Appendix A: A Community Aged Care Hub

This document is part of our main submission, summarised below:

1. **Main submission:** Inquiry into the Future of Australia's aged care sector workforce.
2. **Appendix A: A Community Aged Care Hub**
   This document is derived from our website that describes how the proposed *Community Aged Care Hub* might be structured.
3. **Appendix B: 21st century thinking and research**
   This document addresses the need for an effective customer. It discusses and supplies links to modern thinking about the provision of social services including personalisation, citizenship and community involvement. It examines 20th century failures before addressing the 21st century movement for open government, participatory gdemocracy and a rebuilt civil society. Our proposal can be seen as lying within these movements and to meet their objectives.
4. **Appendix C: Why aged care is a failed market**
   In this document we have simply tabulated our criticisms and assessment of our political system, our providers and other participants as they impact on aged care and address most of these issues in greater depth and support our argument with quotes and references to a large amount of material. We list the large numbers, but largely ignored market failures where vulnerable customers or employees have been ruthlessly exploited. We argue that aged care is a vulnerable market and that the volume of criticism and information is so great that, in the absence of any other reliable data, it must be accepted and acted on. The reasons why it is a failed market are quite clear. This is only a small representative sample of the material we have collected over the years.
5. **Appendix D: Community integration**
   Our proposal is a wide ranging one which sees aged care integrated at a community level and not at a government level. Government will work through and with the community. This will vastly improve its utility to serve the community and its seniors. We have made submissions to other inquiries including those below. These illustrate the manner in which our community proposal will enable all of these services to be integrated and work together. It would also facilitate integration with the health care services and the NDIS locally. It may be possible to reduce the costs by sharing staff.

   Please consider our submissions (already submitted) at these links as supporting evidence to your committee:

   - **Review of Aged Care Advocacy Services:**
     ACC feedback form questions and our responses (web page): http://bit.ly/25tqXxK
     ACC supplementary submission (pdf): http://bit.ly/1PCdyaY
   - **Inquiry into elder abuse in NSW**
     ACC submission (pdf): http://bit.ly/1RMaEZ0

Contents

Introduction: This is based on a page on Aged Care Crisis' website written by an ACC member describing what a hub might look like and what it might do[1].

The links are to pages that expand on each section giving greater detail of the proposal. It is simply to highlight what is possible and we think desirable. It will only be effective if the hub has the power of an effective customer in the marketplace - the capacity to force compliance by putting those who don't meet its requirements and harm its members out of business.

1. The essence of a "Community hub"

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.

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". Its easy to turn an older person into a "has been". Both elderly people living alone and nursing home residents should be "involved" in life so that they are still "someone".

Life in many of our aged facilities seems to be less than optimal. Our nursing homes have been the subject of criticism for years. Too many are living isolated lives at home and, unless we are careful, the new policy to care for them at home could make this worse. There are allegations about the way retirement villages get their money. As a community we need to be there to see what is happening and to help.

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.

We don't want participants at each others throats, or community regulators walking around policing, looking for misconduct. They should all be focused on a common purpose. They will be collecting information for everyone to look at 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.

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 that they are increasingly now both a part of. 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 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.

Summary: This page outlines the sort of community aged care hub that I am suggesting and suggests ways of getting there. It gives some background and describes the relationship to the proposals made by Professor Maddocks (***Big challenge requires bold thinking: Maddocks***[2]).

1 http://www.agedcarecrisis.com/solving-aged-care/part-2

It examines the government's requirements for community partnerships in health care and concludes that there are major difficulties in implementing them successfully. These would be resolved by the proposed hub. The page examines the Harper review of competition policy and shows that the proposal addresses many of the problems where Harper is cautious about the possible adverse consequences of increased commercial competition in aged care because of its vulnerability.

Implementation would begin by creating interested groups in local communities who would soon form a central organisation to coordinate activities. They would start talking to governments and providers and liaising with other community groups. They would form a partnership with government bodies who would have a supervisory and educational role.

The local organisations and their central body would coordinate, supervise and support all aged care activities in each community. They would play a pivotal role in complaints handling, oversight of care, monitoring of standards, the collection of data, data interpretation and data dissemination. They would do so in the interests of the community and its members. The Aged Care Quality Agency (ACQA) would focus on education and work through the local hubs in assessing compliance, standards of care and in evaluating the success of their programs.

The local and central hub would become an effective customer because they would know exactly what was happening in their community and would become the organisation that advised and worked with potential residents and their families. They would be represented on the approved provider process and would ultimately be able to exert a veto. Local communities would have input into the imposition of sanctions and could not be forced to accept the ownership or operation of any aged care facility by a group or individual whom they felt could not be trusted to provide the sort of service they wanted.

The sliders *(ie sections)* on this page give a brief overview of what a community aged care hub would do. Most link to pages dealing with each issue in greater depth.

The Community Aged Care Hub: Genesis of ideas for change

Members of the ACC team have tracked developments in health and aged care in Australia and globally since the early 1990's. In these sectors people were harmed, often by well-motivated people. Our study of these developments over the years has led to a different approach to aged care. We have tried to look at it as an outsider looking closely. A different perspective can often throw a new light on what is happening.

We feel that aged care has moved away from what it essentially was: *a community service provided for members of the community by the community.* The lessons that we learned there have been ignored.

The community is no longer engaged. On a web page I wrote in 2006, I suggested that the community needed to re-engage. I subsequently discussed these ideas with community groups who were addressing failures in care. I developed these ideas further in submissions to separate inquiries into the complaints system and the accreditation system in 2009, and then to the Productivity Commission's Inquiry Caring for Older Australians[3] *(submission 368[4])* in 2010.

2 http://www.australianageingagenda.com.au/2014/07/11/big-challenge-requires-bold-thinking/

3 http://www.pc.gov.au/inquiries/completed/aged-care

4 http://www.pc.gov.au/inquiries/completed/aged-care/submissions/sub368.pdf

On 11th July 2014 *Australian Ageing Agenda* published an article by Professor Ian Maddocks, Senior Australian of the Year in 2013, and a retired palliative care specialist, suggesting a *"Community Aged Care Hub*" model. He wrote:

> ... In essence, it would act as a centre for the coordination and management of all matters affecting the health and wellbeing of older people ...
>
> ***Source:*** *Big challenge requires bold thinking: Maddocks (Australian Ageing Agenda, 11 Jul 2014)*
> http://www.australianageingagenda.com.au/2014/07/11/big-challenge-requires-bold-thinking/

Professor Maddocks sees the hub as based in and around "residential aged care facilities". He proposes that a retrained and committed medical fraternity lead and coordinate his hub.

Please read the "Big challenge requires bold thinking: Maddocks[5]" article before looking at my suggestions in this section.

I am very strongly supportive of his ideas and do not have issues with his proposals. Having the medical profession, with their knowledge and professional leadership play a leading role in the community hub would solve one of the weaknesses in my proposal - the generation of local expertise. While I see wider benefits than he indicated in his paper, and additional functions and roles for the hub, I believe that there is a common purpose. I can legitimately include the suggestions that I am making under the same broad idea of a community hub.

⚠ I see a risk to Professors Maddocks proposal from what I have identified and called "culturopathic tendencies". All marketplaces where customers lack information, or are vulnerable for any other reason, are at risk.

Some providers might only adopt the idea and implement it for their own purposes, rather than for the benefit of the community. My proposals would prevent that.

I have not seen the medical establishment offer, what I consider, constructive suggestions for addressing the problems in aged care. Locally doctors have been deserting the sector. When they put up their hands for their patients in the aged care system, and get on board, then I will focus on their potential to create and lead the hub. To succeed, the hub would depend on both doctors and the community being involved.

Community partnerships

Consumer and community partnerships in almost every facet of health care are now widely recognised as important for safe and effective health care. It is government policy. 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.

These 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.

5 http://www.australianageingagenda.com.au/2014/07/11/big-challenge-requires-bold-thinking/

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 whistle blowers, and academics have spoken out about failures 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 how far they have fallen behind. It points to their unwillingness to confront issues and to involve the community in addressing them.

A recent article on the Medical Journal of Australia examines international experience with partnerships in health care, many of which have failed. They find that it too often is only tokenstic. Success requires a very different way of operating. It needs to relinquish control and allow the community to set the agenda. My assessment is that it would be extremely difficult for government and large corporations to do that successfully. The top down way in which they must operate in order to run the country or a successful business is the very opposite of what is required. We are likely to see ineffective tokenism.

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 community aged care hubs.

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 is a modern broad application of the same principle in the era of government and market run health and aged care.

In the years since the turn of the century 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.

- *For more information about health care partnerships see Community partnerships*
  http://www.agedcarecrisis.com/solving-aged-care/part-2/community-partnerships

Competition Policy Review - March 2015

The Harper Review into competition policy became available on 31st March 2015. It contains both good and bad news for aged care. The focus on increased market competition is potentially bad because it puts negative pressure on those who provide good care because this increases costs and without an effective customer substandard care has a competitive advantage.

The good in the report is that the review panel specifically addressed aged care. The review panel must have recognised some of the problems because in this section the report stresses good management, that it be applied carefully, that the emphasis be on outcomes. It calls for contestable choice, empowering users, and protecting community and volunteer services. It calls for consumers to

have access to data, to be informed, engaged and empowered. It is stressed that markets should be made to work in the long-term interests of consumers.

The aged care community hub that I am proposing is based on a recognition of all of these as they are all already problems. Some of these are responsible for the failure of the current market. It is not possible to meet these objectives with the present structure. Some of these matters are most apparent in the manner in which Consumer Directed Care (CDC) in aged care is being introduced.

The proposed hub is intended to provide a mechanism for addressing or modulating all of them, for correcting existing problems. making sure this market works for consumers, and particularly for ensuring that the benefits of CDC are realised and the pitfalls avoided. There are good reasons for government and the industry supporting it.

- *For more information about implications of the Competition Policy Review*
  http://www.agedcarecrisis.com/solving-aged-care/part-2/competition-policy-review

Building a Community Aged Care Hub

The first step would be to create local communities of interested people to advocate for and create an organised group of local leaders. Doctors interested in aged care would play an important part in leadership. The hub would partner with all local aged care services. In addition to organising and structuring aged care and community activities across the community, they would take an active role in assessing standards of care, complaints resolution and many other aged care related activities in the local region. To do this they would work with local provider partners.

Regions would work together to create a central organisation to lobby for a partnership with government and to have services relocated to local communities where they would be supervised by the community and overseen by government. The services would include oversight, complaints, data collection, and the provision of information. The suggestions I am making are to show how it might be done.

- ***Learn more:*** *Building a Community Aged Care Hub*
  http://www.agedcarecrisis.com/solving-aged-care/part-2/building-a-community-aged-care-hub

Central structure

A representative central organisation, linking and coordinating the community hubs, should aim to form a similar partnership with government. They should be represented on government aged care bodies dealing with finance, standards, information, complaints, sanctions, assessment of information and on the approved provider process. They should aim to assume primary responsibility for the collection, collation and dissemination of information. They should use this information to support local hubs in advising potential recipients and their families.

- ***Learn more:*** *To see how central representation might work - Central structure*
  http://www.agedcarecrisis.com/solving-aged-care/part-2/central-structure

Accreditation

Accreditation should be primarily educational. It should focus on teaching practices that result in good care and train staff appointed by the local community. Most of the monitoring of process and assessment should be done by local staff who visit regularly. The agency should provide remediation for those facilities that have problems but should no longer be a regulatory body.

- ***Learn more:*** *To examine the role of Accreditation*
  http://www.agedcarecrisis.com/solving-aged-care/part-2/accreditation

Reviewing standards of care and quality of life: Oversight, standards and sanctions

The local hub should work with government departments to appoint local surveillance staff. These staff would be responsible for regular visits to the facilities to monitor standards of care, record keeping and quality of life. They would be trained, mentored and paid by the department, but would report jointly to, and be supported by, a representative from the local hub. Reports from these staff and the local hub would be sent to the department, the accreditation service, and to the central community organisation.

- ***Learn more:*** *To see how this could work - Reviewing standards of care and quality of life*
  http://www.agedcarecrisis.com/solving-aged-care/part-2/reviewing-standards-of-care-and-quality-of-life

Complaints handling

Local hub staff monitoring care would be the primary contact for complaints by residents, families and staff with concerns about care. When necessary, monitors would secure records and other documentation and do preliminary on-site investigation.

Monitors would work with their local support person in the hub and liaise with their departmental mentor in seeking resolution and if needed, remediation. When necessary, or if their findings were disputed, then a full departmental investigation and, when required, sanctions might follow. Where appropriate they would support recompense to those who have suffered as a result of negligence and advise them of their legal rights.

- ***Learn more:*** *Complaints handling* http://www.agedcarecrisis.com/solving-aged-care/part-2/complaints-handling

Supporting potential residents and their families

If the market is to work then it is essential that the hub assume responsibility for advising potential residents and care seekers. It is important that those actually monitoring services have input into the advice given to potential residents. While potential residents will be interested in how local services compare with those nationally, the really important information they need is about local services. The local hub will have that at its fingertips.

- ***Learn more:*** *Supporting potential residents and their families*
  http://www.agedcarecrisis.com/solving-aged-care/part-2/supporting-potential-residents-and-their-families

The Approved Provider process

Prior to 1997, owners and providers of nursing homes were vetted under probity requirements to be sure that their past conduct showed that they were good citizens and could be trusted to care properly for vulnerable people. Citizens with knowledge of bad behavior by an applicant could supply it to the departmental vetting body, and object to the issuing of a license to operate.

In 1997, that system was replaced by a secretive behind closed doors *"approved provider"* process. Owners who bought an existing provider, and so came to control the purse strings, no longer needed to seek approval. All that is required is that the managers (*"key personnel"*) that they appoint to run the newly acquired subsidiary do not yet have a criminal conviction.

Any criminal or company that has harmed it's customers, can buy a company already owning approved facilities without seeking approval, and then appoint managers to do what they want them to do. Owners can appoint managers to do their bidding, provided those managers do not have a criminal record. An owner could require them to squeeze care in order to increase profits.

There is clear evidence that ownership is one of the most important determinants of the sort of care that is given in nursing homes.

Residents, families and communities who have worked hard to find a suitable facility operated by managers they can trust have no say in who is going to control the care they receive when their facility or service is sold. **They can find themselves sold off into the hands of a totally different type of service, one whose only focus is on squeezing as much profit from their care as they can.** This is unacceptable. A totally different vetting system is required.

- ***Learn more:*** *To see how those who buy or run aged care services could be vetted see The Approved Provider process* http://www.agedcarecrisis.com/solving-aged-care/part-2/the-approved-provider-process

Healthy ageing: Community health and ageism

Healthy ageing means active ageing. This means being physically and mentally active, stimulated, socially involved, and having a sense of self value generated by continued contribution to society.

In some countries, communities are actively pursuing these objectives in innovative ways. The ageing population are being reintegrated into communities. Australia lags behind because our community has been disengaged from the aged care debate and there is a deep-seated ageism in place.

The creation of a community hub of interested and motivated people would re-engage the community, initiate debate and, critically, form a nucleus from which ageism could be challenged. The organisation, coordination and management of these activities would be core functions of the community hub and the community members it recruits. This is what most would be directly involved in.

- ***Learn more:*** *To see how the hub might drive these issues further, see Healthy ageing* http://www.agedcarecrisis.com/solving-aged-care/part-2/healthy-ageing

De-medicalising aged care: Doctors and allied health care professionals

The frailty and health needs of residents in nursing homes is rapidly increasing. At the same time health professionals including geriatricians, doctors, and trained nurses are becoming increasingly thin on the ground in nursing homes. Instead, care is provided by minimally trained aides.

Frailty: The elderly are the most frail in our society and the most prone to serious diseases and organ failures. With increased and improved home care, only the sickest end up in nursing homes. The care needed to give them a worthwhile life is complex, yet it is increasingly being provided by minimally trained staff.

History: I understand convicts assisted in the institutional care of the elderly after settlement in the 18th century. The aged were not thought to need medical care. But in the 19th century convicts were replaced by trained nurses. The level of care progressively increased during the 20th century with doctors playing an increasing role and with specialist geriatricians playing a greater and greater part.

The growing costs of providing care and the steady increase in the number of aged citizens pushed up costs. By the end of the 20th century governments were being forced to find the money and this meant raising taxes and diverting money from more popular and politically rewarding projects. Industry advisers in the USA suggested that there was commercial potential in "playing on politicians pain". Business groups took their advice.

Politicians were very receptive to claims by nursing home executives in the USA who claimed to be experts. The claim that you did not need expensive trained nurses to change bed pans, wipe bottoms and bath the elderly, and that the market would keep costs down replacing them with aides, was music

to politicians ears. They ignored protestations. These ideas were embraced in the USA and then in the 1990s by politicians in this country, a regression to 18th century attitudes.

Aged Care Reforms: Since the marketplace aged care reforms in Australia in 1997 there has been progressive de-medicalisation of aged care. Nurses have been replaced by low paid and minimally trained staff. Nursing is the largest cost of aged care and those who do not reduce costs struggle to compete in the market. There is a clearly demonstrated close relationship between staffing and standards of care. Doctors and other medical professionals have found working in this environment unrewarding financially and professionally. They have steadily vacated the sector.

Changing perceptions: As aged care was turned into a market this de-medicalisation was made to sound legitimate by changing the words used so that they reflected market thinking. Most discourse about aged care was soon about markets. Doctors nurses and many other professionals have complained about the consequences.

The hub: The proposed hub creates a situation where community, the medical profession, the nurses and the providers can come together around real practical issues where they will have to sort out their ideas and work for the best that is possible with the resources that society is prepared to supply - dealing directly with community and government in deciding what staffing and what resources should be directed to supporting the aged and how much of this can be afforded.

Quality of life in addition to good care has become a key consideration. Doctors are often accused by the community of prolonging and treating needlessly or without sufficient benefit and so reducing the quality of life. The hub would provide a venue close to where it is happening where this can be looked at together.

- ***Learn more:*** *To explore this further, see* *De-medicalising Aged Care*
  http://www.agedcarecrisis.com/solving-aged-care/part-2/demedicalising-aged-care

Structured change

The hub would have a range of experts from providers, the professions and the community. It would have direct experience, and the knowledge that oversight brings. With direct experience, close to the coalface, it would be well placed to understand issues, suggest solutions and then promote structural improvements. This would be a bottom-up democratic process based on experience, rather than a top-down one driven by managers responding to political ideology and stockmarket analysts.

Proposed changes would aim to serve the community rather than serve a belief system.

Advocating for aged care

The Community Hub and its central representatives would be well placed to join local managers in pressing their corporate masters for improvements. They would be advocates for aged care when dealing with government and when it was warranted on behalf of the providers. They would disseminate information publicly, as well as initiate then facilitate public discussion and public action.

- ***Learn more:*** *To learn how the hub could advocate, see* *Advocating for aged care*
  http://www.agedcarecrisis.com/solving-aged-care/part-2/advocating-for-aged-care