impact of the new market based system introduced at that time and for illustrating the ineffectiveness of accreditation as a basis for regulation over the last 20 years.

Post 1997 figures: We are aware of material from the Department of Health in 2017[5] that quotes more recent, but still dated figures. We have not found anything more recent:

> "... **Pressure injuries:** Pressure injuries are a major contributor to morbidity and decreased quality of life in residential care. **Australian research in this area has reported prevalences of pressure injuries ranging from 26% to 42% of care recipients.**[12] Organisations would be expected to minimise the risk of pressure injuries for susceptible consumers ..."
>
> [12] For example, Santamaria, N et al. 2009, *'Reducing pressure ulcer prevalence in residential aged care: results from phase II of the PRIME trial'*, Wound Practice and Research, vol. 17, no. 1, pp. 12-22[6]

Aged Care Crisis quoted these figures in our submission to the Carnell Review noting that:

> "... The Aged Care Quality Agency does not collect objective data of failures in care, but some Australian academics have looked and found a 26 to 42% (average 34%) incidence of pressure ulcers - over 5 times that across the USA ..."

That is what you might expect from the difference in staffing skills and numbers.

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1 2006 RACGP Silver Book: https://www.racgp.org.au/your-practice/guidelines/silverbook/common-clinical-conditions/pressure-ulcers/#216

2 Prentice JL, Stacey MC. Pressure ulcers: the case for improving prevention and management in Australian health care settings. Primary Intention 2001;9:111–20 (http://www.woundsaustralia.com.au/journal/0903_03.pdf)

3 Rice J. Where are the pressure ulcers? Poster presentation: Australian Wound Management Associations Conference Breaking Down the Barriers; Feb 21-23; Sydney, 1996.

4 Madsen W & Leonard M. Monitoring pressure ulcers in nursing homes. J Quality Clin Prac 1997; 17:209-213. 89.

5 Single Quality Framework - Draft Aged Care Quality Standards Consultation Paper 2017, Department of Health, Pgs 22-23 http://bit.ly/2icTc1j

6 Reducing pressure ulcer prevalance in residential aged care: http://bit.ly/2A2BhSM

We suspect the 32% figure the Minister actually used in his speech at the *Better Practice Conference* may have come from our submission to the Carnell Review or from his own department.

The Santamaria et al[7] trial was conducted over a 15-month period between November 2004 and February 2006. It drew those figures from reports in 2003 and 2005. Published in 2009, this paper was one of a series of red flags that were ignored at this time.

They are an indication of what happened in the first 6 to 8 years after the changes made to aged care in 1997.

Another red flag was the study of our regulatory system at the same time by Braithwaite and his team. They found it seriously wanting. In his 2007 book[8] reporting this research he warned that:

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

What has been revealed at Oakden and in multiple other aged care homes is in our view, a consequence of ignoring multiple red flags, uncritically assuming that recurrent scandals are *'rare exceptions'* and taking no account of the problems actually described by those providing care. In our view, this blinkered response was needed to maintain the illusion that we have a *'world-class system'*. When we read accounts of 11 pressure sores on one resident[9], we doubt the credibility of claims about good care.

Over the years Aged Care Crisis and many others have tried to have the problems in this system confronted, but neither industry nor politicians have listened.

Staffing and pressure Injuries: Prevention of pressure injuries is labour intensive and failures here are recognised as a key indicator of deficiencies in both staff numbers and skills.

One of us has a medical background working overseas and in Australia. Pressure sores are almost always preventable with really good nursing care and their incidence is a marker of failures in care.

We can only wonder at what the incidence of pressure injuries is today, 12 years after those figures were collected - 12 years during which staffing skills have been markedly reduced and numbers have not kept up with increasing acuity.

> When Santamaria's figures are compared with the earlier figures, they suggest that the **incidence of pressure injuries in aged care increased almost 8 times during the first 8 years after the introduction of the *Aged Care Act 1997*.**

If it continued to increase at the same rate in the 12 years since, then it would be over 18 times – an incidence of well over 100%. Clearly that is not the case but it shows that no one was interested in looking critically perhaps because this might challenge core beliefs and policy.

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7 Reducing pressure ulcer prevalance in residential aged care: http://bit.ly/2A2BhSM

8 **Regulating Aged Care** by J. Braithwaite; T. Makkai; V. Braithwaite e.Books.com: http://bit.ly/2rnUgU8

9 Family speak out about mother's care (16 Jan 2015), The Canberra Times: http://bit.ly/2hxvCQq

The nearest we get is in financial documents looking at the costs of care such as an Ansell review of ACFI modelling[10] that suggests that a total of over 35% of residents are funded for Complex Skin Management (29.11%) or chronic wounds (6.35%). We do not know how many of these are pressure injuries, how many were acquired in the facilities or how many were preventive in high risk cases. This is an illustration of the extent to which financial considerations rather than care and real world outcomes for residents dominates the sector and drives policy.

Imagine for example, if road fatality figures in Australia increased 8 times for a similar period of time? (actual figures: 1997 - 1,767 deaths; 2017 - 1,295 deaths[11]). There would be a national outcry. But the point here is that we don't know and can only speculate – if wildly. In our view those figures and Braithwaite's findings should have sent shock waves through the system leading to accurate data collection, particularly of pressure injuries. If this was road fatalities it would have.

Promises broken: In response to criticism by the Auditor General in a 2002/3 report, the (then) Accreditation Agency promised to start collecting data so that it could evaluate its effectiveness.

These matters were also raised in Parliament during a hearing of the *Joint Committee of Public Accounts And Audit* in August 2003 where the lack of consistency of audits was acknowledged and the failure to collect data to evaluate the accreditation process questioned.

The industry and the Agency indicated that they were addressing these issues[12]. The industry (Mr Mundy) indicated a willingness to use a *"resident-mix-adjusted basis - -(to) - look at the incidence of quality failures. For example, -- the incidence of ulcers from pressure sores and so on".* Another industry representative (Mr Young) indicated that many were already doing so.

It is clear that those were hollow promises and 14 years later no one is collecting even the most basic data that might reflect poorly on our *'world class system'*.

In 2007, the Agency appointed its own reviewer who supported their failure to collect and evaluate data about failures in care. Failures in care like pressure ulcers, became 'indicators' and:

> "... the basis for the indicator development was the clear understanding that they were being developed not to measure performance, but as tools to assist aged care homes to monitor and improve the quality of their care and services ..."

The Agency's assessors did not support the collection of data to measure performance. The role of accreditation was to assist providers and not to measure their performance or to regulate. We agree that it is not suited to regulate but verifiable data should be collected so that their own effectiveness and continuous improvement can be based on the impact they have on care rather than their success in accrediting a high percentage of facilities as Braithwaite found they were doing in his study. This regulatory role was imposed on a system that was not designed or motivated to regulate.

In 2010 the (then) Accreditation Agency asked the Productivity Commission to recommend that they be released from their regulatory role. It clearly stated the danger of the duality of their educative and oversight roles.

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10 Budget 2016 ACFI Modelling - Summary Finding June 2016 by Ansell Strategic

11 List of motor vehicle deaths in Australia by year: https://en.wikipedia.org/wiki/List_of_motor_vehicle_deaths_in_Australia_by_year
Road Trauma Australia: https://bitre.gov.au/publications/ongoing/road_deaths_australia_annual_summaries.aspx

12 Joint Committee of Public Accounts and Audit, Review of Auditor-General's reports, 4th quarter 2002-03, 18 Aug 2003: http://bit.ly/2A1xAgm

To quote directly from their (second) submission:

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

The Agency went on to say:

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

Logic dictates that the new Agency should have been relieved of this burden and a new, more appropriate, non-conflicted system built around community surveillance substituted. The practices of the late 1990s that they criticised did ensure transparency and were effective in curbing the industry's excesses.

It was the industry's resistance to this and their close relationship with government that saw something that worked simply removed and not replaced with anything effective. It could have been improved in order to address real issues that the industry had. The Agency's criticism of this reveals the dominance of the industry's discourse and the extent to which our regulatory system has been captured by the market and its ideas.

In our view what this system lacked was integration with the community whose support it needed to build a bridge with providers. Accountability in this sector should be to each local community. We are all responsible for the wellbeing of those around us and this is a role that governments cannot fill but must foster and support – not assume.

We are interested in designing a regulatory system that is effective and less intrusive because it is integrated into the day-to-day care of residents - there every day and ready to step in at the first sign of problems.

The Agency's assessors in 2000's conclusion that accreditation was performing well was based not on the hard data the Agency agreed to collect in 2003, but on a survey of staff who identified with its objectives. As explained earlier, such assessments are unreliable. We suspect that had hard data about pressure injuries and other failures been collected, the inadequacy of the accreditation process as a regulator would have been recognised many years ago.

Large numbers of residents who have suffered neglect and poor care in Oakden and other homes[13] [14] [15] [16] over the years would have been helped rather than harmed. This is a human tragedy that Australia is still not prepared to acknowledge and address.

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[13] Elder abuse inquiry: Man dies in hospital after Gold Coast nursing home staff fail to properly treat wounds (27 Sep 2016, ABC) http://www.abc.net.au/news/2016-09-27/man-dies-after-nursing-home-staff-fail-to-properly-treat-wounds/7877820

[14] Dawn's final days reveal aged care horror (23 Sep 2017, SMH): http://bit.ly/2BxPJGM

[15] TriCare Bundaberg 'understaffed', patients receiving inadequate attention, families say (10 Mar 2017, ABC): http://ab.co/2BVGakw

[16] Nurse adds voice to call for Royal Commission (18 Jul 2013, ABC): http://ab.co/2kVYfEq

The problem revealed

The problem here is much more than just the incidence of pressure injuries. It illustrates the way aged care policy has been developed and managed in the past. The real problem here is that none of us, even the Minister responsible for making aged care policy and his Senior Adviser, have any accurate recent data on what the incidence of pressure injuries is. They are using dated figures that range from 3% to 46% for a complication that has been a marker of poor nursing for as long as some of us can remember – at least 60 years!

We appreciate the Ministers genuine attempt to bring this issue into the debate about aged care and understand the need to quote data to do so.

The CEO of LASA, the body that is lobbying against Registered Nurses and mandated staffing levels also did not know the incidence of pressure injuries when we met him. Decisions are being made and the debate distorted by people who do not have direct experience or the knowledge needed to form an opinion.

Pressure injuries in hospitals: Pressure injuries cause extensive suffering and premature deaths from sepsis. They are hard to miss as hopefully every resident is washed or showered.

When pressure injuries are detected early and treated effectively, the serious Level 3 and 4 ulcers are preventable. In hospitals where many patients may be anaesthetized, paralysed, ventilated, and given pain relief, increasing the risk, the incidences of pressure injuries are taken very seriously.

In Queensland, Pressure Injuries (PI) are classified as an 'adverse event' that incurs funding penalties of $30,000 and $50,000 for the more serious injuries[17]. By improving nursing care and allowing nurses who do have knowledge and experience to drive the process the incidence of hospital acquired pressure injuries has been reduced - in some hospitals by over a third.

Aged care has looked the other way.

Pressure injuries in aged care: Aged Care Crisis and others have repeatedly highlighted the incongruity of promoting choice as a virtue of the current system, and then not collecting or publishing the data on which informed choices can be made.

A major problem for residents, family members and community members who support them, is the absence of useful data such as staffing levels and pressure injuries.

The confusion about pressure injuries is a graphic illustration of the core problems in this system and the patterns of thought of those who are responsible for it.

What is very worrying is that those who pass laws and refuse to regulate staffing numbers, the CEOs of the companies that control staffing in their organisations, probably the managers in nursing homes, as well as StewartBrown (the organisation that advises providers and sets the benchmarks that nursing companies use in staff planning), do not seem to understand the relationship between staffing and pressure injuries.

None of them know their incidence when they make decisions about staffing. If they do know, then this information is being withheld from the public and we are left to fear the worst.

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[17] Miles SJ et al **Decreasing pressure injury prevalence in an Australian general hospital: a 10-year review** Wound Practice and Research Volume 21 Number 4 – November 2013 pages 148-56 http://www.woundsaustralia.com.au/journal/2104_01.pdf

Confusion: The problem in this system are illustrated by the difficulty your office had and the confusion after I questioned the vast differences in the prevalence of pressure injuries quoted in the Minister's speech to an industry related audience[18] (32%) - nearly three times more than the (initial) published figure of 10.3% (now removed) given to citizens via the media hub[19].

The more accurate and apparently most recent 32% figure was never publicly proclaimed and a different, much lower figure was published then removed from the media hub[20] after we highlighted the differences and asked for clarification.

Even the Minister and his staff with all their resources do not know where the 10.3% figure given to the public came from.

Upon pressing for the source of the Minister's data, we were pointed to figures that were more than 20 years out of date - different statistics again, 3.4% and 5.4% (average of 4.4%).

We suspect that the figures were reduced and then reduced again at the insistence of the government's PR experts, who do not understand the significance of what they are doing. It is because people now realise that this is happening that there is so much disillusionment. It is little wonder that citizens have lost all faith when image creation is so dominant that the accuracy of the information they are given is compromised.

Transparency: When we and other advocates and family members met with the Minister earlier this year, during conversations one of the prevailing themes was the lack of transparency and accountability in the system. Aged Care is a sector where trust and trustworthiness are vitally important. Information should not be this difficult.

Sadly all this suggests that instead of transparency, censorship by controlling information and then reporting it selectively is alive and well in Australia. We conclude that the prevailing discourse in the market and in politics sees the manipulation of data to serve market or political interests as a legitimate strategy.

We suspect that you as Minister do not support this or like it any more than we do but politics is being run like a business. Image, branding and marketing have become the route to success and neither are constrained by data, science or logic. Good government and needed changes in policy become impossible and the interests of the public are not served. This seems to be another example of what academic analysts have described as the "post-truth era" – and the erosion of democracy. It shows why it is happening. Data has lost its objective and trusted position in our society. Motivated politicians struggle but are trapped in this.

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18 Minister's speech - video capture - Better Practice Conference: http://bit.ly/2BPRWu4

19 Minister's speech original transcript: http://bit.ly/2Dsgg5Y
Minister's speech updated transcript: http://bit.ly/2kWk5HU

20 Australian Aged Care Quality Agency Better Practice Conference 2017 - The Federal Minister for Aged Care and Minister for Indigenous Health, Ken Wyatt AM, MP spoke at the Australian Aged Care Quality Agency Better Practice Conference 2017 on 12 October 2017 http://bit.ly/2gVg2hm

In conclusion

The market: The introduction of the *Aged Care Act 1997* introduced a competitive free market and made no provision for the accurate collection of any useful data. The government was being challenged and its popularity was falling. Information was challenging and understandably in that situation politicians preferred not to go there. As a result, aged care policy has been created in a vacuum and without the evidence needed to assist community members to make informed decisions about care. The government is now under pressure because the policy failures at that time have not been acknowledged and addressed. It is past time to do so.

Commercial competitive pressures for profit and growth have been unopposed and uncontrolled resulting in self-serving cost cutting of staff and other resources – activities that compromise care but are supported, welcomed and given legitimacy by the dominant discourse in the sector.

Staffing: The US recognises staffing and care are inextricably tied together. Their data shows the relationship to fewer hospitalizations, fewer infections, fewer pressure ulcers, less skin trauma, less weight loss and improved functional status.[21]

Because commercial pressures caused deceptive reporting it set in place processes for checking that self-reported staffing levels are accurate.

As Professor Michael Fine and his team's analyses[22] show, care is the product of an interdependent but close relationship between caring staff and those they care for. When staffing is compromised in any way the relationship and the obligations created by it suffer and care fails.

Unlike Australia, the US Center for Medicare and Medicaid Services (CMS) acknowledges the significance of staffing levels, employee turnover and tenure[23]. It *"has utilized staffing data for a myriad of purposes in an effort to more accurately and effectively gauge its impact on quality of care in nursing homes*…" Australia has fought a 20 year battle to keep this information away from those who need to know it.

The CMS sets out recommended minimum staffing levels that are required for safe care if residents are not to be harmed[24]. These are based on careful research and expert opinion.

The CMS collects and publishes this information for each nursing home in a web friendly and machine readable format[25]: It has been doing so for nearly 20 years.

The importance of data: In contrast with Australia, even the very poor US system, where data about care and staffing is collected and published, offers the diligent and unstressed some choice. Here, staffing has slowly improved and the incidences of failures in care have fallen over the years. The incidence of pressure ulcers in over 15,000 Medicare funded nursing homes collected annually by state officials is 6.2%[26].

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21 Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2009 Through 2015. Henry J Kaiser Foundation July 2017 page 13 http://files.kff.org/attachment/REPORT-Nursing-Facilities-Staffing-Residents-and-Facility-Deficiencies-2009-2015

22 The Nature of Care (a brief review of several papers on Inside Aged Care Web site) https://www.insideagedcare.com/aged-care-analysis/theory-and-research/nature-of-care

23 Centers for Medicare & Medicaid Services (CMS) http://go.cms.gov/2frxXuQ

24 Medicare.gov | Staffing charts: https://www.medicare.gov/NursingHomeCompare/Data/Staffing.html

25 Data.Medicare.gov: Nursing Home Compare datasets: https://data.medicare.gov/data/nursing-home-compare

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

Pressure injuries are a red flag to what is happening. The failure to collect data properly is endemic. For example a recent 2017 study by ex Agency Director Professor Ibrahim[27] and his team examined reported deaths due to resident on resident aggression. He found that the figures were "just the tip of the iceberg" as cases were not properly reported.

In addition to underreporting, the data collected was of poor quality as was its analysis and reporting. He stressed the limitations and inadequacies of the legislation. In reference to resident on resident incidents he stressed that *"ensuring accurate reporting - - - , and raising community awareness of ageing-related issues, are important first steps to improve our aged care system - - ."*

Ibrahim we think understands that it is ultimately the local communities and not as Carnell asserts the providers who are responsible for ensuring that adequate care is provided. The providers are providing care on behalf of the community to whom they are responsible but their attention is diverted by competition and profits. It is government's responsibility to design a system where communities are on top of what is happening and where they can insist that the providers meet their responsibilities.

Accurate information and data on performance is crucial for policy makers, regulators, customers and for informing providers about weaknesses in what they are doing, but more is needed. We recognise that an excessive focus on data has been counterproductive and its effectiveness depends on the context within which it is collected and used.

Braithwaite for instance did not focus on accurate data because of his disenchantment with the way a single-minded focus on data collection in the USA diverted the focus from everything else and distorted the service. But data constrains our very human tendency to wander into fantasy if that works for us or hides our failures. But we do need to be careful when collecting it and in how we use it.

An effective and directly involved community is needed to confront dysfunctional thinking and decision-making, and so prevent problems. But to regulate effectively accurate data collection and oversight are essential in informing the community and in detecting problems when they occur. Action can then be taken by formal processes.

Importantly, research is needed in Australia to address the relationships between staffing parameters, failures in care, standards of care, elder abuse, provider type, profitability and management structure. Policy should be informed by the results.

Our request for transparency: We ask that you as Minister take a stand on transparency by insisting that your department publish the correct information given by you as Minister to the industry. This is the most recent data available to the government and was quoted in your speech at the Quality Agency's 2017 Better Practice Conference[28].

It would also be appropriate to add a footnote indicating that the available figures suggest that the incidence of pressure injuries may have increased from a figure of 4.4% since the 1997 changes and that steps are being taken to investigate further and then act.

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27 Violence between residents in nursing homes can lead to death and demands our attention The Conversation 14 Nov 2017 https://theconversation.com/violence-between-residents-in-nursing-homes-can-lead-to-death-and-demands-our-attention-87087

28 Australian Aged Care Quality Agency Better Practice Conference 2017 - The Federal Minister for Aged Care and Minister for Indigenous Health, Ken Wyatt AM, MP spoke at the Australian Aged Care Quality Agency Better Practice Conference 2017 on 12 October 2017 http://bit.ly/2gVg2hm

It will be a damning indictment of the government's claims to addressing the issues exposed at Oakden if this, like much other information in aged care, is withheld? We ask you to resist the pressure that will be put on you not to do so.

If more recent verifiable figures are available, they should clearly be published to set the record straight.

The Carnell Review: As indicated our initial impression is that, unlike many previous government appointed reviews it has identified and acknowledged the failings and has attempted to address them. We welcome this first step forward. However, we also feel that the extent of the failures has been glossed over, and that the flaws in the system responsible for these problems in the system have once again been ignored.

The review has been highly selective in the material it has chosen to examine and reference. As a consequence the recommendations do not challenge the dominant discourse, do not confront what we see as core problems in the system and fall short of the sort of changes that are needed. We are currently analysing this report and will provide your office with our full analysis.

Groundhog Day: Our concern is that this report is a repeat of the response to the rape and sexual abuse failures in 2006[29] – another example of the recurrent attempts to patch the system and make it work by regulating within the prevailing discourse and the same failed and unsuitable regulatory processes.

We expect more from a government that promotes innovation as central to its platform. Innovation starts by thinking outside the square and questioning prevailing ideas and discourse. We hope that you as Minister will take a stand and be more innovative when taking action.

Respectfully,
Lynda Saltarelli.

[29] The Rape and sexual Abuse Scandal - 2006: http://bit.ly/1ibLEWg