

INQUIRY INTO ELDER ABUSE IN NEW SOUTH WALES

Organisation: Aged Care Crisis

Name:

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The Director
General Purpose Standing Committee No. 2
Parliament House
Macquarie St
Sydney NSW 2000

Re: Inquiry into elder abuse in New South Wales

Aged Care Crisis (ACC) welcomes the opportunity to respond to this Inquiry. ACC is an independent group of Australian citizens. Members of our group are engaged with the aged-care sector in a variety of ways – as health professionals, legal experts, consumers of services and as volunteers. Our website provides accessible information on many aspects of elder abuse and aged care and an opportunity for site visitors to express their views and concerns. The tenor of much of our feedback indicates a high level of community concern relating to elder abuse and aged-care issues generally.

We urge the inquiry to address elder abuse and to make recommendations, which reference community organisations. We believe that existing community organisations addressing this issue would work well by cooperating with and working through the *Community Aged Care Hub*¹ that we propose.

We believe that by integrating all of these services as part of a coordinating body not only will money be saved, but also the services would build on each other and would therefore be far more effective than the fragmented services we have now.

We acknowledge that Government alone cannot stop elder abuse and it requires a co-operative approach and support from the community. Our recommendation to the Inquiry is that in looking at the proposals made for addressing elder abuse, it considers whether they can be best implemented through a community structure. In doing so, we hope that it will see the merit in what we are proposing within our submission and make recommendations accordingly. We ask that it should mention and support a broad community solution for the problems in aged care on the basis that this would be the best way of dealing with elder abuse at the source.

Government and corporate adoption of a top/down managerialist mode of operation for structuring society has resulted in what social critics describe as a "hollowing out" of communities and of civil society. The term embraces a loss of knowledge, experience and confidence, as well as the consequent disengagement of citizens from the affairs of the community. Elder abuse is occurring in these communities. Our proposal can be seen as part of the process of re-engaging and rebuilding communities. By reversing the hollowing out of our communities, we alter the context within which elder abuse occurs and the way it can be addressed.

Under our proposal, there would be funded and voluntary staff working across community services and aged care homes, as well as in supporting age related community activities. They would be in close contact with staff, managers and the community at all levels, talking and listening to them. They will be in an excellent position to hear what is going on and will know when community, staff, family or friends are worried. They will be in a position to assist or intervene in a sensitive way. Volunteers already engaged in residential and community aged care² could leverage from the hub that we propose.

There is a desperate need for real change in the prevention of elder abuse and the provision of aged care. The aged care sector is particularly well suited to be the vehicle for introducing and showcasing ideas of citizenship, partnership and open government in Australia.

In summary

While we strongly support legislative change and revision of laws governing elder abuse to make them more effective, we also believe this should be combined with a concerted push in the community to combat ageism and elder abuse.

A market requires an effective customer to make it work and in almost every sector where customers or employees are vulnerable they have been ruthlessly exploited and abused. Where government has contracted services like jobs or vocational training to the market, the services have been rorted and consumers harmed. Aged care fits into both categories and the many examples of failures in care suggest that this might be happening here.

Over the years frail older people have found themselves cast first as patients needing medical and nursing care in nursing homes where they lived and formed close relationships with those around them. They were largely cared for by their communities. As governments funded and took control of aged care, they became 'residents' not needing much more than basic care, which was provided by poorly trained nurse aids and a diminishing number of nurses. The community were increasingly marginalised and "hollowed out" as aged care was managed from above.

Most recently, they have become 'consumers' (or customers) who, in theory but not in reality, are able to pick and choose from a range of (increasingly) commercial providers. 'Choice', 'consumers' and 'customers' are the new currency where aged-care services are increasingly exposed to the market economy^{3 4 5}. These changes have everything to do with changes in political and community ideology and little to do with the aged themselves, although they have suffered the consequences.

The aged remain frail, confused, vulnerable, and in need of support and the social interaction that gives their lives meaning and relevance - something each ideology offering solutions conveniently ignores.

'Choice' implies that there is ample information to be able to base an informed decision in aged care. It has little relevance or meaning when the information needed to make the most important choice - who is going to care for you and help you to die without suffering - is not available.

ACC believes that the important practical step to address the rapidly developing problems is to re-engage with the community by putting data collection, oversight and advocacy as well as management and control of local⁶ aged care services into the hands of local community groups who should be given the powers to function as effective customers. Government's role should be to work through these groups by supporting and mentoring them - a partnership. Local communities are in the best position to identify elder abuse and we believe that elder abuse organisations should operate through local community structures.

This proposal is in keeping with 21st century thinking about the successful provision of human services and gives practical form to the concept of partnership between civil society and government. This partnership is one of the principal underlying the 21st century global Open Government Partnership⁷ movement to which Australia claims to subscribe.

We also refer to the submission that has been made by Rodney Lewis entitled *An Elder Abuse law for New South Wales* and wish to support that submission⁸. It appears that the legal remedies for elder abuse either do not exist or are scattered throughout the laws of NSW. There is probably a natural reluctance on the part of police in the first place to interfere with family relationships. Anecdotally, for example with abuse of powers of attorney, it seems the police prefer to leave those matters to the civil courts. We believe a single law dealing with most elder abuse issues is the best way forward. Any efforts to improve elder abuse strategies should also account for issues that span both Federal and State level to be truly effective.

Introduction

Aged care is currently undergoing major changes following the Federal Government's decision to open the aged care sector up to the market. We believe that these changes will increase many of the pressures, which currently prevail within the sector⁹. For example, staffing is the largest on-going expenditure faced by aged-care providers and pressures to reduce costs will undoubtedly affect staffing levels. There is evidence to suggest that nursing home managers are under pressure to meet their profit targets and reducing staff to do so, often placing vulnerable residents at risk of elder abuse¹⁰.

When staffing is reduced and registered nurses are replaced by lower-skilled staff, care quality suffers.

1. No reliable data

The major difficulty for the Committee and those making submissions is the absence of any reliable data in Australia about elder abuse.

The introduction of the *Aged Care Act 1997* made no provision for the accurate collection of any useful data about the services provided and as a consequence, aged care policy has been created in a vacuum and without the evidence^a needed to confront and moderate ideology so that its application was appropriate. The lack of information about elder abuse should be seen within this context.

In aged care generally there is a fragmented approach to the collection of data and this extends to elder abuse where different agencies or organisations may receive reports of abuse. Missing from the aged care sector is the sort of accurate data that tells us what is happening - data from which we can draw conclusions and on which we can base actions. It is impossible for an aged care market to operate effectively if the customer is in the dark. Planning and policy cannot be made in a vacuum.

There is no reliable data on:

1. Incidence and prevalence of elder abuse
2. Location of where elder abuse is occurring
3. Who is committing abuse
4. Types of elder abuse

Information including that about elder abuse should be collated as a whole so that a clear picture can be formulated of the problems and their relationships to one another. They should not be housed and hidden away in separate silos, as is currently the case.

Elder abuse and the conflicted role of providers: This is important because elder abuse cannot be separated from the culture of the organisations and the personnel providing care both in nursing homes and in the community. Staff play an important role in detecting and preventing elder abuse. The sort of relationships they have with those they care for, their families and the community is vital if they are to be trusted and confided in.

More worrying is that the perpetrators of elder abuse are too often those providing care. Typically this occurs in facilities that have dysfunctional cultures. These facilities very often have dysfunctional and unsuitable management and therefore staffing problems. There may be too few or untrained staff and a high turnover of staff. There are likely to be failures in care and families who find the care wanting.

^a (2015) Baldwin, R., et al., Residential Aged Care Policy in Australia – Are We Learning from Evidence? Australian Journal of Public Administration. doi: 10.1111/1467-8500.12131 University of Technology Sydney, <http://onlinelibrary.wiley.com/doi/10.1111/1467-8500.12131/abstract>

Anyone with basic skills will identify the ambience and unhappiness in these facilities and realise that things are not as they should be. It will be important to see if there is any relationship between the documentation of errors in care and elder abuse and what the relationships of both are to management structure.

Effective and accurate data collection and oversight might point to potential problems. An area of potential research would be the relationship between staffing parameters, failures in care, standards of care, provider type and management structure, and elder abuse.

The provision of substandard care in order to boost profitability is a form of elder abuse.

Disclosure of institutional elder abuse is critically important for potential "customers" and because of this it has significant commercial consequences. There are therefore, strong incentives in the market system towards concealment. That whistleblowers are usually fired is a major deterrent to staff wanting to report abuse. This has been a major problem in the past and will undoubtedly become worse as government's marketisation and competitive consolidation of the aged care system advances.

It is hardly surprising that infrequent government oversight, including accreditation, has been singularly unsuccessful in addressing the increasing number of problems that are occurring and are highlighted by the submissions from the *School of Nursing at the Charles Sturt University*^b and from the *Quality Aged Care Action Group*^c. The information we receive from families and nurses who contact Aged Care Crisis is congruent with their observations. Far closer regular oversight and involvement is required and ACC believes that in a marketplace this can only be done by local organisations that have acquired the necessary skills and knowledge. We are advocating for this in our submissions and on our website.

Recommendation 1: The NSW Government fund a study into the abuse of older people including incidence, prevalence, who is committing the abuse and what type of abuse is being committed.

Recommendation 2: Reports of abuse of older people should be collated. Agencies or organisations receiving reports of abuse should share their de-identified data.

Recommendation 3: That the NSW government press the federal government for the establishment of integrated community based aged care services controlled by and operated by local communities, whose functions would include data collection. Government aged care services should be provided in partnership with these communities who would also act as customer in dealing with providers. Elder abuse services should be provided in close cooperation with these groups as they would often be the first port of call for the abused and be in a position not only to address the issue sensitively but protect the complainant or whistleblower from retribution.

^b [http://www.parliament.nsw.gov.au/prod/parliament/committee.nsf/0/72efc2ebf1cf239dca257f10007f5694/\\$FILE/0072%20M%20Bernoth.pdf](http://www.parliament.nsw.gov.au/prod/parliament/committee.nsf/0/72efc2ebf1cf239dca257f10007f5694/$FILE/0072%20M%20Bernoth.pdf)

^c <http://bit.ly/1QcUwip>

2. Narrow definition of elder abuse in aged care

'Compulsory reporting' laws were introduced in 2007, as a result of alleged sexual assaults in a Victorian nursing home. A 'reportable assault' is defined in legislation and means *unlawful sexual contact or unreasonable use of force* that is inflicted on a person receiving residential aged care.

Prior to the introduction of the 'compulsory reporting' regime¹¹, concerns at the time pointed to the limits of the proposed Bill in addressing all potential forms of abuse, which included concerns around poor nutrition, hydration, hygiene, verbal and emotional abuse or financial fraud. The limitations in the scope of reporting requirements fail to address other forms of abuse, which include neglect, financial and residents-on-resident abuse.

“... There is no duty of care to protect residents from the actions of other residents with cognitive impairment who may put others at risk. The government talks about *'behavioural management'*. Too often the latter fails and we note the refusal of the Government to commit to safe staff/resident ratios. As well, there has been no commitment to fund dementia units to separate residents who put other frail residents at risk - although there have been several cases where serious injury to frail people due to resident assault (perhaps even resulting in death) have occurred¹² ...”

Source: Aged Care Crisis submission: Aged Care Amendment (Security and Protection) Bill 2007

Whilst the MyAgedCare government website has adopted the definition of elder abuse according to the World Health Organisation, this conflicts with the narrow definition of government legislation's definition of elder abuse in aged care:

Elder abuse concerns

No older person should be subjected to any form of abuse, often referred to as 'Elder abuse'. Elder abuse can take various forms such as physical, psychological or emotional, sexual or financial abuse. It can also be the result of intentional or unintentional neglect.

Elder abuse can be defined as “a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person” (World Health Organization).

Source: MyAgedCare website: <http://www.myagedcare.gov.au/financial-and-legal/elder-abuse-concerns>

Recommendation 4: The NSW Government includes a clear definition of abuse of older people.

3. Elder abuse: speak out ... if you dare

For most of the 18 years (since 1997) of the reformed aged care system, the victimisation of whistleblowers and the fear of retribution against family members in care have served to hide what has been happening.

This is a problem in almost every sector where people are vulnerable¹³. Under the new Consumer Directed Care model much of the care currently provided in nursing homes will be provided in the resident's own homes. Will providing care at home when the person receiving care will be alone with the person the family have complained about be any different?

Elder abuse and market forces: Under the new regime, where aged care will be exposed to much greater market forces, elder abuse may not be immediately obvious to uninitiated and inexperienced family members. Many are unaware of the real human costs involved for frail residents and the impact on their lives.

Feb 2016: Report - 'Who will keep me safe? Elder Abuse in Residential Aged Care' In October 2015, the NSW Nurses and Midwives' Association (NSWNMA) invited members to complete a survey regarding elder abuse¹⁴. The report raised major concerns about the prevalence and management of elder abuse in residential aged care settings. When survey respondents were asked what they thought increased the risk of elder abuse in their workplace, almost 76% of respondents cited inadequate staffing as a precursor for elder abuse. In addition, 61% of staff feared repercussions if they reported elder abuse¹⁵. Information we receive is congruent with this report.

In a competitive, corporate marketplace the vulnerable too often become simply 'beds' - in effect, depersonalised profit vehicles being managed for profit and when market forces dictate, traded on an impersonal corporate market¹⁶. Businesses are sold to the highest bidder, the one who feels they can extract the most profit from these vehicles who, despite all the rhetoric about choice, still have no say in this.

These frail, older people need stability and do not shop around. This impersonal exploitation can in itself be a form of inadvertent elder abuse - integral to the market system. The instability inherent in a competitive market system places stresses on the services provided, creating a context where abuse more readily occurs but is less easily exposed.

A revolving door between providers, government, accreditation agencies, complaints schemes and the various programs implemented ensures that alternate views are marginalised and deficiencies consequently overlooked. Despite multiple changes, it is clear that problems in aged care persist and these regulatory structures have been singularly ineffective¹⁷.

Aged care failures: Over the years, aged care residents in nursing homes have been raped¹⁸, robbed¹⁹, bathed in kerosene²⁰, attacked by rodents²¹, suffered injuries or death from other residents²², burnt to death²³, strangled²⁴, cooked²⁵, melted²⁶, sedated to death²⁷, overmedicated^{28 29} or choked to death³⁰. Some staff have amused themselves by taunting, teasing³¹ or mocking residents and playing demeaning games on them like 'spot the body part' (photos)³², or rolled in tomato sauce³³. Some have endured DIY staffing (*no staff rostered on for over 10 hours at night*) in a fully accredited nursing home, resulting in recurring incidents of patients absconding, wandering and falling³⁴.

Family members have been kept in the dark^{35 36 37}, banned from visiting loved ones^{38 39} or bullied by facility staff after complaining about care⁴⁰. Some family members (out of desperation) have taken their concerns to media⁴¹, setup websites (or blogs)⁴², established social media^{43 44} presences, published diaries of care online⁴⁵ or setup online petitions to have their concerns heard^{46 47}. Some have been threatened with letters of legal action⁴⁸ and a few of these have refused to buckle.

At one public meeting, family members recanted allegations that frail residents were mistreated at a nursing home already connected to claims a lady (twice) had to have maggots removed from a wound⁴⁹. In another home, staff complained of *"maggots crawling over the floor and a lack of basic infection control equipment such as gloves and liquid soap"*⁵⁰. We have also seen stories of overgrown nails, untreated infections, medication mix-ups, and research showing up to 80% of aged care residents are malnourished and reports of dehydration⁵¹.

There are cases of residents dying prematurely because of over-prescription of anti-psychotic medication⁵². Many are suffering needlessly from untreated infections, urinary tract conditions⁵³ and pressure injuries, - lying in soaked pads brimming with urine and faeces (compromising skin condition) for hours⁵⁴ on end because there are not enough care staff to clean or turn them regularly. Then there are the cases of rationing of incontinence pads⁵⁵ with a daily 'limit', to save on costs.

The majority of correspondence we receive is due to a critical lack of trained staff, leaving many to die unnecessarily, in great pain⁵⁶, or without proper palliative care⁵⁷. One partly blind frail patient admitted to a NSW hospital from her aged care home after a serious fall, was forced out of the hospital with an eviction notice (*"It was read out to her in a crowded ward, which must have been quite humiliating"*) – despite protestations from her low-care home that she needed acute care⁵⁸. Various research concludes that many resident transfers might be avoidable with better primary care in place including staff skill mix, primary care services⁵⁹ and that inadequate documentation negatively impacts on the resident's journey through emergency departments⁶⁰.

Other family members have appealed to their local or state-based politicians around Australia for support or help. Although rare, some politicians have recorded the concerns of their constituents in parliament⁶¹. **There is an abundance of information for those who want to look.** ABC Lateline has exposed widespread human rights abuses in Australia's aged-care industry. The series found many vulnerable people are suffering abuse and neglect in Commonwealth-accredited facilities with little accountability⁶².

Countless inquiries and reviews in and around aged care (including institutionalised care) have consistently revealed the daily struggles faced by vulnerable people in care.

Little, if anything, has been done to implement measures or to address the issue of retribution.

Residents acting themselves: Residents themselves are at an even greater disadvantage. If they are unhappy about anything or make allegations, they are considered to have dementia and discounted. If they do speak out publicly, then staff and management see them as troublemakers and treat them accordingly. The lady in the quote below knew she was being robbed and had contacts in the surveillance industry. With a hidden "grannycam", video footage was soon in the hands of police. She is leading the way by doing this in Australia, but in countries with market systems like ours (UK and the USA) CCTV is increasingly being seen as the answer to the problems of elder abuse we are having in nursing homes.

"... When the disabled 75-year-old attempted to report the incident to retirement village company, they dismissed her claims.

"They thought I had dementia - and for that reason I was a trouble-maker and I would have been making it up," Ms said.

Source: Victorian retiree sets up hidden camera to catch thieving aged care worker - Channel 9 News, 2 Jul 2015
<http://www.9news.com.au/national/2015/07/02/18/45/victorian-retiree-sets-up-hidden-camera-to-catch-thieving-aged-care-worker>

Family members ignored: When family members reported their father was being abused to management, their concerns were dismissed. Distraught for their father's safety, they installed a video camera in his private room and caught the suspect abusing their father in broad daylight. The perpetrator was charged with several criminal assault charges ranging from recurrent torment, physical abuse and attempted suffocation. As a result of their experience, the family are petitioning for video surveillance cameras in residents rooms in aged care⁶³. This has been an ongoing concern⁶⁴.

Despite both the complaints system and accreditation of aged care homes being updated, renamed, claims of 'independence' or 'strengthened' in response to pressures from the community or 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 system of oversight 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.

The importance of whistleblowers: The vast majority of reports are based on or consequent of tip-offs by whistleblowers - either nurses in the system, or the relatives of residents. Staff who tried to complain to their superiors have been ignored⁶⁵ ⁶⁶ or fired⁶⁷. Others were fired after speaking out or going to the media. They are seen as troublemakers and struggle to find another job in the sector.

Here are examples from disability care where a similar situation exists. In one, it is only coming to light 20 years later:

"...People with disabilities have been found severely neglected, repeatedly raped, with broken bones and left humiliated in their own faeces for hours at a time, a Senate inquiry has been told.

Ms _____ said people with disabilities often did not report abuse because they feared retribution from people within the facility they lived in.

"They are very vulnerable and unable, more often than not, to speak up for themselves," she said.

"They are worried about retribution ..."

Source: *People with disabilities raped, beaten, neglected while in care, hearing told ABC News 10 April 2015*
<http://www.abc.net.au/news/2015-04-10/disability-hearings-in-perth-report-rape-neglect/6384308>

Illustrative of the way in which these things are swept under the carpet and ignored is something that happened 20 years ago, which those involved, are only now speaking out about. There are many more examples.

"... The wheels of the self-protecting Victorian bureaucracy were turning, making sure that the complete story of the shameful treatment of the Mornington Peninsula residents would stay hidden ..."

Source: *Disabled were abused in house of horrors and governments covered it up The Age, 11 April 2015*
<http://www.theage.com.au/victoria/disabled-were-abused-in-house-of-horrors-and-governments-covered-it-up-20150410-1mgq13.html>

Speaking out about failures and institutional elder abuse is always stressful and confronting. Because the only oversight system, "accreditation" is failing so badly we have no choice but to depend on whistleblowers for the information we get. Despite the criticism and evidence of failures, government and industry continue to describe accreditation and the equally criticised complaints system as "robust". They use it to discredit critics. This is intolerable and both need to be replaced by fully transparent systems where civil society itself has control and oversight.

November 2015: A Senate committee found a royal commission is needed into the abuse of people with disabilities in care, including aged care^{68 69}, after a parliamentary inquiry heard evidence of that the committee called "shocking" and "cruel" examples of violence and neglect around Australia⁷⁰. The Inquiry found existing abuse reporting mechanisms did not provide adequate protection, and in some cases could cause abuse⁷¹.

Senator Siewert presented the report of the *Community Affairs References Committee on the treatment of people with disability in institutional and residential settings*, together with the Hansard record of the proceedings and documents presented to the committee:

Senator Siewart: We heard accounts of violence, abuse and neglect in institutional settings, in residential conglomerate settings, in schools, in aged care — across the board. **Nobody at all in this country can say that this is not happening. This report clearly articulates that...**

... The other issue that came up really strongly and repeatedly was the need for national workforce and workplace regulation to address some of the systemic workforce and workplace issues that increase the prevalence of violence, abuse and neglect. There is a need for ongoing training, so we are calling on the government to consider the implementation of such a process.

One of the key things here was access to justice and the denial of justice for people with disability. Not only were people scared to report assault, abuse and violence, but when they had the strength to and could report it they were not believed by the police, by the service provider, by the judicial system.

People were told: 'No, this would never stand up in court. People wouldn't believe you as a witness because you've got a disability,' and this was particularly so for those people with a cognitive impairment. **So, even when people could report it, they were not believed.**

... We need to be working at a national level, and our states and territories also need to be working on this issue. **I will come back to the issue of data because it came up again and again.** I am sure Senator Moore will also address the issue around data, because it comes up for us again and again...

Source: *Community Affairs References Committee - (25 Nov 2015)*

http://parlinfo.aph.gov.au/parlInfo/genpdf/chamber/hansards/2ea0ef30-380c-493d-adf4-0223f89e0720/0174/hansard_frag.pdf;fileType=application%2Fpdf

Nurse academics speak out: Nurse academics from university departments have written theses and articles on their findings. They have accepted their responsibility as academics and spoken out about what they have seen and found. Instead of addressing their findings and criticisms, like Gillian Triggs⁷², they have been attacked, their research criticised and their universities asked to discipline them. This is one example - there are others:

"... The other thing that I wanted to talk to you about was the issue of research in aged care and the issue of researching in residential aged care. When Prof ... published her PhD in the mid 90s she was banned from residential aged care facilities on the mid north coast because her findings were adverse to those wanted by the industry.

"... I have been subjected threats of violence, verbal abuse, constructive dismissal. I've had contracts terminated and we sold our home and moved to another town because of the professional bullying that I was undergoing because I was revealing the outcomes of that PhD research ..."

Source: *Productivity Commission Inquiry - Caring for Older Australians: - evidence of Dr Bernoth: Transcript of Proceedings - see pages (39) 1371 (Canberra, 5 Apr 2011)*

<http://www.pc.gov.au/inquiries/completed/aged-care/public-hearings/20110405-canberra.pdf>

Relatively unknown: Outside of the government and advocacy websites and their own publications, there is limited public evidence to suggest that advocacy services exist. For example, advocacy is rarely mentioned in the many reports in the press, feedback to ACC, comments made to many review/feedback websites, in coroner's reports, or when criticisms of the complaints system are made.

Complaints about advocacy services also seem to be absent or rare. This in itself is unusual because it is seldom possible to satisfy all of your customers and indicative of the lack of awareness of services. In addition, feedback to ACC indicates that some problems are outside of the government advocacy agency's brief and they lacked the resources to assist.

Advocates working for these government-funded advocacy services should be among the first to encounter elder abuse and report it. That they are so low key is troubling and fuels our concern that governments are more interested in creating an image of aged care that they can sell to the Chinese under the new trade agreements than in protecting frail older people.

Addressing the problems in elder abuse including aged care

A changing system based on changing ideology: Aged Care Crisis has carefully examined the manner in which the move from community to government and then to market for the provision of community services to the vulnerable has impacted on society and on the services provided to vulnerable members of the community.

The consequences for the aged are significant. These factors, as well as deeply seated ageism within society, may well account for the increase in elder abuse. Particularly worrying is the way in which a market in aged care has been introduced without adequate attention to the vulnerability of seniors and the presence or creation of an effective customer - a "necessary condition" for any market to operate in the interest of the community and its members. The importance of this is revealed in the many frequent failures involving financial misuse and abuse of vulnerable people in Australia and globally. Elder abuse within aged care is another example.

Pressures in aged care: Particularly worrying is the situation in aged care in Australia. Here, profit is taken and care is provided from the same pool of money and there is no publicly available data that shows how many staff are provided, what sort of care is actually provided and how often there are failures in care.

When markets consolidate, competitive pressures and the need for increased profits to fund acquisitions escalate rapidly. Enthusiastic managers readily find justifications for "efficiencies" that allow them to spend less on care and so increase profits (and so their own rewards and prospects). Once one company finds a way of doing this, others must follow if they are to compete and survive. Explanations are developed to justify this. The outcome is institutional and government sanctioned under-servicing of the elderly - essentially an abuse of their rights as citizens and a form of elder abuse. We stress that this is usually not deliberate, but a very human response to a system that is seriously flawed.

Good care is given by many providers - but this is in spite of the system and not because of it. The actual incidence of failures is hidden behind the opacity of the system, but it is clear that they occur far too often. Clearly, both government and the marketplace have contributions to make and responsibilities they are expected to meet. Unfortunately, the incentives and rewards within the system create pressures away from care and towards justification and rationalisation in the face of evidence.

The various oversight and community services including accreditation, complaints handling, sanctions, advocacy, education and support are separated into isolated silos that do not work effectively together and are ineffective in countering the pressures towards dysfunction.

Looking for a way forward: Aged Care Crisis is pressing for a practical, community-based solution to the many problems in elder abuse and aged care that will work within the context of the current system. Our solution is also intended to be a broadly-based structure where information and data can be examined and where practical, balanced, and innovative solutions developed into the future.

ACC has opened public debate on this issue on its website with a proposal suggesting how this could be done by creating a coordinating community service through which all aged care services would be delivered, integrated and monitored. It would work cooperatively with the providers, where it would act as effective customer by working with and advising prospective recipients of services. Government would work through these groups by supporting and mentoring them. All the government services would be delivered by or working closely with this organisation.

Wider role: This organisation would also have a wider function within each community. It would coordinate community aged care services and activities, educating and supporting the community. It would address the problem of ageism and elder abuse. It would be well placed to play an active role not only in detecting elder abuse, but in identifying contributing factors and playing a key role in prevention.

We have called our proposal a "Community Aged Care Hub", borrowing the name from a proposal made earlier by Professor Ian Maddocks, but building on his ideas. An outline of the proposal is given in this submission 4. *The essence of the "Community Aged Care Hub"* and more detail is available on our website⁷³.

The proposed "Community Aged Care Hub" would be communicating with recipients of services and their family members continuously, getting their views and suggestions, whilst maintaining confidentiality. The hub would be there for the community and its members. It would be watching and protecting anyone at risk of victimisation. There would be strong disincentives to avoid addressing issues when things were wrong.

Motivated providers would benefit from the close relationship with the community, the reliable feedback they would get as well as the support and appreciation they will receive when they address issues and improve the service. It is not intended that providers be excluded but that they become a part of the solution and identify with it.

Trust and trustworthiness: The intention is to rebuild the trust between providers and the community they claim to serve and to rebuild it on a solid knowledge base that both share. Trust has been seriously eroded by the well-documented failures, the anger of many families as well as the opacity of the system and its often, impersonal nature.

Vulnerable services cannot be provided successfully in this sort of situation. Without support and praise from the community, morale and motivation rapidly decline. This is particularly so in services to sick or frail people because the careers of employees are driven by humanitarian motives and when these expectations cannot be met, staff become alienated and disinterested.

By making both for-profit and not-for-profit services part of a wider community enterprise, we bring them back into the community and out of the cultural silo that they are now in and where elder abuse has occurred.

Those providers who are serving the community will not have anything to fear, and will gain help and support. Those that maintain a silo mentality and a dysfunctional culture will find themselves out in the cold and will have a tough time if they don't sort themselves and their community values out. The community must be in a position to act and make the market work. This is currently not the case.

Whistleblower support and legislation is needed to support and encourage workers to speak up without fear of being persecuted or targeted by their employers when a report of elder abuse is made in good faith. But legislation to protect whistleblowers is rarely effective as the biases and pressures in their working environment remain. The proposed hub would be well placed to ensure that they are viewed as having made a valuable contribution and are protected and rewarded.

Recommendation 5: That the committee not address elder abuse as an isolated entity but instead recognise that it is part of a serious societal problem that we have in caring for the aged, one where many factors are interrelated.

Recommendation 6: That the committee recognise elder abuse as a community problem (including aged care services themselves) and as such, seek community solutions in which elder abuse's relationships to a multitude of factors are recognised.

Recommendation 7: We advance our proposed community aged care hub as an integrated community service that would be well suited as a vehicle for addressing elder abuse as well as the interrelated problems in aged care. We urge the committee to support this as the most sensible way forward and progress this in their dealings with the federal government.

4. The essence of the "Community Aged Care Hub"

Introduction: ACC is pressing for, and seeking community support, for the creation of an informed customer with sufficient market power to insist on the service that is needed. We are advocating for the creation of a network of local community groups with the knowledge and the power to insist on the care required. In effect, a "Community Aged Care Hub"^d.

All of the regulatory and support services that protect consumers of aged care would be channeled through these groups, which would be supported and mentored by government. This would give the community the knowledge and the power to change this to a system driven by care rather than profit. This would create a knowledgeable civil community to drive future change.

Previous submissions: ACC has researched and analysed the aged care system over many years and proposed new pathways for reform. We have attempted to open public discussion on our website⁷⁴. We have advocated for a community-based solution in submissions to reviews of the complaints and accreditation systems as well as to the Productivity Commission in 2010. We have urged greater involvement from local communities and indicated how this might be achieved in a more recent submission to the *Review of the Government's Aged Care Advocacy Service*⁷⁵.

"... Importantly, nursing homes are only one part of a community hub. A hub is the centre of something that extends across the community, coordinating and supporting every facet in managing the ageing process.

It should make each of us a participant and helper as we age. There should be no age limits ..."

^d The essence of a "Community Aged Care Hub": <http://www.agedcarecrisis.com/solving-aged-care/part-2>

The proposal: The initial proposal for the *Community Aged Care Hub* is that members would be drawn from local communities. Much of their activities would be voluntary, but they would have some paid officers and employees. Each local hub would be responsible for the oversight and management of all aged-related activities in the community. Local communities would elect representatives to a central controlling and coordinating body. This body would work closely with government and have representation on government advisory panels, particularly on the approved provider committee. Volunteers already engaged in residential and community aged care⁷⁶ could leverage from the hub.

The hubs would work with providers in monitoring the provision of care, collecting data and in assessing quality of life. It would use this information to assess the performance and assist the accreditation body who would work with them.

The hub would be at the front line in handling complaints and in mediating disputes - ensuring that issues were addressed and that whistleblowers were protected. It would play an important role in advocating for residents and families and in supporting them. It would largely replace the ill-considered and inappropriate MyAgedCare website as the primary source of information and support for prospective residents and their families.

Very importantly as community customer, it would play an important role in the selection of which providers would be approved to provide aged care services both nationally as well as locally. Local hubs would form relationships with academic departments at universities and so facilitate, support and be involved in aged care research. It would be well placed to participate in the investigation, detection and management of elder abuse.

Principles: Involvement in hub activities should extend from schools and through universities, as that is where attitudes form, as well as to the very old. From helping, our roles gradually change to being helped when we need it, but still being focused on the needs of others.

Continued constructive activity and involvement in society and its activities are the keys to healthy ageing, both physically and mentally. We are "who we are" because of what we do in society. When we stop doing and contributing we cease to "be someone". It's easy to turn an older person into a vulnerable at risk "has been". Both elderly people living alone and nursing home residents should be "involved" in life so that they are still "someone".

In nursing homes and community: Elder abuse in nursing homes has been the subject of criticism for years. Too many others are living isolated lives at home where they are also at risk. Unless we are careful, the new policy to care for frail, older people and those with dementia at home could make this worse. A far broader system of caring for the elderly in the community is needed. All of the innovative developments in providing this sort of integrated "at home" community and self-supporting environments have come from the community itself. These ideas are not compatible with the market model although commercial providers might contribute services.

Retirement villages: There are allegations about the way retirement villages obtain their money and exploit the vulnerability of gullible retirees who do not understand what they are signing. As a community we need to be there to see what is happening and to help.

Community responsibility: An organised and well-structured customer base that directly monitors services and outcomes would be the best way to address these issues. They would steer prospective residents away from any group they considered would pose a risk.

ACC has tracked developments in aged care over the years and noted that government reviews and government strategies repeatedly fail to address core weaknesses and deficiencies. Until there is an informed and effective customer base supported by an involved and effective civil society ACC, as a responsible organisation, has no choice but to warn members of the community of the problems and risks in the system.

Citizens need to be vigilant and highlight any behaviour or allegation that might be concerning and we make no apology for doing that. We realise that this does erode trust further, but the current situation demands this.

We would much rather be part of a solution that rebuilds trust, but that must be based on a solution, which a fully informed community can reasonably identify with and support.

The objective

The intention is to develop a cooperative venture where parties are on the same page, with all of the information, all focused on doing something constructive together, all dependent on one another, none with the power to impose their solutions unilaterally.

We don't want participants at each other's throats, or community regulators walking around policing, looking for misconduct. They should all be focused on a common purpose. The hub will be collecting information for everyone to consider and discuss and will be contributing thoughts and ideas. **Trust and trustworthiness are essential in a sector like this. Care suffers when participants don't trust one another. Currently a defining feature of aged care is the lack of public trust.**

By making for-profit and not-for-profit services part of a wider community enterprise, we bring both back into the community and out of the cultural silo where they now currently sit. Those providers who are serving the community will not have anything to fear, and will gain help and support. Those that maintain a silo mentality will find themselves out increasingly isolated.

Local communities are adept at supporting and understanding their local situation and are well placed to support a range of issues, including elder abuse:

- The **BC Association of Community Response Networks**⁷⁷ in Canada was established to support local communities in managing their own affairs and addressing community problems. **It has recognised elder abuse as a problem that has arisen in their communities and that it requires community action and change to address it.** Large community organisations are focusing on the problem of abuse of citizens in their local communities and are doing something about both addressing and preventing it.
- **The South Australian Community Visitors Scheme**⁷⁸ in its submission (Number 16) to the *Senate Standing Committees on Community Affairs' national enquiry into Violence, abuse and neglect against people with disability in institutional and residential settings*, indicated that Community or Official Visitor programs to all institutions and residential facilities were an important means to detect violence, abuse and neglect of people with a disability. Visitors build trusting relationships not only with residents but with staff who disclose matters of concern. This is one of the roles of the proposed Community Aged Care Hub, which would be as well or even better placed to do this in aged care. Visitor's schemes would work with and through the local community hubs.
- **Waverton Hub in NSW**⁷⁹ is an active ageing initiative seeking to make the community more age-friendly and help each other to age meaningfully in their own homes in their own community as long as possible.
- **The Hastings Elder Abuse Protection Network (HEAPN)** submission acknowledges the importance of local community networks in a collaborative approach to addressing issues locally. They are also urging the Committee to consider providing resources to support local groups such as HEAPN in order to set up a coordination agency.
- **An excellent research project by researchers**⁸⁰ **on behalf of the Blue Mountains Council** engaged the community in multiple discussion sessions in order to determine the resilience and capacity of the community to cope with crises and look after itself. It focused on vulnerable groups including the aged who needed help.

It found that: ***"In emergency situations most people are assisted by family, neighbours and friends. For others, assistance may be much harder to find"***. In other situations, the study ***"demonstrates that vulnerable people typically relate to various community services and Non Government Organisations (NGOs) in the first instance, rather than friends, neighbours or family"***.

Their report considered that it was ***"imperative that existing community services and NGOs are maintained and resourced appropriately within the Local Government Area. To support enhanced approaches to accessing and supporting vulnerable people within the community, Neighbourhood Centres need greater recognition as trust builders with vulnerable residents"***.

The report was critical of the www.myagedcare.gov.au website stating ***"This approach, whilst plausible in theory, will create a number of issues for our most vulnerable - namely the potential loss of local community connection and engagement with local service providers as their essential point of contact"***. The report describes what others have called a ***"hollowing out of the community"***.

This report in our view highlights the problems created by the provision of services within preconceived ideological frameworks and by excluding rather than embracing the community in making policy.

Recommendation 8: ACC believes that help and assistance would be better facilitated and improved by a structure in which there was a closer link both with the community and with other organisations which have a role in the oversight of aged care. Advocates and the community are in a unique position to contribute to the collection of data including the incidence and nature of elder abuse. This would become a part of the integrated aged care knowledge base. To contribute in this way would require a realignment of all these services along the lines that we advocate.

Community partnerships

Consumer and community partnerships are widely recognised as important for safe and effective health care and we believe that in this context health care includes aged care. The Australian Commission on Safety and Quality in Health Care, in its 2012 document *"Partnering with Consumers"*, sets standards that require health care providers to arrange partnerships with consumers and community groups across a broad focus of activities. This remains government policy, although implementation has lapsed under the current government

Partnerships include the planning and implementation of care, safety systems, quality initiatives, staff training, feedback, governance, design of health services, analysing feedback and ***"ongoing monitoring, measurement and evaluation of performance"***. The importance of sharing information is stressed.

That aged care lags far behind health care is illustrated by the quality of the information available to the public, and the extent to which the public, staff whistleblowers, and academics have spoken out about failures and elder abuse in care and have, in desperation, gone to the press.

The response of the industry to nurses who complain, to residents' families who are unhappy, and to adverse publicity, illustrates their lack of awareness of community expectations. It points to their unwillingness to confront issues and to involve the community in addressing them.

Experiences in partnering - success and failure: A recent article on the *Medical Journal of Australia*⁸¹ examines international experience with partnerships in health care, many of which have failed. They find that it too often is only tokenistic. Success requires a very different way of operating. Governments need to be prepared to relinquish control and allow the community to set the agenda. Our assessment is that it would be extremely difficult for government and large corporations to do that successfully. This is because of the current top-down manner and the prevailing notion that caring for people is a 'business'. This is the very opposite of what is required and we are likely to see ineffective tokenism. Human society is a social enterprise and needs to be run as such. It is one to which the market contributes but on the terms and within the parameters set by civil society.

Community at the centre: While aged care is slightly different, the proposed *Community Aged Care Hub* adopts the same principles and the ethos of partnerships with providers. It aims to address all of these partnership objectives.

By placing the community at the centre of the provision of care in each locality, the hub will institutionalise the principles and practices of these partnership standards. It creates a context within which partnership standards, directly tailored to aged care, can be developed. Because they would control the process and use their power as effective customers, there would be a good chance of their working successfully and improving aged care.

If governments and industry are serious about partnerships that actually work, then they should strongly support and assist in the development of Community Aged Care Hub.

There is actually nothing new in this. Not-for profit-hospitals have traditionally had governing boards drawn from the community running the hospitals. Health care professionals and hospital managers could only operate in ways that were sanctioned by the controlling board. The proposed hub can be seen as a broad modern application of the same principle in the era of government and market run health and aged care.

Community engagement: In recent times there has been a lot of interest and a growing number of studies evaluating the benefits of involving citizens and giving them real power in decision making and community projects at all levels of society and politics. These programs have been shown to be very effective. They also counter the "hollowing out" of knowledge, influence and involvement in communities that occurs in the hierarchical service delivery structures that currently characterise government and corporate activities.

Studies have looked at the sort of engagement that has been successful, particularly when providing services or in introducing services where support from communities is required^e. Others have looked at what is taking place across the local government sector^f, compared projects that have succeeded, and ones that have failed.

A key to success has been engagement with the community and their direct involvement in designing and running their services. It is important that the community's concerns be given priority over those of the service provider. It is essential that control is handed over to the community so that they engage, learn about, identify with, innovate and in doing so, come to "own" the service. The key to success is a willingness to trust the community and hand the service over to them.

One of the main reasons for failure has been an unwillingness or inability to build relationships with the community and trust them. In many instances, community engagement has been with selected individuals and not with the entire community. It has become tokenistic - a self-serving illusion.

^e The Centre for Welfare Reform, Birmingham England: <http://www.centreforwelfarereform.org/>

^f Herriman, J. 2011. Local Government and Community Engagement in Australia. Working Paper No 5. Australian Centre of Excellence for Local Government, University of Technology Sydney: http://www.acelg.org.au/file/1567/download?token=2Mj4DjYFRfGHtAVkoeUFOyO2ixyP0EMAJEtt_5BKAik

6.3 Fostering trust through accountability

Being clear about limits to consultation.

Processes which are not truly designed to influence decision making are what Janette Hartz-Karp describes as “**DEAD**”: **D**ecide, **E**ducate, **A**nnounce and **D**efend. It is a ‘false model of consultation’ which often results in community anger and frustration at the tokenism of the consultation, and ultimately decreases community interest in consultation (Hartz-Karp 2010, cited in The Australian Collaboration: p. 1).

Source: Herriman, J. 2011. *Local Government and Community Engagement in Australia. Working Paper No 5. Australian Centre of Excellence for Local Government, University of Technology Sydney: (p.54)*
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The *Centre for Welfare Reform* in the UK has been a driving force in developing, applying and testing the concept of citizenship in the provision of services to the disabled, the aged and the marginalised. Key to their activities has been the assertion of the rights of the disadvantaged as citizens through a process they call “personalisation”, driven and organised by supportive community participation.

The Community Aged Care Hub and open government

The proposed *Community Aged Care Hub* can be seen as part of 21st century thinking that has resulted in the *Open Government Partnership*⁸² to which 70 countries now subscribe including Australia. This seeks to foster transparency and openness in government as well as civic participation in government decisions and in the process of government. Closely related is the idea of, and movement towards, participatory democracy⁸³.

These movements are a response to the problems that western societies are currently experiencing with simple two-party representative democracy. This system is no longer engaging with citizens or serving them. Australia is a good example and the paradigm paralysis afflicting aged care policy⁹ illustrates this well.

In conclusion

Our suggestions are designed to ensure total transparency by making civil society - in the form of the proposed hub - responsible for the collection and evaluation of aged care data. The suggested structure creates a forum for community discussion and education - so creating the civil knowledge base for effective participatory democracy. The integrating representative central body dealing directly with government and industry is a structure well suited to implement participatory democracy in matters affecting aged care.

⁹ (2015) Baldwin, R., et al., Residential Aged Care Policy in Australia – Are We Learning from Evidence? Australian Journal of Public Administration. doi: 10.1111/1467-8500.12131 University of Technology Sydney, <http://onlinelibrary.wiley.com/doi/10.1111/1467-8500.12131/abstract>

Endnotes

All hyperlinks were checked as at 12 February 2016.

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4.8 Volunteers in Residential Aged Care (pg 103) ; **6.8 Volunteers in Community Aged Care** (pg 188)
- 3 The aged care gravy train (The Age, Jan 2016):
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