

## **National Seniors Australia Opening Statement – Professor John McCallum CEO**

A National Seniors publication on 25th September 2018 contains new and relevant evidence, namely in: **'You don't know what you don't know': The current state of Australian aged care service literacy by** Rees, K., Maccora, J. & McCallum, J. Brisbane National Seniors (68 pages). Using this research our statement provides a consumer-focused context for our issues about the Bills and the other documents giving effect to the Bills.

The research from Australians 50+ indicates a lack of knowledge on matters before this Committee:

- 60 per cent of older Australians have never heard of the Aged Care Complaints Commissioner
- 65 per cent felt that there are no options to complain
- 84 per cent didn't understand the role of the Aged Care Quality Agency
- 80 per cent hadn't heard of the Charter of Care Recipients' Rights and Responsibilities for Home Care.

This new research clearly shows many older Australians lack the knowledge, skill and motivation to access aged care services how and where to lodge complaints. The research further indicates that older Australians needed to become more literate in aged care matters. If they don't, they may be caught out when they need to access care, let alone if they have to deal with the types of neglect and abuse issues we're now seen documented. Many are unable to represent their view through cognitive and physical limitations and they need representatives and advocates.

***The National Seniors data provides strong support for the need to have representatives fully and clearly written into the Bills, clear rights of access to nominated advocates and having carers on the Advisory Council. National Seniors supports these improvements to the Bills.***

The essential required goal is to have zero tolerance for the types of endemic problems that have been revealed recently, many of which have surfaced since the introduction of unannounced accreditation assessments. Consumers can also help drive change by becoming better informed, and providers and government need to assist in developing consumer knowledge and literacy, so information is more readily accessible.

We also have found that after experiencing the aged care sector, one of the main issues for consumers and their families is the feeling that complaining about services will lead to retribution.

*If you make a complaint about what you get, guess what you then get?  
Aged care inhabitants are too afraid to say anything for fear of repercussions. It's never a confidential process.*

Many who have worked in the sector vow to never use its services if they can avoid it, because they are so scarred by their experiences. Such negative attitudes provide barriers to service literacy.

Looking at consumer literacy more generally we found that there was limited use of information and limited knowledge of the system:

- 70 per cent had never looked at the My Aged Care website
- 85 per cent had never phoned the government service, which aims to make it easier for older people, their families and carers to access information on ageing and aged care
- 80 per cent didn't understand how consumer contributions to aged care were assessed

Consumer feedback through quality and complaints systems is a key to resolving bad care and improving the system. Despite the national centralisation of quality issues and complaints, the focus of consumers remains local and facility or service provider focused. In this study, when National Seniors members were asked whether they'd heard of these agencies in preparatory forum discussions for the survey, they responded by referring to the absence of a State Minister for Ageing.

*You were also asking about Pricing and Complaints Commissioners. Our State doesn't have someone representing Seniors in its ministry. We used to, but they cut it out.*

There is a need to create greater confidence in the process of dealing with complaints and these issues will now pass on to the new Aged Care Quality and Safety Commission. But these matters are first and foremost community and local issues for people, rather than ones they expect to escalate to national and government agencies. This raises the important issue of better industry self-regulation the industry establishing its own code such as the one recently revised in the banking industry.

***National Seniors supports a greater concentration on issues of quality improvement as well as the focus on quality assurance in the Bills.***

As well as creating a quality and complaints system that works, the government and providers need to communicate much more clearly and often about the processes that are available. This is a lesson to be learned from on health literacy work and it requires training and behaviour change among service providers. Previous work on Home Care for the Aged Care Workforce Strategy Taskforce recommended that education processes be improved in quality and content for example with good quality *in situ* experiences in learning and compulsory completion of units on dementia.

One of the inadvertent consequences of the *Four Corners* program and the Royal Commission is the negative image of aged care homes is reinforced. Sadly, some bad players in the industry tar the good ones with the same brush. We must therefore be careful not to make things worse as we're trying to make them better. The reality is some people are going to need residential care when they reach old age, so we must ensure they meet the required standard, that people can learn how to access the information they need quickly and easily, and they can complain without fear of retribution or being ignored.

Information-seeking behaviours and digital literacy affect the access of aged care services. However, in a system in a system experiencing continual change and emerging disruptions it isn't an easy task

to be a 'literate' consumer as one might be as a shopper. As summed up succinctly by one survey respondent:

*The main problem with age services, you don't know what you don't know. When a problem comes up, one is not too sure of where or how to obtain the right information.*

**National Seniors strongly supports the progress of these Bills with the ideas for improvement listed above and the creation of the single framework Safety and Quality.**

National Seniors notes that there are now strong functioning models in health care for complaints handling that reaches resolution, improving consumer literacy through better provider behaviour and more generally in the operations of the Australian Commission for Quality and Safety in Health Care relating to clinical matters. These should be taken into account in considering the implementation of the Bills.

National Seniors also encourages the progress of these matters ahead of the findings of the Royal Commission into Aged Care Quality and Safety

Professor John McCallum

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**Additional National Seniors material requested on 'retribution' pp 42-43 of National Seniors publication "You don't know what you don't know" referenced above.**

### Complaining is a fraught process

The fear of retribution or repercussions was expressed again and again, for example, by saying complaints have consequences or reprisals, care will be diminished, and frail older people are afraid to "upset the apple cart" or "stir the waters", which would create a more stressful situation for them:

*If you make a complaint about what you get, guess what you then get?*

*Aged care inhabitants are too afraid to say anything for fear of repercussions. It's never a confidential process.*

*As a registered nurse when I was working in Aged Care there were many options available to the residents' and family members for making a complaint if they were not happy. Many were reluctant to do so as concerned they would be treated badly.*

*Complaints tend to be ignored/glossed over, some people can tend to be nasty following complaints.*

*There are reprisals if a complaint is made.*

**National Seniors was established in 1976 and is the largest independent advocacy group for older Australians.**

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*I had complaints about my aunt's care but felt if I spoke up it would be detrimental to her in my absence. She had dementia and the administration staff played on that.*

*I ran the Residents Rights in Nursing Homes and Hostels Program for the Department of Human Services plus performed Standards Monitoring. There is lip service for making complaints but nobody will dare because the client can receive retribution when nobody is around.*

*I know there are moles in the Dept of Health and Ageing. Any complaints will probably be met with some kind of persecution. I am basing this opinion on what happened to my mother when I complained about various problems in the corporate aged care centre where she was a resident.*

Certainly, being powerless to complain made residential aged care unappealing:

*I have heard that residents are at the mercy of the operators, and have very few avenues for complaint. Going into care would be a last resort as it would be too upsetting seeing others neglected or abused, treated unfairly - and being powerless to get fair treatment for ourselves.*

Some residents ask their family members not to complain:

*I know that my mother is very reluctant to allow me to complain on her behalf or complain herself, she lives in fear that this will come back at her and she will be set upon, stolen from, mistreated, or not get the services any more.*

The dependence created by needing care makes people vulnerable:

*Older people rarely complain, they try to please their carers because they are dependent on them.*

One respondent said this situation created the need for unannounced visits, something announced by the Government in 2017 and now active:

*Anecdotal evidence is that aged care residents are not able to make any complaints without negative repercussions on them! I think aged care homes need to have more inspections without notice. I think many residents are treated somewhat poorly, especially re poor quality and quantity food.*

***National Seniors recognises that 'retribution' is a breach of standards and should be actioned as that, but also that this is often invisible to outsiders or, even a reasonable fears without evidence in the current situation. Consequently, National Seniors supports proactive action to improve staff behaviour in residential care through improved training, routine steps towards improvement following serious incidents to achieve continuous improvement in aged care services.***