

30 August 2016

Australian Law Reform Commission  
GPO Box 3708  
SYDNEY NSW 2001

## **Re: Australian Law Reform Commission (ALRC) - Inquiry into Elder Abuse**

**Aged Care Crisis (ACC)** welcomes the opportunity to make a submission to the ALRC. 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, users of services and as volunteers. Our websites provide accessible information on many aspects of elder abuse and aged care, as well as 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.

Current laws not only fail to address elder abuse but also, are too costly and inaccessible for most. Any efforts to improve elder abuse strategies should also account for issues that span both Federal and State level to be truly effective. We support the proposals in a submission made by Rodney Lewis, Solicitor and **ACC** Legal Issues Columnist<sup>i</sup>, who is well versed in elder law. These proposals include changes to the law and the introduction of a pathway through arbitration to affordable and accessible legal redress for aged care complaints at the option of the resident.

**Elder abuse is a complex problem that will require a well-integrated multifaceted approach. In addition to essential legal remedies, we are also proposing a co-operative approach and support from the community.** Additional measures are needed to prevent elder abuse by changing community attitudes, detect it early and stop it, document its frequency and when required initiate further action. Current regulatory structures have failed on all of these counts.

**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 these 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.

### **Changing the context within which abuse occurs**

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.

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<sup>i</sup> Legal Issues Column: <http://www.agedcarecrisis.com/opinion/legal-issues-column>

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 care<sup>1</sup> could leverage from the hub that we propose.

### **The need for a new direction**

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.

**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*<sup>2</sup> that we propose.**

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

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# 1. Executive Summary

Aged Care Crisis argues that elder abuse is a complex issue and requires a multifaceted cooperative approach that requires, legal, legislative and community participation. The main focus of his submission is on the role of community.

## The problems

There are societal factors that contribute to the problem of elder abuse.

1. Twentieth Century neoliberal policy has resulted in the introduction of free markets into sectors where, because participants are vulnerable, the necessary conditions for an unrestricted market to operate do not exist. The high-pressure competitive contexts have led to emotional blunting and undermined social responsibility. Vulnerable customers and/or employees in many sectors including aged care have suffered and been misused. The aged are particularly vulnerable and this is one of the root causes of the multiple failures in our aged care system.
2. The associated managerialist top/down organisational structure introduced across society has led to social structures that are inflexible, process driven and task focused, rather than person and outcome focused. This results in emotional blunting.
3. These developments have led to a “hollowing out of society”. Control by distant managers and the dominance of markets in the provision of human services has led to community disengagement from these services with a loss of knowledge, skills, interest and involvement in the affairs of society. Values and norms atrophy from a lack of engagement with the misfortune of others.
4. The community’s dependence on government and its delegation of responsibility to make society work is misplaced. Government is distant from the community and without supportive community structures and community involvement it is an ineffective regulator.
5. These factors create a society where elder abuse more readily occurs and where others are less emotionally responsive to it so that it is not reported or addressed.
6. The government’s Aged Care Roadmap<sup>ii</sup> is based on neoliberal principles and does not address the problems in aged care. It’s central structure largely ignores the community. Its implementation may well increase the problem of elder abuse, particularly in home care where humanitarian services are increasingly process and market driven.
7. A core problem in the entire aged care sector is a failure to collect any accurate information or to evaluate what we have so that policy is based on ideology and not evidence. Without data the oversight structures are ineffective and do not work. The lack of data about elder abuse is simply part of the larger problem.
8. Elder abuse is badly defined in legislation and this should be addressed.

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<sup>ii</sup> Aged Care Roadmap: <https://www.insideagedcare.com/introduction/aged-care-roadmap>

## The consequences

1. Aged care is a failed market and it has been failing citizens for a long time. Society and government have turned a blind eye. This submission describes what has been happening giving many examples. The failure to provide basic and empathic care to the vulnerable is a form of elder abuse.
2. A major problem has been the resistance of the aged care system to any attempt to expose its failures. Residents, families and whistleblowers who expose problems have been labelled, discredited, victimised and threatened with law suits. Instead of red flags to a pervasive problem, failures that cannot be contested are seen as rare exceptions. There are far too many rare exceptions.

## A way forward

1. Twenty first century thinking is responding to the social consequences of 20<sup>th</sup> century ideology by searching for ways to rebuild civil society, re-engage citizens in the affairs of society and in the political process. This aims to make government work with and be accountable to civil society. The focus is on social responsibility and on developing responsible citizenship. The open government and participatory democracy movements are part of this.
2. Human services and particularly services to the elderly and the disabled are particularly suited and would benefit most if community became closely involved in and had a controlling role. Participation and responsibility are critically important in rebuilding society.
3. Aged Care Crisis is advocating for the progressive delegation of the control of aged care to what it calls community aged care hubs, a network of community groups that would participate and work with government in collecting information. It would provide oversight and guide the implementation of regulatory and other functions at a local level. It would take these functions to the homes of the elderly and to the bedside in aged care facilities. It would advise, support and empower customers. It would progressively take control of the way aged care services operated in each local community. It would work with the providers to ensure that the market becomes socially responsible and works for the community.
4. Its close contact with the elderly community would place it in a good position to prevent, detect and address elder abuse. Elder abuse organisations and structures could work through or in close association with this hub.
5. More detail of this proposal is supplied in the **Appendix** section (pg **25**) in this document.

## 2. Introduction

**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.**

**Changes in the structure of aged care:** In 1997, government turned aged care into a market. In the last few years, market pressures have been increased with a drive to consolidate into large corporate entities, which can capitalise on the opportunities created by trade deals. We believe that these changes have increased many of the pressures within the sector<sup>3</sup>.

For example, staffing is the largest on-going expenditure faced by aged-care providers and pressures to reduce costs 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 places vulnerable residents at increased risk of elder abuse<sup>4</sup>. International research shows that staffing is closely tied to failures in care and both are adversely impacted by increased pressures for profit<sup>iii</sup>.

**When staffing is reduced and registered nurses are replaced by lower-skilled staff, care quality suffers. Elder abuse is more likely.**

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<sup>iv</sup>. Where government has contracted services like jobs or vocational training to the market, the services have been rorted and consumers harmed<sup>v</sup>. Aged care fits into both categories and the many examples of failures in care strongly suggest that this has happened here.

**Current Aged Care structure is a serious problem<sup>vi</sup>:** The structure of the current aged care system creates contexts, which if anything, predispose the elderly to abuse and frustrate attempts to expose and address the issues because:

1. Government structures including the funding, accreditation, complaints and advocacy systems are centrally controlled and process driven so that the services provided are task focused rather than person focused. This results in a failure to enter into the lives of others, to develop empathy and to engage emotionally. Abuse when it occurs, does not confront.
2. The free market approach with its emphasis on competition, efficiency and the demands of shareholders for profitability creates a high-pressure environment, which has a similar impact on staff. Nurses and carers whose motivation is humanitarian are overworked and time short. They become task focused and have no time to engage and develop empathic and empowering relationships with consumers. In a system driven by profit rather than care, they become alienated and emotionally blunted<sup>vii</sup>. We are seeing an increasing number of instances where carers take out their frustration on those they are supposed to care for.

<sup>iii</sup> A recent survey of literature and research provides an excellent summary and state of the world on the fundamental problem with nursing homes – too few qualified nurses: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4833431/>

<sup>iv</sup> Failed markets and culturoopathy: <https://www.insideagedcare.com/aged-care-analysis/cultural-perspectives/failed-markets-and-culturoopathy>

<sup>v</sup> Contracting government services to the market: <https://www.insideagedcare.com/aged-care-analysis/cultural-perspectives/contracting-government-services-to-the-market>

<sup>vi</sup> Inside Aged Care: <https://www.insideagedcare.com/>

<sup>vii</sup> Aged Care Analysis: Conflicting cultures - <https://www.insideagedcare.com/aged-care-analysis/cultural-perspectives/conflicting-cultures>

3. The highly competitive corporate driven market<sup>viii ix x</sup> creates a context where pressures can institutionalise profitable but potentially abusive practices and where exposure of abuse has reputational consequences. Total loyalty from staff is expected, internal criticism is not welcomed and whistleblowers lose their jobs.

When good care is provided, this is in spite of the system and not because of it. An increasing number of aged care providers are failing residents at an unacceptable rate<sup>xi</sup>. As the pressures in the system increase, so does the risk that disillusioned and disinterested staff will abuse consumers and that others will not speak out.

## Proposals for change

Aged Care Crisis believes that these issues should be confronted and commented on by the ALRC. It is pressing for wide debate for an alternative approach to how we address the aged in our community.

In our proposal<sup>xii</sup> for change, the current cumbersome and insensitive bureaucracy would delegate most of its activities to local organisations largely controlled by and responsible to local communities. The system would become flexible, responsive and humane. Government and other central structures would train, support, mentor, work through and provide backup for local organisations delegating as many functions as the local organisation could manage.

ACC argues 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 local<sup>5</sup> 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.

These local organisations would gradually assume overall control and integration of aged care locally. Services might include funding, data collection, independent analysis of data, oversight of standards of care, complaints handling and advocacy, advising seniors and their families and community engagement in ageing issues. They would work closely with staff and providers in order to counter and if necessary terminate the pressures and practices that are eroding our aged care system.



<sup>viii</sup> Aged Care Marketplace: <https://www.insideagedcare.com/aged-care-analysis/aged-care-marketplace>

<sup>ix</sup> Market processes in simple terms: <https://www.insideagedcare.com/aged-care-analysis/aged-care-marketplace/market-processes-in-simple-terms>

<sup>x</sup> Private equity in aged care: <https://www.insideagedcare.com/aged-care-analysis/aged-care-marketplace/private-equity>

<sup>xi</sup> 19 years of care: <https://www.insideagedcare.com/aged-care-analysis/19-years-of-care>

<sup>xii</sup> Solving Aged Care: <http://www.agedcarecrisis.com/solving-aged-care>

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 principles underlying the 21st century global Open Government Partnership<sup>6</sup> movement to which Australia claims to subscribe.

## **An alternative to the government's aged care roadmap**

Our assessment is that because the government's roadmap for aged care does not address these problems it is most unlikely to reach its lofty objectives. The proposals we have made would fundamentally change<sup>xiii</sup> the social and marketplace dynamics of the system in order to obtain the desired objectives. It would bring oversight and implementation of all of these services into the community, into homes and to the bedside in aged care facilities. The community would bring their empathy and their sense of social responsibility to the table and change the culture in the sector.

## **Addressing elder abuse**

This change to the way aged care is structured would be much more effective in combatting ageism, make the community aware of the problem of elder abuse, discouraging abuse, detecting and addressing it early, encouraging and motivating staff to express their humanity, engaging peer pressure and encouraging reporting of abuse. It would prevent, detect, document, address and guide those who need to go to arbitration or seek legal redress.

*“Elder abuse occurs within our communities and will require a co-operative approach and support from the community”*

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<sup>xiii</sup> (An alternative) Aged Care Roadmap: <https://www.insideagedcare.com/introduction/aged-care-roadmap>



### 3. 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.** We support the call for data and transparency in the submission from others including CPSA and Alzheimer's Australia who echo our concerns.

Nearly a decade of 'compulsory reporting' of elder abuse in aged care has produced little, if any, insight into the cause and prevalence of assaults. Community and researchers are annually drip-fed meaningless numbers.

ACC concurs with the sentiments expressed by Dr Catherine Barrett:

“... It happens every year, like clockwork. Government figures showing an annual spike in the number of alleged or suspected assaults reported in residential aged care make headlines in newspapers across the country.”

Dr Catherine Barrett, the lead author of Norma's project, a groundbreaking 2014 study into the sexual assault of older women in Australia, said it was not enough for the government to simply collect and publish the numbers of reportable assaults in aged care each year.

“In other areas of assault – if you look at violence against women, for example – what we are doing is an analysis by perpetrator, of the context, factors that make women vulnerable. All that kind of analysis, that evidence informs prevention strategies and that's the bit that's missing,” she told Australian Ageing Agenda.

Dr Barrett said while compulsory reporting was a controversial topic in Norma's project and there was a wide range of views among participants about its effectiveness, there was much broader agreement that **the data captured and reported needed to be more comprehensive and to inform prevention and intervention strategies.**

**“It's not enough just to collect the numbers. We have to say what they mean and how they can be used to better understand what is happening so we can prevent assault.”**

**Better access to data and greater public discussion around the issue would also improve awareness of the prevalence of assault and challenge the misconception that the sexual assault of older women does not occur, Dr Barrett said...**”

*Source: Special report: Shedding light on mandatory reporting in aged care (AAG), (24 Aug 2016)*  
<http://www.australianageingagenda.com.au/2016/08/24/special-report-shedding-light-on-mandatory-reporting-in-aged-care/>

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<sup>xiv xv</sup> needed to confront and moderate ideology so that its

<sup>xiv</sup> (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>

<sup>xv</sup> Aged care in the dark: <https://www.insideagedcare.com/aged-care-analysis/aged-care-marketplace/aged-care-in-the-dark>

application was appropriate. The lack of information about elder abuse should be seen within this context.

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<sup>xvi</sup>.

### **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. The local and centrally integrated structure of the proposed community aged care hubs is intended to address this issue.

**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. Their ability to act for them can be restricted by their employer's insistence on loyalty to the corporation rather than community.

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 a dysfunctional and unsuitable management that is more focused on the efficient management of costs than on care. This impacts on staff. 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. Anyone with basic skills working with the proposed hub 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.**

**Preventing adverse publicity:** 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<sup>xvii</sup> is a major deterrent to staff wanting to report abuse. This has been a major problem in the past and will

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<sup>xvi</sup> Aged care in the dark: <https://www.insideagedcare.com/aged-care-analysis/aged-care-marketplace/aged-care-in-the-dark>

<sup>xvii</sup> Death in a five star nursing home: <http://www.abc.net.au/radionational/programs/backgroundbriefing/2014-09-21/5753372>

undoubtedly become worse as government's marketisation and competitive consolidation of the aged care system advances.

**Failed regulation:** 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 *Combined Pensioners and Superannuants Association*<sup>xviii</sup> and from *Alzheimers Australia*<sup>xix</sup>. Information we receive from families and nurses who contact ACC 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.

**Withholding reports:** Families wanting to make informed choices about loved ones in care are unable to do so. The vast majority of reports published on Australian Aged Care Quality Agency's (AACQA's) website are the result of cyclical visits<sup>xx</sup>, all announced, which are performed once every three or five years, at a convenient time after homes have spent weeks or months preparing for them.

These reports tell us that management of an aged care home knows what it is supposed to do, but give no information about what happens in the other 1,095 or 1,825 days of the accreditation cycle. Prior to publication of these reports, homes are provided ample opportunities to rectify issues.

While the publicly-available reports on the AACQA website may contain 'perfect scores', these can vastly contrast with the unpublished reports, which may paint a dismal picture of understaffing, neglect, untreated wounds, medication failures and complaints. Aged care consumers can only have real choice when family members have access to all information and fear the worst when information is withheld.

The community is entitled to see a home's performance at all times and not just when it had been given time to prepare for a visit or after providing a response to an adverse finding so it could stay in business. Because it would be directly involved in accreditation, the hub would ensure total transparency. It would also make staffing numbers and skills fully transparent. Efforts to encourage transparency around staffing in aged care, has been tenaciously resisted by industry and the government<sup>xxi</sup>.

For example, the many reports resulting from 'Assessment contacts'<sup>xxii</sup>, or 'Unannounced visits'<sup>xxiii</sup>, (including the annual checks) are not made publicly available. Concealing these reports to hide failures or withhold crucial information from those who need to know about them is untenable and deceptive. Privacy is an important consideration but it should not be used as an excuse to conceal information from the public. Technically, it would not be difficult to remove identifying or sensitive data from existing reports.

A further issue is that it is possible for a home to breach responsibilities as an approved provider, as well as having serious complaints substantiated against the home, and yet avoid any public scrutiny.

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<sup>xviii</sup> [https://www.alrc.gov.au/sites/default/files/subs/76\\_combined\\_pensioners\\_and\\_superannuants\\_association.pdf](https://www.alrc.gov.au/sites/default/files/subs/76_combined_pensioners_and_superannuants_association.pdf)

<sup>xix</sup> [http://www.alrc.gov.au/sites/default/files/subs/80\\_alzheimers\\_australia.pdf](http://www.alrc.gov.au/sites/default/files/subs/80_alzheimers_australia.pdf)

<sup>xx</sup> About accreditation: <https://www.aacqa.gov.au/for-the-public/for-providers>

<sup>xxi</sup> No staff for 10.5 hours per day: <http://www.agedcarecrisis.com/opinion/articles/213-no-staff-for-10-5-hours-per-day>

<sup>xxii</sup> Assessment contacts: [http://www.aacqa.gov.au/for-providers/residential-aged-care/copy\\_of\\_processes/assessment-contacts](http://www.aacqa.gov.au/for-providers/residential-aged-care/copy_of_processes/assessment-contacts)

<sup>xxiii</sup> Unannounced visits: [http://www.aacqa.gov.au/for-providers/residential-aged-care/copy\\_of\\_processes/unannounced-visits](http://www.aacqa.gov.au/for-providers/residential-aged-care/copy_of_processes/unannounced-visits)

Under the current system, after a complaint has been investigated and found to be valid, aged-care homes are simply required to agree to make some amendments to policies and procedures.

The 5<sup>th</sup> reincarnation of the complaints system, the Aged Care Complaints Commissioner, like accreditation, is ineffective as both deal primarily with systemic defects in process and breaches of standards. A resident may have suffered injury, their health may have been seriously affected or perhaps they may have been wrongly restrained. Some may have died through neglect. In such cases the complaints system is entirely incapable of providing any satisfaction. An ordinary person with full rights would be entitled to seek redress and compensation. Frail aged residents have no such rights, despite the *Aged Care Act* or its supporting Principles inferring otherwise.

Consumers need to be fully confident that the current scheme, and any future scheme, will protect the residents of our aged-care homes.

Aged Care Crisis gave evidence regarding the protections around vulnerable residents in care at the Community Affairs References Committee - *Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)*. We highlighted the inadequate protections afforded to vulnerable people in care in relation to the Complaints Scheme and the reasons for this<sup>xxiv</sup>.

**Recommendation 1:** The Government set in place a process for the ongoing monitoring and 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 federal government establish 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.

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<sup>xxiv</sup> Community Affairs References Committee - *Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)* - 14 February 2014 <http://bit.ly/1iyT2OH>

## 4. 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' regime<sup>7</sup>, 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 occurred<sup>8</sup> ...”

**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>

Industry has been vocal in opposing 'compulsory reporting'<sup>xxv</sup> and is not motivated towards addressing the issue. We believe that a community-based system like the *Community Aged Care Hub* that we are proposing would be far superior, as the providers seem to view the reporting requirements as onerous and impacts negatively on their business:

“ ... Other data sources should be used rather than expecting an approved provider to undertake reporting that does not have positive outcomes for the service or the care recipient ...”

“ ... What is not known is the outcome of these reports and whether they were found to be true, especially as they include suspected cases, where evidence is not necessarily available...”

**Source:** *LASA submission to ALRC Inquiry into Elder Abuse*

**Recommendation 4:** The Federal Government develops a clear definition of abuse of older people.

<sup>xxv</sup> **Inquiry into residential and community aged care in Australia:** Aged and Community Services Tasmania: Answers to questions on notice from public hearing, 27 Mar 2009, Launceston - (Pg 9, Question 4: Examples of over reactions to a small number of incidents that have resulted in an unnecessary regulatory response) : <http://bit.ly/2bC0R4i>

## 5. 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 vulnerable<sup>9</sup>. Under the new 'Consumer Directed Care' (CDC) 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 abuse<sup>10</sup>. 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 abuse<sup>11</sup>. 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 market<sup>12</sup>. 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 ineffective<sup>13</sup>.

### Aged care failures

Over the years, aged care residents in nursing homes have been raped<sup>14</sup>, robbed<sup>15</sup>, bathed in kerosene<sup>16</sup>, attacked by rodents<sup>17</sup>, suffered injuries or death from other residents<sup>18</sup>, burnt to death<sup>19</sup>, strangled<sup>20</sup>, cooked<sup>21</sup>, melted<sup>22</sup>, sedated to death<sup>23</sup>, overmedicated<sup>24 25</sup>, endured horrific infected pressure sores<sup>26</sup> or choked to death<sup>27</sup>.

Some staff have amused themselves by taunting, teasing<sup>28</sup> or mocking residents and playing demeaning games on them like 'spot the body part' (photos)<sup>29</sup>, or rolled in tomato sauce<sup>30</sup>. 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 falling<sup>31</sup>.

Family members have been kept in the dark<sup>32 33</sup>, banned from visiting loved ones<sup>34 35</sup> or bullied by facility staff after complaining about care<sup>36</sup>. Some Coroner's reports are particularly revealing<sup>37 38</sup>. Some family members (out of desperation) have taken their concerns to media<sup>39</sup>, setup websites (or blogs)<sup>40</sup>, established social media<sup>41 42</sup> presences, published diaries of care online<sup>43</sup> or setup online petitions to have their concerns heard<sup>44 45 46 47</sup>. Other family members have published detailed reviews, one commenting on the difficulties in obtaining records from an aged care home regarding the care of their father, who died after 4 weeks in respite:

"... I, as a relative, cannot get a hard copy of (my father's notes) but an independent body is able to, read them on my behalf and decide whether my father was treated with respect and dignity. There is no legislation, which can make a care home give this information to a family. I will be advocating for this and feel that Aged Care Facilities need to be more transparent and accountable ..."

**Source:** *Why can't I get the records regarding my father's care?* (Patient Opinion Australia):  
<https://www.patientopinion.org.au/opinions/62204>

Some have been threatened with letters of legal action<sup>48</sup> and a few of these have refused to buckle. One health care worker who says she was sacked after blowing the whistle on severe understaffing and appalling patient conditions at a nursing home is suing her former employer for unfair dismissal:

Ms xxxxx told of shocking incidents she saw, including patients not being given -adequate pain relief and going days without showers.

"I'd come home from work distraught about the care the residents hadn't received," she said.

"Someone needs to stand up and say, 'That's enough'."

**Source:** *Health care worker says she was sacked for blowing whistle on nursing home launches legal action*, Gold Coast Bulletin, 3 Aug 2016  
<http://www.goldcoastbulletin.com.au/news/crime-court/health-care-worker-says-she-was-sacked-for-blowing-whistle-on-nursing-home-launches-legal-action/news-story/c2e25294d4909b9f093c1efa946b8fb8>

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 wound<sup>49</sup>. 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*"<sup>50</sup>. 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 dehydration<sup>51</sup>.

There are cases of residents dying prematurely because of over-prescription of anti-psychotic medication<sup>52</sup>. Many are suffering needlessly from untreated infections, urinary tract conditions<sup>53</sup> and pressure injuries, lying in soaked pads brimming with urine and faeces (compromising skin condition) for hours<sup>54</sup> on end because there are not enough care staff to clean or turn them regularly. Then there are the cases of rationing of incontinence pads<sup>55</sup> 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 pain<sup>56</sup>, or without proper palliative care<sup>57</sup>. 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 (which was read out loud to her in a crowded ward, which must have been quite humiliating). This was despite protestations from her low-care home that she needed acute care<sup>58</sup>.

Research has indicated that many resident transfers might be avoidable with better primary care in place including staff skill mix, primary care services<sup>59</sup> and that inadequate documentation negatively impacts on the resident's journey through emergency departments<sup>60</sup>.

It is also of considerable concern that the sector now relies, to a large extent, on the employment of inexperienced carers; some have poor English language skills and are unable to communicate effectively with residents. One recent case in this instance included the death of an older woman who had difficulty communicating with her carers<sup>xxvi</sup>. Her son at the inquest contended that as his mother did not speak fluent English, the language barrier might have seemed like she was being uncooperative with carers. This illustrates the potentially dangerous consequences of communication barriers and the need for multilingual staff working in the sector.

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 parliament<sup>61</sup>. 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 accountability<sup>62</sup>.

**There is an abundance of information for those who want to look**<sup>xxvii xxviii xxix</sup>.

## Residents acting themselves

Residents and their families 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 or their families 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.

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. The regulator in the UK, the Care Quality Commission, publishes guidelines on how to do so<sup>xxx</sup>.

"... When the disabled 75-year-old attempted to report the incident to retirement village company (xxxxx), 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 (xyz) 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>

<sup>xxvi</sup> ABC News: Home care examined after 75yo Perth woman died with infected pressure wounds(4 Jul 2016)  
<http://www.abc.net.au/news/2016-07-04/inquest-into-death-of-perth-woman-maria-niceforo-kincare/7567784>

<sup>xxvii</sup> 19 Years of care: <https://www.insideagedcare.com/aged-care-analysis/19-years-of-care>

<sup>xxviii</sup> Scandal after scandal: <https://www.insideagedcare.com/aged-care-analysis/19-years-of-care/scandal-after-scandal>

<sup>xxix</sup> Those who know: <https://www.insideagedcare.com/aged-care-analysis/19-years-of-care/those-who-know>

<sup>xxx</sup> Care Quality Commission - Using hidden cameras to monitor care: <http://www.cqc.org.uk/content/using-hidden-cameras-monitor-care>



## 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 when a video camera was recording for 48 hours. The perpetrator was charged with several criminal assault charges ranging from recurrent torment, physical abuse and attempted suffocation.

### If that is what is revealed in 48 hours, what would we find if everyone had this option?

As a result of their experience, the family are petitioning for video surveillance cameras in residents rooms in aged care<sup>63</sup>. The change.org petition has accumulated nearly 43,000 signatures, with thousands of comments by concerned supporters. This has been an ongoing concern<sup>64</sup>.

**change.org** petition:

**Without a voice and evidence** elderly people have **no ability to protect themselves from abhorrent abuse, assault and neglect.**

My father (89y.o. with dementia, bedridden, non verbal and frail) was physically/mentally abused and tormented in Residential High Care facility by a male staff carer over many months.

I became suspicious of my father being abused. My **concerns were dismissed** by Management. Frustrated and distraught for the safety of my father I installed a video camera in his private room and caught the suspect abusing my father in broad daylight while he was feeding him lunch.

**Source:** <https://www.change.org/p/australian-human-rights-commissioner-advocate-rights-video-surveillance-cameras-vulnerable-peoples-safety>

The daughter when interviewed, commented that she felt she had no option to protect her father and was prepared to go to jail:

(nursing home's) response when South Australian Police detectives showed the secret footage to management was to forbid Ms Hxxx from any further recordings.

"Instead of offering Ms Hxxx empathy, they instead sent her a letter to cease and desist from filming, as if she was the problem," Mr Dxxx, lawyer for the (family), told 7.30.

"[nursing home] said that I had breached [the] Privacy Act, the Aged Care Act and Video Surveillance Act," Ms Hxxx said.

Mr Dxxx said Ms Hxxx was fortunate the evidence she collected was found admissible and that it led to the successful conviction of Lxxx.

**"I was prepared to go to jail for whatever I did and if I'd breached whatever [nursing home] said I'd breached, I would be responsible for all that," Ms Hxxx said.**

**"But to me I had no option but to do what I did to protect my father."**

**Source:** <http://www.abc.net.au/news/2016-07-25/secret-camera-captures-nursing-home-attempted-suffocation/7624770>

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 ignored<sup>65 66</sup> or fired<sup>67</sup>. 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.

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.

The Aged Care Complaints system has not been productive in resolving these types of issues, leaving many family members and staff traumatised. Sadly, the system frustrates the exposure of deficiencies instead of supporting it.

The stories below, are further examples of situations where vulnerable people experience elder abuse and neglect, family or staff were not listened to, were disregarded and discredited, or blatantly bullied:

- **18 Mar 2016: Disabled people experience violence, elder abuse and neglect in 'epidemic proportions', says rights group:** *"... Other case studies outlined in the submission include allegations of staff at an aged care group home stuffing tissues into the mouth of a resident to prevent them from calling out and multiple claims of boarding house proprietors sedating and drugging disabled residents ..."*  
<http://www.abc.net.au/news/2016-03-18/disabled-people-experience-violence-abuse-and-neglect/7256198>
- **7 Mar 2016 : Newcastle nursing home accused of failing to deliver care, resulting in elderly resident's death:** *"... The Newcastle nursing home at the centre of a year-long police investigation, where a staff member was charged with poisoning three elderly residents in late 2013, has now been accused of failing to deliver the proper standard of care in another elderly resident's unrelated death earlier that year ... I think the failures in care that we believe have occurred in this facility broadly reflect the failures in care that we have seen up and down the state and across the country ..."*  
<http://www.abc.net.au/news/2016-03-07/newcastle-nursing-home-summitcare-wallsend-another-death/7213038>
- **7 Mar 2016: Former aged carer speaks out at parliament meeting:** *The carer said she witnessed failures of duty of care "on a daily basis and when I lodged formal complaints to supervisors I was told leave it with them, but they only went through the motions". The carer resigned in 2015 in heartbreak and frustration after just under 12 months. "If some of the staff took a set against a client, they would neglect them, for example deliberately make them miss out on a bath or a shower, or not perform other care tasks," "People like me who were prepared to stand up got bullied and ostracised," she said.*  
<http://www.ulladullatimes.com.au/story/3767475/resigned-in-heartbreak-and-frustration/>
- **6 Mar 2016: My Dad was given drugs 'like potato chips': how the elderly are being restrained:** *A palliative care clinical nurse consultant and lecturer in nursing, said her dad was given a lot of olanzapine, a lot of risperidone. "He just kept getting it like potato chips," she said. She said it took 10 days to detox her father when he was moved to another health facility that took a different approach to the use of drugs.*  
<http://www.theage.com.au/victoria/my-dad-was-given-drugs-like-potato-chips-how-the-elderly-are-being-restrained-20160218-gmxc3o.html>

Further examples below, are 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 Richards 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-20150410-1mqg13.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 Inquiry (below) found a royal commission is needed into the abuse of people with disabilities in care, including aged care<sup>68 69</sup>, after the inquiry called the evidence "shocking" and "cruel" examples of violence and neglect around Australia<sup>70</sup>. The Inquiry report<sup>xxxii</sup> found existing abuse reporting mechanisms did not provide adequate protection, and in some cases could cause abuse<sup>71</sup>.

<sup>xxxii</sup> **Report:** Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability: [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Violence\\_abuse\\_neglect/Report](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report)

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 Siewert:** 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](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 Triggs<sup>72</sup>, 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 to 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<sup>xxxii</sup> than in protecting frail older people<sup>xxxiii</sup>.

## Addressing the problems in elder abuse

**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<sup>xxxiv</sup>, 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.

<sup>xxxii</sup> Aged care - ABC Saturday Extra, 11 Jun 2016: <http://www.abc.net.au/radionational/programs/saturdayextra/aged-care/7497400>

<sup>xxxiii</sup> Market processes in simple terms: <https://www.insideagedcare.com/aged-care-analysis/aged-care-marketplace/market-processes-in-simple-terms>

<sup>xxxiv</sup> When markets consolidate: <https://www.insideagedcare.com/aged-care-analysis/aged-care-marketplace/when-markets-consolidate>

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.

## 6. 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 the Appendix. *The essence of the "Community Aged Care Hub"* and more detail is available on our website<sup>73</sup>.

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 ALRC 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 ALRC 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.

**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.



# Appendix

## 7. 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" (the hub)<sup>xxxv</sup>.

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 website<sup>74</sup>. 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*<sup>75</sup>.

"... 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 ..."

**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 care<sup>76</sup> 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.

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

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 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<sup>77</sup>** 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<sup>78</sup>** 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<sup>79</sup>** 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<sup>80</sup> 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](http://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.

## 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*<sup>81</sup> 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<sup>xxxvi</sup>. Others have looked at what is taking place across the local government sector<sup>xxxvii</sup>, 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.

## 6.3 Fostering trust through accountability

### Being clear about limits to consultation.

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

<sup>xxxvii</sup> 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](http://www.acelg.org.au/file/1567/download?token=2Mj4DjYFRfGHtAVkoeUFOyO2ixyP0EMAJEtt_5BKAik)

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*<sup>82</sup> 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 democracy<sup>83</sup>.

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 policy<sup>xxxviii</sup> 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.

<sup>xxxviii</sup> (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>

# 1. Summary of recommendations

**Recommendation 1:** The Government set in place a process for the ongoing monitoring and 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 federal government establish 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.

**Recommendation 4:** The Federal Government develops a clear definition of abuse of older people.

**Recommendation 5:** That the ALRC 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 ALRC 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.

**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.

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## 8. References

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

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- (23 Feb 2015) Aged care quality arrangements (ABC Radio) <http://bit.ly/210pdfQ>
- (15 Jan 2015) Profits rise, quality called into question in aged-care industry (Crikey) <http://bit.ly/1U2zGRY>
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- (13 Sep 2014) Low staffing levels in ACT nursing homes put elderly at risk (The Canberra Times) <http://bit.ly/1LJ9Bou>
- (13 Sep 2014) Sad plight of the neglected elderly in aged-care facilities (SMH): <http://bit.ly/1HSiZCh>
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- (22 July 2013) Deregulation of the aged-care sector has led to staff cuts and lower standards of care for the elderly and frail (The Courier Mail) <http://bit.ly/1U0NN9j>
- Behind open doors - A Construct of Nursing Practice in an Australian Residential Aged Care Facility: [PhD -Anita De Bellis, Lecturer, Flinders University, South Australia]: <http://theses.flinders.edu.au/uploads/approved/adt-SFU20061107.122002/public/02whole.pdf>
- (22 Jul 2013) University of Tasmania study finds strong sedatives prescribed at high rate in nursing homes ABC News <http://bit.ly/136ALLo>
- (17 Aug 2013) Premature deaths linked to drugs in nursing homes, ABC Lateline <http://www.abc.net.au/news/2012-08-17/dementia-patients-dying-as-anti-psychotic-drugs-over-prescribed/4204536>
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- (2013) Hospital complaint about WWII veteran posted to YouTube [https://www.youtube.com/watch?v=xn\\_KOlfK0Rc&feature=youtu.be](https://www.youtube.com/watch?v=xn_KOlfK0Rc&feature=youtu.be)
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[http://anmf.org.au/media-releases/entry/media\\_110121](http://anmf.org.au/media-releases/entry/media_110121)
- (15 Aug 2010) Media release (AMA): More aged care beds welcome, but medical care for older Australians ignored: <http://bit.ly/1S3UD08>
- (31 Jan 2010) High-quality care for the elderly is a human rights issue (The Age) Beth Wilson, Health Services Commissioner for Victoria: <http://bit.ly/1U0PBz4>
- (22 Jan 2010) ABC radio - National Interest: Australia's ageing aged care system: <http://ab.co/112Dvvhx>
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## 9. Endnotes

*All hyperlinks were checked as at 20 August 2016.*

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**4.8 Volunteers in Residential Aged Care** (pg 103)  
**6.8 Volunteers in Community Aged Care** (pg 188)
- 2 The essence of a “Community Aged Care Hub”: <http://www.agedcarecrisis.com/solving-aged-care/part-2>
- 3 Nursing home profits soar as patient care declines (The Age, 1 Jan 2016)  
<http://www.smh.com.au/federal-politics/political-news/nursing-home-profits-soar-as-patient-care-declines-20151224-glupug.html>
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<https://agedcare.health.gov.au/ensuring-quality/aged-care-quality-and-compliance/guide-for-reporting-reportable-assaults>
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<http://cpsa.org.au/aged-care/aged-care-media-releases/130-nursing-home-mouse-infestation-was-present-for-months>
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