



4 September 2015

TO: advocacy@ahaconsulting.com.au

Re: Review of Commonwealth Aged Care Advocacy Services Supplement to Submission

Introduction

Aged Care Crisis (ACC) welcomes the opportunity to respond to the review of Commonwealth Aged Care Advocacy Services.

ACC is a community organisation that listens to what individuals who experience aged care have to say and seeks to advocate on their behalf. We believe that community discussion and transparency are a vital component of policy development. We asked Australian Healthcare Associates whether submissions and the final report would be publicly available. At the time of lodging our submission, we have not received an answer. If that is not planned, we intend to publish information on our website to stimulate and engage public discussion and invite comment and suggestions.

The focus of this review is the actual service provided by advocates in communities to individuals that need support. ACC believes that the utility of the service to these communities would be better facilitated and improved by a structure in which there was a closer link both with the community and with other oversight organisations.

Advocates are in a unique position to contribute to the collection of data – the aged care knowledge base. To contribute in this way would require a realignment of all these services.

Our suggestions are within the scope of the Options Paper Feedback Form, but the format is far too restrictive for an adequate explanation. We are therefore attaching this supplement to our submission.

The thrust of this submission is an analysis of the processes in aged care and their impact on advocacy at the coalface. We suggest strategies that will have a greater and positive impact on the process of advocacy.

To do so we:

- Examine different perceptions of the extent and success of the current advocacy system;
- Look at the aged care system itself – the context within which advocacy occurs;
- Examine modern thinking about the way in which community services are best provided; and
- Suggest a way of integrating community services that we believe would make advocacy a far more effective tool in the community. It would empower advocates so making them more effective.

We believe that advocacy should make a far greater contribution to aged care.

Conflicting information

As with almost every other activity in aged care we find contradictions that are difficult to understand. There is no way of resolving this because accurate data about the sector is not collected. A key focus of ACC's advocacy is directed to establishing an accurate and independent means of collecting data, evaluating it properly, and then distributing it to all those who need to know transparently.

Two different pictures emerge:

- 1. Organised and well resourced:** Based on information published on advocacy websites and their Annual Reports, we find that in some states (eg. Queensland) there seems to be a highly organised and active advocacy service providing a range of services to a large number of people. There is every indication that it is delivered by dedicated, motivated and well-trained people. QADA also provides advocacy services to other sectors as well as aged care across the state.

The amount of information available varies from state to state. In some instances aged care advocacy has been contracted to groups who provide a range of other services as well as advocacy. In some instances the only advocacy provided is to aged care.

The NACAP (National Aged Care Advocacy Program) contracted services are not the only bodies providing advocacy to individuals. Carers Australia provides advocacy services across Australia. Seniors Rights, an organisation run by COTA (Council of the Ageing Australia) in Victoria also does so. It is likely that some advocacy services in other states are not NACAP services and similarly fragmented.

It is impossible to properly assess the quality and adequacy of the advocacy services provided as no data is collected or published. The impression is of a well-structured service across Australia doing a good job, but it is impossible to confirm that.

- 2. Relatively unknown:** Outside of the government and advocacy web sites and their own publications, there is limited public evidence to suggest that the service exists. 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 Aged Care Complaints Scheme 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.

In many of the reported failures in care it is clear that there has been a large imbalance in power and the facilities involved have handled the complaint very badly¹. These are situations where, as ACC submissions to the 2009 Walton Review of the Aged Care Complaints Scheme indicated, a knowledgeable mediator assisting the family was critically important².

An example of this is the way in which the Review virtually destroyed the utility of the whole complaints system by embracing our recommendation to place more focus on local resolution, but critically ignored supporting information on the logic behind this and the essential linked recommendation that the complainant should be supported and advised by a trained local facilitator with investigative powers.

¹ Anger at quality of Canberra nursing home food, hygiene (Canberra Times), 13 Sep 2014: <http://bit.ly/news-anger-qty-nh-food-hygiene>

² Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia - Community Affairs References Committee (14 Feb 2014): <http://www.agedcarecrisis.com/protecting-vulnerable-people-in-aged-care>

Not surprisingly, this unequal barrier - in which there is a gross imbalance in power, where victimisation is possible - has proved to be an effective barrier to lodging a complaint as well as resolution, leading the disaffected even more disillusioned.

Whilst complainants are encouraged to raise their complaints with the service provider for resolution³, there is a large imbalance of power and many families fear their relative will be victimised if they complain and many elect not to do so⁴. We are concerned that providers may not always suggest that complainants seek assistance from an advocate. The issue of retribution has been raised repeatedly, but has not been adequately addressed by government or providers.

Recent changes to the oversight and regulatory aspects of aged care may place further strain on advocacy services⁵.

Our submission proposes a reordering of services by making advocacy a core service aligned with local on the ground community organisations. One of the most important functions of these will be gathering accurate information and ensuring that the aged care system works for consumers. The quality and adequacy of advocacy services would be readily apparent and accurately assessed.

Background to aged care

We believe that the aged care system is structured and constrained by the thinking and policies of the 20th century. These policies have not served the aged as well as they should. The extent of the failures is reflected in the large numbers of public exposures of serious problems in nursing homes and in the correspondence we receive.

While excellent care is provided in many facilities, the nature and extent of the information emerging strongly suggests that the exposures are the tip of an unacceptable iceberg and in many instances it is mediocre. The data to resolve this issue is not collected, therefore not available. We argue that the structure of aged care is largely responsible for the failures and also impedes the effectiveness of advocacy. The largest senior's organisation, National Seniors Australia's⁶, as well as experienced geriatricians working in the sector, have described aged care as failing or 'broken'^{7 8 9}.

20th Century aged care

The most heavily criticised parts of the system are those, which should serve the community and protect them. They include:

1. The Australian Aged Care Quality Agency (AACQA) (supersedes the Aged Care Standards and Accreditation Agency) is currently the only Agency that conducts reviews of aged care (including home care) services. None of these activities are aligned with its core methodology and functions, which are to educate and support providers in setting up good processes.

³ How to make a complaint (MyAgedCare) Last reviewed: 1 Jul 2015 : <http://www.myagedcare.gov.au/financial-and-legal/how-make-complaint>
Aged Care Complaints Scheme: <https://agedcarecomplaints.govspace.gov.au/about-us/about-the-scheme/>

⁴ Aged Care complaints kept secret (Sydney Morning Herald), 27 Sep 2014: <http://bit.ly/smh-aged-care-complaints-kept-secret>

⁵ Budget 2015 updates (CPSA), 1 Jun 2015: <http://www.cpsa.org.au/news/other-news/1291-budget-2015>

⁶ Aged care under strain (National Seniors, Michael O'Neill - ABC 7.30 Report), 14 Sep 2010 <http://www.abc.net.au/7.30/content/2010/s3011781.htm>

⁷ Aged failings (MJA Insight), 2 Jun 2014 by Dr L Mykota (experienced geriatrician)
<https://www.mja.com.au/insight/2014/19/ludomyr-mykyta-aged-failings>

⁸ Aged care is "fatally flawed" (ABC Radio - Ian Henschke), 8 Sep 2014 <https://soundcloud.com/891-abc-adelaide/aged-care-fatally-flawed>

⁹ Aged Care is broken (MJA Insight), 7 Apr 2014 <https://www.mja.com.au/insight/2014/12/aged-care-broken>

2. The Walton Review of the *Aged Care Complaints Scheme* in 2009¹⁰, found it to be seriously deficient. The failure to recommend a local mediator to assist family simply compounded the problem. The community does not have confidence in the complaints system.

There is very little, if any comment about or by advocacy services in this debate. You would expect advocacy services working in the community to be well informed about what is happening in the communities, where aged care is provided. These are issues where advocates have information and in a democracy they should be active participants.

One of the problems in Australia and globally is that when community services depend on government or corporate funding, the groups providing services seldom criticise and speak out. Rightly or wrongly, they feel that this puts their service at risk.

Contributing factors

In our view the major factors contributing to the failures in the aged care system include:

1. **Data collection:** The failure to collect any accurate data on which to base sensible decisions¹¹, poor analysis of data¹², and the use of flawed data to market government and industry agendas rather than to inform¹³. There is little reliable data to inform policy decisions or that researchers can use.

When research has revealed problems then, instead of addressing the issues, the industry has attacked the messenger¹⁴ and tried to limit further research¹⁵. Advocacy groups were not there to support or speak out on behalf of the academics.

The absence of data has enabled vastly different understandings and assessments of the operation of the aged care system to go unchallenged and unresolved. Policy decisions have been based on opinion and not on reliable information.

2. **Ignoring market theory:** The success of markets depends on a balance of competing forces. In successful markets the customer is served and his/her needs met. The customer has the power to determine whether the product or service offered is wanted. The success of the market depends on an informed and effective customer. This is currently not the case in aged care. The market has also failed badly in most other sectors where customers lack knowledge and/or market power.

Western Capitalist Democracies have been successful because an active civil society (the community) sets the parameters in which markets operate and holds both the market and politicians to account.

During the latter part of the 20th century, a new enthusiasm and belief in markets chose to ignore these well-established market principles. Civil society has lost its way and is no longer fulfilling its role in society. Fraud and the misuse of citizens have characterised many of those sectors where these principles were ignored when turning them into markets.

¹⁰ **Aged care complaints system found wanting** (ABC Radio National), 16 Apr 2010: <http://bit.ly/abc-accs-found-wanting>

¹¹ **The financial viability and sustainability of the aged care sector** (ACSA report), 2013: <http://bit.ly/acsa-fin-viab-sust-aged-care-sector>

¹² **Aged care report card** (Aged Care Crisis), 2008: <http://agedcarecrisis.com/aged-care-report-card>

¹³ **Quality Agency rejects ownership factor on accreditation** (Australian Ageing Agenda), 25 Mar 2015: <http://bit.ly/aag-qa-rejects-oship-fact-accred>

¹⁴ **Academic scaremongering with unsubstantiated claims** (ACSA Media release), Aug 2014: <http://bit.ly/acsa-academic-scaremong-unsubs-claims>

¹⁵ **Evidence: Maree Bernoth, Productivity Commission Inquiry - Caring for Older Australians**: Transcript of Proceedings (Canberra, 5 Apr 2011) <http://www.pc.gov.au/inquiries/completed/aged-care/public-hearings/20110405-canberra.pdf>

3. **Ignoring vulnerability:** The vulnerability of the ignorant, the sick and the frail aged, has been recognised for over 2,000 years. Society developed and established structures based on values and norms that addressed this. The late 20th century economists chose to ignore or downplay the significance of this. Rebadging customers by calling them “consumers” has not changed their vulnerability. Market failure has characterised those sectors, including aged care where they are unable to perform this role.
4. **Hollowing out of communities:** Associated with these changes has been an organisational structure that saw government and large corporations become the organising and managing structures in society. A top-down organisational and management structure has placed all the decisions in the hands of government and corporate management.

The focus in our democracy has moved away from a community-focused model. Instead of engaging around issues in the community, decision-making has been delegated to government and corporate leaders. Tokenistic consultation has left the community disillusioned, powerless, helpless and often angry.

The factors described above have resulted in what many analysts are now calling a “*hollowing out of society*” – a loss of knowledge, skill and confidence - and ultimately a lack of engagement in the community¹⁶.

In particular, the community has disengaged from aged care and civil society is no longer fulfilling its important role in debating, criticising and closely evaluating proposals for change.

5. **Cultural conflict:** Well established and distinct subcultures operating in the provision of health, aged care and other vulnerable sectors developed over hundreds of years. They were based on value systems that supported and protected the vulnerable. The success of services depended on motivation generated by a humanitarian ethos, engagement and commitment. Because trustworthiness was essential, an assessment of character (probity requirements - a fit and proper person) was used by civil society to screen out those who might pose a risk in the most vulnerable sectors.

However, in a ‘one size fits all’ approach, this character restriction was removed in aged care in 1997 (with the introduction of the *Aged Care Act 1997*). Cultures in these vulnerable sectors have now been subjugated to a dominant free market culture whose primary focus is on profits and whose duty it is to serve shareholders. Those providing services have had to adapt to the new priorities. Even though the for-profit market in aged care lays claim to the same values, the extent to which that influences their conduct is debatable. Humans are not adept at serving two masters.

The adaptive strategies within these sectors, including the aged care sector, varies from enthusiastic conversion to disillusionment and alienation. This has consequences throughout the sector. Not-for-profit providers, whose roots lie in the community, are deeply conflicted. The legitimacy of the market system in the community has deprived not-for-profit of the community support on which their existence is based and they struggle to maintain their caring ethos and mission.

6. **Fragmentation:** The parts of the system that seek to protect the community have been fragmented in order to meet political and organisational priorities. These include the accreditation system, the complaints system and the advocacy system which all operate separately. There seems to be little

¹⁶ **Community Sourcing and Social Care** - Chris Yapp and Chris Howells, The Centre for Welfare Reform, 2013
<http://www.centreforwelfarereform.org/library/by-date/community-sourcing-and-social-care.html>

effective collaboration between these services and separating them in this way reduces their effectiveness. Each agency or group is organised in a hierarchical structure and the community is engaged by invitation and only on the terms of engagement already decided at the top. More recent research indicates that this is not likely to be effective. Much of the information feeding these reviews or surveys, are not readily available.

The absence of reliable data means that none of them are able to assess their performance and that practices and policy are based on belief rather than evidence.

- 7. Fear of retribution:** A worrying problem is the incidence of retribution or fear of retribution for those who complain or speak out about problems for residents. Nurses who complain to management are particularly at risk and if they dare speak out when their complaints are ignored they lose their jobs¹⁷. It is one of the main reasons why nurses, family and residents elect not to lodge complaints or withdraw those they have lodged.

QADA Annual Report 2013-14 expressed significant concern about the increasing number of older people fearful of retribution who have chosen not to proceed with advocacy support or to lodge a complaint. Accurate data collection will not be possible until this issue is adequately addressed. Our proposal is intended to do that.

Recent developments

Social analysts are now looking critically at what has been happening in order to separate the positive aspects of organisational structure from the negative ones. This new focus represents a shift from a leader dominated belief driven society, to one driven by analysis, assessment and broad discussion – a community dominated focus.

Integral to this is a new sense of citizenship focussing on both the right of citizens to participate and be heard and their responsibility as citizens to engage and participate in the affairs of the community and of the nation.

Late 20th century philosophy was underpinned by a belief that self-interest was the dominant driving force in our psyche and that this could be harnessed and used to drive beneficial change. Individuals defined themselves and their identity by competing for money and status, mostly in a marketplace context. In the enthusiasm, believers ignored the fact that we are social animals and our social selves languished. The aim is to restore a balance between self-interested individuality and social beings with responsibilities for others and the world.

To counter the attitudes that resulted from an inward looking self-interested focus on competition and personal advancement, the focus has shifted to engagement and participation in the society we all live in. Civil society is seen to be in need of revitalisation. The digital revolution has opened up new ways of engaging and accomplishing this. The process is in its infancy.

¹⁷ Death in a five star nursing home (ABC - Background Briefing), 21 Sep 2014: <http://ab.co/1wE9NL9>

Community engagement

Developments and pilot studies in this broad movement have flourished since the turn of the century. Participants in these global developments in Australia include organisations like 21st Century Dialogue¹⁸, New Democracy Foundation¹⁹ and Mosaic Lab²⁰. They each have a number of examples on their web sites where citizen engagement has made contributions.

The wide-ranging projects use terms like Citizens juries²¹ (community decision making tribunals), participatory democracy²², deliberative democracy, generative democracy, community governance, crowdsourcing²³, citizen's senate, electronic town hall, co-design²⁴, etc.

Bodies that have been involved in projects include

- Melbourne City Council
- Victoria Council of Social Services,
- New South Wales Independent Local Government Review Panel,
- the Local Government Association of South Australia's Expert Panel,
- Council on the Future,
- Local Government New Zealand,
- Marion City Council in South Australia,
- Mitchell Shire in Victoria and
- the Australian Centre of Excellence for Local Government.

These schemes cover a broad range of citizenship projects addressing issues in international trade²⁵, government (national to local²⁶) and a number of other sectors like science²⁷ - even self-advocacy where disadvantaged groups form associations²⁸. Information and communication technology are integral to many projects²⁹.

¹⁸ **21st Century Dialogue** - (a) Deliberative Democracy Initiatives: <http://bit.ly/1hW6Jsr>; (b) Publications: <http://bit.ly/1LWvr8u>

¹⁹ **New Democracy Foundation**: <http://www.newdemocracy.com.au>

²⁰ **Mosaic Lab**: <http://www.mosaiclab.com.au>

²¹ **Citizens Juries**: (a) Citizen juries - leadership for a new democracy (ABC Radio National), 9 Jun 2015: <http://ab.co/1OasTRx>
(b) 10 Year financial plan 2015-2025 - Citizen's Jury plan adopted by Melbourne City Council: <http://bit.ly/1UnZvP0>
(c) Melbourne citizens' jury success offers fresh hope for democratic renewal (ABC Sunday Extra), 3 Jul 2015: <http://ab.co/1KspEYf>

²² **Participatory Democracy** Wikipedia: https://en.wikipedia.org/wiki/Participatory_democracy

²³ **Crowdsourcing**: (a) **Government crowdsourcing** https://en.wikipedia.org/wiki/Government_crowdsourcing
(b) **Crowdsourced policymaking - The motivations, expectations and profile of the crowd**. audio of lecture by Tanja Aitamurto Swinburne Institute Seminar Series <https://commons.swinburne.edu.au/items/74d5f22c-8b6e-4e2d-b708-9e5d72cf0cc8/1/>
(c) **Crowdsourcing for Democracy: A New Era in Policy-Making** by Tanja Aitamurto Publication of the Committee for the Future | 1/2012 Parliament of Finland: https://www.dropbox.com/s/kqpn2dfi2rjpbdr/Crowdsourcing_for_DemocracyF_www.pdf

²⁴ **Walk alongside: Co-designing social initiatives with people experiencing vulnerabilities** by Michelle Clarkson Victorian Council of Social Services July 2015: http://vcoss.org.au/documents/2015/08/Codesign-paper-Jul15_Final.pdf

²⁵ **Beyond Trade: Getting Economic Integration Right**: ANU Centre for European Studies Policy Notes Issue 1, 2015 <http://politicsir.cass.anu.edu.au/sites/politicsir.anu.edu.au/files/documents/ANUCES-Policy-Notes-2015-1.pdf>

²⁶ **Australian Policy Online - Community-Level Governance**: A report prepared by McKinlay Douglas Ltd, Jul 2014, for a number of local governments in Australia and New Zealand: <http://apo.org.au/research/community-level-governance>

²⁷ **Building Australia Through Citizen Science** - Occasional Paper Series Issue 11 July 2015 Australian government : Office of the Chief Scientist http://apo.org.au/files/Resource/citizen-science-op_web.pdf

²⁸ **Self-advocacy and inclusion: a summary of the study 'What can be learned from speaking up over the years'** Christine Bigby Living with Disability Research Centre (LaTrobe) from Australian Policy Online 21 July 2015 <http://bit.ly/1LkkyZ>

²⁹ **ICT, open government and civil society** John Restakis, Daniel Araya, Maria José Calderon, Robin Murray Journal of Peer Production ISSN: 2213-5316 - 14 Jul 2015: <http://apo.org.au/files/Resource/ict-open-government-and-civil-society.pdf>

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 required³⁰. Others have 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.

A good example in Australia is Aboriginal Health³¹, one where millions of dollars have been wasted in well meaning projects over the years. Since responsibility for their health has been handed to local communities, there have been dramatic improvements. This experience has been replicated in overseas studies.

The Centre for Welfare Reform³² 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.

An aged care example:

An excellent research project by researchers³³ 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"*.

³⁰ The Centre for Welfare Reform, Birmingham England: <http://www.centreforwelfarereform.org/>

³¹ Planning, Implementation and Effectiveness in Indigenous Health Reform (The Lowitja Institute), July 2015 <https://www.lowitja.org.au/sites/default/files/PIE-Report-PB-FINAL2.pdf>

³² The Centre for Welfare Reform, Birmingham England: <http://www.centreforwelfarereform.org/>

³³ Community Connections - Vulnerability and Resilience in the Blue Mountains - Project Report (Mar 2015): http://www.csu.edu.au/_data/assets/pdf_file/0008/1367576/Community-Connections-Report-March-2015.pdf

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

This report in our view highlights the problems created by the provision of services within preconceived ideological frameworks and by excluding rather than embracing the community in making policy. This is well illustrated in aged care by the close relationship between NACA (National Aged Care Alliance) and the government³⁴. ACC is also critical of the “MyAgedCare” website. We consider it to be out of touch with the community and of little value.

Aged Care In Australia

Aged care in Australia has, we believe, been a victim of 20th century thinking. Care of the age was originally within the community and was provided by community organisations, mostly churches. When socialist governments gained power in the mid-20th century and costs increased beyond the capacity of local communities government assumed responsibility for oversight of and provision of services.

The hollowing out of communities commenced at this time but the process took off when government delegated its responsibility for providing aged care to the market. The process has escalated rapidly since the turn of the century. Governments locked into 20th century thinking have sold off its services or contracted them to the marketplace. All community aged care and disability services are now to be organised around competitive contracting and market principles.

Tokenistic engagement: What could be described as the “debris of the 20th century littering the 21st,” is well illustrated by the manner in which the government formed a close association with National Aged care Alliance (NACA). Instead of fostering community input, NACA, an industry dominated organisation, sought to restrict it by preventing its members from publicly criticising its decisions once they had been made. This was unacceptable to seniors groups with the largest membership. Both National Seniors (approx. 200,000 members) and the Combined Pensioners and Superannuants Association (CPSA approx. 30,000 members) withdrew from NACA, and have therefore been able to criticise what NACA has done³⁵. Out of the 40 plus members of NACA, only three senior’s groups (COTA - approx. 50,000 members), Alzheimer’s Australia and Carers Australia remained NACA members. The latter two have to work closely with providers in their activities and most probably have had little choice.

As a consequence, aged care policy in Australia has been dominated by industry and has not had input from two of the biggest seniors organisations in the country. Both have been very critical of the system we have. While government is aware of the broad movement for community engagement, we believe that they and NACA have not fully embraced it. They have attempted to do so within the constraints imposed by the past, rather than adjusting to the future.

While a vast amount of dedicated and very valuable work has been done, an attitude that in 2015 describes the critics that have been excluded as *“the cacophony of voices from different interests in the sector had torpedoed previous efforts”*³⁶ illustrates the current unwillingness of government, industry and their allies to engage and address the issues raised by those who criticise because they see things from a different point of view.

³⁴ Senate transcript (5 Jun 2013): <http://bit.ly/1EAwLLq>

³⁵ Pensioners warned: Age Well Campaign - CPSA (30 Jan 2012): <http://bit.ly/1fWdtEK>

³⁶ Consumer Directed Care - past, present, future (PICAC CALDWays Conference - Embracing Change), 19 Jun 2015: <http://bit.ly/1NOj3rt>

This reflexive labelling and attack on the messenger is what 21st century thinking seeks to eliminate. We are worried that the potential benefits of highly desirable developments including Consumer Directed Care and the idea behind Quality Indicators have been compromised by the way they are being introduced. Our proposal seeks to rescue them.

The limited attempts NACA has made at genuine community involvement have been strongly criticised. It has adopted a policy of consumer empowerment, but the community has not been included in that. Local communities have little if any say in what is being done. It seems to be consumer empowerment on their terms. Government and industry are marketing reform and innovation, when what is being done is retrogressive and anything but.

Advocacy programs

Aged care advocacy services have operated within this government-organised structure, centrally organised by NACAP, in the Department of Social Services. They fund and provide the service through a competitive selection process in each state.

If we look back, we see that reports and submissions made to the Productivity Commission's Inquiry *Caring for Older Australians* in 2010/11³⁷, indicate that significant problems were being experienced at that time. ARAS in South Australia complained that it received only \$380,812 for aged care advocacy and could only afford 3 advocates to cover residential services in the entire state. This reduction in staffing was impacting on services and contrasted starkly with the increased funding of the Aged Care Complaints Scheme. In both residential and community care settings, they were forced to rely on aged care providers to inform residents and families of their availability to help.

Advocates were only able to visit facilities once every 2 years. There were many services they could not provide. People wished *"they had known about ARAS when they were having a problem"*. A *"resident centred approach - - is often not much more than rhetoric"*. ARAS was unable to adequately support residents in retirement villages³⁸.

In 2011, Carers Victoria³⁹ considered that in aged care, carers had reasonable access but the level of unmet need was unknown. It is not clear how they determined "reasonable access" when they did not know what the need was.

In their submission to the PC in 2010⁴⁰, NACAP argued for a greater focus on support structures and a greater integration in the aged care system. In a proposal in one submission⁴¹ (Section D, page 41) by an ACC contributor, advocacy would have become an integral part of the proposal for a reformed system.

It is clear that the situation has improved since 2011, with an increase in funding and staffing. There is no data to indicate whether it is now adequate or how much advocacy is provided outside NACAP contracts.

³⁷ Productivity Commission Inquiry: Caring for Older Australians - <http://www.pc.gov.au/inquiries/completed/aged-care/submissions>

³⁸ Ref ARAS-SA-sub137 to PC in 2010 <http://www.pc.gov.au/inquiries/completed/aged-care/submissions/sub137.pdf>

³⁹ Discussion Paper - Individual Advocacy and Caring Families
<https://www.carersvictoria.org.au/Assets/Files/Discussion%20Paper%20-%20Individual%20Advocacy%20and%20Caring%20Families.pdf>

⁴⁰ <http://www.pc.gov.au/inquiries/completed/aged-care/submissions/sub167.pdf>

⁴¹ <http://www.pc.gov.au/inquiries/completed/aged-care/submissions/sub368.pdf>

The lack of data about the actual performance of individual services and the aged care sector itself (as contrasted with accreditation status) must hamper the ability of advocates to support members of the community.

This difficulty we believe, is compounded by the separation of advocacy from the processes of oversight, data collection, accreditation and complaints handling. While these processes are all directed to protecting the vulnerable, they are structured separately and “*pass like a ship in the night*”. Much of the information collected is never assessed or publicly released.

Addressing the Options Paper

The options paper is restrictive in that it is fairly prescriptive and limited in scope. We have completed the form asked for and have pressed to have advocacy delivered through a local community organisation. Other services such as data collection, complaints and accreditation monitoring should be delivered through the same organisation under the control of the community. This would be an implementation of current thinking.

Each of the services would work with and benefit from the others. They would complement each other. The integrated whole would exceed the sum of its parts.

In order to give greater depth to what we have said in the Options paper feedback form, we have written this supplement.

Options Paper comments

Like National Seniors Australia and many geriatricians working in the sector, the information that ACC receives from staff and families leads it to conclude that the aged care system is broken and that it needs to be fundamentally re-evaluated. Like the Productivity Commission in 2010, governments are trapped in the 1990's, therefore may not be in a position to drive this process effectively.

Embracing Diversity: ACC recognises that there are big differences between local communities in terms of wealth, race, culture and attitudes. A ‘*one size fits all*’ structure will not serve all communities. Each community has the capacity to innovate and adapt processes to suit their particular needs, as well as learn from the successful activities of other communities.

Restructuring: ACC is interested in adopting and fostering the best of current thinking and organisation in aged care by pressing for the collection and rigorous assessment of data and by supporting involvement of local communities in aged care. We will be doing so on our website.

We believe that the process should start and end with the community. The community should be engaged in initiating this process by debating the sort of aged care system it wants, looking at how it should be structured, and then finally at how that can be implemented and paid for.

Government's role should be in supporting this process by ensuring that all sections of the community, but particularly those sections that have been looking in from outside and criticising, participate in this process. Outsiders often see more clearly than insiders. Every policy should be honed by subjecting it to its critics and addressing their criticisms.

Government should engage with the community and assist by passing enabling legislation. It would hand control of the new system to the community, but it would continue to play an important role in educating, supporting and advising local communities.

Community structures: We envisage the establishment of independent community run and organised structures. This would include services such as data collection, oversight, measurements of standards, accreditation monitoring and community feedback. Support of seniors in the community and advice for potential consumers would be provided under the control of and through the local community. Advocacy would be an integral part of the service and community advocates would leverage off the knowledge of others. The system would tap into the wealth of experience and intellectual potential of the entire Australian community. Existing services would provide their services by supporting and working through these local organisations.

This organisation would be there for consumers, supporting them and ensuring that they are able to exert their rights and responsibilities to the limits of their capacity. Advocacy would be a major and important part of the process.

Support: The role of government would be to work through local communities by supporting and mentoring these activities and monitoring their effectiveness. Their staff would work within and with them.

We believe that the DSS and NACAP would best serve Australia if they encouraged their advocacy staff and their state groups to participate in a public debate to be sure that the views of advocates are represented and that any new structure meets the advocacy needs of the community.

DSS and NACAP would have an important role to play in supporting advocacy in any new structure. The new structure should not undermine or diminish what has already been done but would provide those services through a local community organisation, in which their advocates would be participants.

Consequences: We feel that the evidence indicates that this will result in a reinvigoration of advocacy which would usually be face to face and delivered in cooperation with people known and trusted in the community - people who understand that community and its problems, cultural attributes, language and uniqueness - people who have a detailed knowledge of the services provided locally.

If any reformed system is to be effective it must recognise and stop any retribution against staff or residents and it must be absolutely clear that this cannot happen. The community organisation we are suggesting would be local and regularly on site. Its staff would be regular visitors to the facilities and to those getting home care. They would be talking to staff, consumers, and to families as well as actually observing the services being provided - assessing the standard of care given and the quality of life.

They would be working with staff to review records and extract data so that both the service providers and the community customer would be fully aware of the standards of care and of what was being done to address any problems. They would have their ears to the ground.

One of the most important functions of the community service will be carefully watching and protecting staff and residents when they raise issues about the care or services provided. They would be mediators in any issues that arose and advocacy would be integral to that. As representatives of consumers they would be concerned and want to be involved. Providers that failed to behave responsibly would not prosper.

Falling through the cracks: NACAP documents⁴² show that “the provider must give the resident information about residents’ rights and obligations as specified in the Charter, and the requirements of the User Rights Principles 1997” but it is only “generally accepted that the principle as quoted above incorporates an obligation on providers to provide information to consumers relating to advocacy support”. It is not a legal requirement.

Significantly, when residents or family complain to the provider, there is no requirement that the provider inform them that they have a right to have an advocate assist them. The regulations sound good, but they are full of cracks where people who are not knowledgeable can fall through and not access the support they need.

With the proposed community organisation, both residents and their families will be in contact with the community representatives who will not only know of their unhappiness, but will also know how the provider operates and what problems are present. They will be the first port of call when anyone is unhappy. The number of people falling through the cracks will be markedly reduced.

Accurate information: Information on the MyAgedCare website is of limited value for anyone requiring real information about local services. The MyAgedCare website now functions similar to an online shopping website. It provides little more than costs, contact details and whether the facility is compliant or not⁴³. Users are left to source information directly from the provider and/or their websites. The glossy brochures and impressive websites seeking their custom can be deceptive.

In the absence of useful information regarding each service, families are faced with performing the impossible task of searching through various commercial websites who offer guidance and reviews about aged care facilities, although we are concerned about whose interests some are serving. This is often done at a time when families are under extreme pressure from hospitals to vacate beds⁴⁴ or after an adverse event⁴⁵. The proposed community organisation would not abandon members of their community in this way.

Detailed information would be collected and they would know exactly what the situation in that region was. This would put them in a position to assist prospective residents to find the service that fits their requirements. It will often be done in a face-to-face discussion based on detailed local knowledge by people whose advice is not commercially compromised.

Aged care cannot be treated like any other market. There must be greater access for the community’s representatives so that they know exactly what is happening and can exert their market power. The sort of confidentiality that is thought to be a right in other sectors is unacceptable here. Aged care requires a far greater level of openness, trustworthiness and cooperation than any other market.

These proposals are not new: ACC itself or its supporters have advocated a restructuring of aged care along these lines to the Walton Review of the Aged Care Complaints System (2009), the review of the Accreditation process (2009) and the Productivity Commission Inquiry in 2010. These options were not thought to be worth mentioning in those reports. We believe that if the community were fully engaged then ideas like this would be strongly supported.

⁴² Reference National Aged Care Advocacy Program (NACAP) FAQs https://www.dss.gov.au/sites/default/files/documents/02_2015/nacap-faqs.pdf

⁴³ MyAgedCare website - aged care org detail/view (as at 4 Sep 2015): <http://bit.ly/myagedcare-52IKIA>

⁴⁴ Elizabeth Rogers, the elderly patient threatened with eviction from hospital, dies (Sydney Morning Herald, 21 Aug 2015): <http://www.smh.com.au/nsw/elizabeth-rogers-the-elderly-patient-threatened-with- eviction-from-hospital-dies-20150821-gj4umk.html>

⁴⁵ Aged-care response a true test of society’s caring (Sydney Morning Herald - Comment, 24 Aug 2015): <http://www.smh.com.au/comment/agedcare-response-a-true-test-of-societys-caring-20150824-gj6a8b.html>