

Thank you for the opportunity to participate in the process of informing the new legislation for the benefit of government, the aged and the taxpayer.

I am 78 years of age with a chronic rare neuroimmunological disorder that has been worsened in some ways by age as most, if not all, preexisting conditions are impacted with ageing.

I have been the recipient of a HCP since mid 2017. I have 2 years experience with one fully managed business aka provider and briefly with one Self Management and then almost 4 years with a genuine and caring Self Management business.

Hence I am writing predominately about the legislation affecting Self Management and how the overarching proposed legislation is likely to impact Self Management.

I see evidence that NOW is a vital time in history and the evolution of the aged.

We have a new generation of ageing coalescing with new legislation being drafted. What better opportunity than NOW for government to get it right. I am extremely concerned that instead of grasping this once in a generation opportunity which will have a huge impact on the aged for future generations government is taking retrograde steps in terms of Self Management.

The new generation of ageing I reference is those who are self managing their HCPs. Whilst there has always been vast individual differences in the symptoms and abilities/disabilities of ageing the current generation of ageing more than ever before has able minds and not so able bodies. We have lost strength, balance, pace, flexibility, agility, skin integrity, energy, acuity of vision and/or hearing and picked up along the way pain, stiffness, slowness and fatigue.

Whilst maybe not always as quick or as sharp as we used to be, and for some naïve to the ways and ethics of the 'double speak' that currently permeates society and government we remain intellectually active and relevant. Our essence and capacity for autonomy is intact. We read, research, discuss and try very hard to do whatever is necessary to retard the deterioration of ageing of brain and body. No one truly understands this imperative other than those close to the end of life. Repeated studies have demonstrated that we want to age in our homes.

To that end decisions based on the assumption that we are incompetent and lack capacity for self responsibility and self determination as is happening with the recent and proposed changes to Self Management is likely to be harmful to us and government/taxpayer by driving us into Residential Facilities long before we otherwise would. There is nothing more guaranteed to drive people into 'care' than by treating them as if they need 'care'.

Self Management is currently regulated by the same standards and guidelines as full management. Regulating one model by the standards of another model is fraught and has resulted the abolition of many aspects of self management - except its title.

Self Management needs new thinking. Self management needs a Section of the act dedicated to maintaining it.

The rapid and very large growth of self management in the last 3 or so years reflects this new category of ageing and indicates NOW is the time to have a Section of the Act dedicated to Self Management.

The proposed legislation fails to cater for Self Management in any way that I can see. Combined with current changes Self Management is being pushed out of existence without an announcement to that effect. The 'Strengthening of Standards' document actually weakens the standards of self management.

I understand Liability is an issue. As no clear announcement has been made I am left to deduce that government is in some way removing the 'self management' aspects of self management in order to transfer liability from government to the provider. Certainly the government is being prudent by trying to address the Liability issue in some way. Surely what is currently happening and forecast is moving in the wrong direction to achieve this.

Surely the new legislation could provide for an indemnity clause to be written into the contract for Self Management that indemnifies government and provider. If a person wants self management carrying their own risk or indemnity is part of that responsibility – as they have to do with every other aspect of their life. Maybe an Insurance policy to cover this could be paid for out of the HCP. Simply indemnifying government and provider is essential to management and the new legislation should provide for this.

I see that the use, misuse and abuse of the word 'care' as contributing to this focus on Liability in self Management. Aged 'care' implies more than the standard 'Duty of Care'.

The word 'care' no longer has any meaning. It has been seen to be so successful at manipulating minds that it is now used across industry as a cheap marketing tool. Where it has replaced 'service' as in customer service has become customer care it has become seen to mean 'no care'.

If government is going to continue the use of 'care' a clear definition of the meaning of the word should be supplied in the new legislation.

If government could move away from the deeply entrenched 'care' mentality and into a subsidised goods/services mentality this self indemnity might be legally acceptable to government for self management. It would be an asset to the tax payer and the electorate.

Ageing is expensive – of that there can be no doubt. What the government is providing especially with the recent withdrawal of so many items is only subsidising the cost of ageing. Subsidising the costs of workers, goods and services to compensate for the loss of strength etc of ageing.

Natural concomitants of 'care' are control and condescension. Words such as care, support, assistance etc are used pejoratively to create one party adopting a posture of super of superiority and control over the other – one party lesser than the other. Hence the Liability issue.

'Care' has no place in the self management of government funded subsidised services to the aged with autonomy and Liability carried by recipients. Hence it is imperative that a Section of the new Act be dedicated to the needs of this fast growing section of the aged population.

In the absence of a dedicated Section of the Act for Self Management auditors have already begun auditing Self Management with the same guidelines and standards as the fully managed model. Obviously this is fraught.

This has resulted in self management being characterised by confusion and inconsistency generally and even with different staff members of the same company.

Whilst this may not be the intended result it is the inevitable result in the absence of a Section of the Act dedicated to genuine self management with

indemnity to government and providers with autonomy for Liability by recipients of subsidised services – currently known as care.

I refer to the new government requirement that workers report on health and OH&S issues of recipients.

One reason given for this is that a recipient might slip into dementia without realising it. This might be applicable in full management. With self management there is sufficient regular contact between recipient and provider for the provider to become aware if the recipient has lost the capacity for self management. Having unqualified gardeners, outdoor maintenance workers, lawn mowers, cleaners reporting on the health of a recipient of a HCP who is self managed is an incomprehensibly demeaning insult. This insult is compounded by the fact that the recipient is not allowed to see the report. It too is fraught and open to abuse.

As has been demonstrated with NDIS and fully managed HCP once a worker knows government funding is involved the standard of work is very likely to deteriorate and the charges increase. The dynamic of the worker/payer relationship changes.

Requiring all workers enter into agreements with a business/provider and write reports on recipients after each shift is a recipe for disaster. These workers are sole traders who do not want to do this. This is a sellers market. The hapless self managed HCP recipient will be left to choose from only those who cannot fill their schedule with other jobs – in other words the dregs of the market. This is in a market where full service providers have trouble getting the workers they require.

Relating to us in a manner that is condescending, gaslighting, disingenuous or dishonest is harmful and causes significant stress, and a retrograde step for government. The recent and forecast changes to Self Management are significantly increasing the symptoms of stress to the extent that this could be costly for the government. This was the result of a recent Study by Brian Corless, psychologist, where he postulates why Self Management recipients currently are experiencing very high levels of stress.

It should be noted here that almost all of the early Self Managers and some of the current ones are refugees from Fully Managed – I use the term ‘refugee’ advisedly. Many have been harmed by full management in a variety of ways, mentally and physically and some very seriously. Many of these, including my

own, do not get recorded in statistics. I have never heard of harm occurring to anyone who is Self managing and I am a member of several online groups dedicated to self management. Self Management Saves Lives.

The new generation of the aged do not want care/support. We want and need to empower our ageing in the home thus saving taxpayer immeasurable \$. We need a mentality and services that fosters independence. We need to be able source contractors to do the work approved in a competent and cost effective manner.

At what age does a cleaner, housekeeper, outdoor maintenance person become a carer/support worker. I employed these people occasionally before the HCP and their title was their work. Now I am insulted and demeaned by government calling those who perform exactly the same work carer/support worker. This is ageist. A worker performs the work. It should not be relevant to the age of the employer/recipient.

The best way to force a person 'into care' is to persistently tell them they are being given 'care'. Support of course is just the ugly sister of care. Why does support have to be put in front of worker. The title should reflect the work performed not the age or health of the recipient of that work.

The removal of Consumer Directed 'Care' is also of concern. Science has long recognised the vast differences in humans and age is no different. In fact how ageing affects each individual may be more significant than the differences in early life.

We need the provider to have the authority to liaise with us about our specific conditions and how best to deal with those. Each individual needs different things to deal with ageing/illness. Eg. Some have digestive incompetence and need a juicer. Some do not qualify for a juicer. Some have allergic reaction of medication and topical remedies so need natural alternatives – others can take PBS items successfully. This is an very IMPORTANT part of the legislation that needs to be remedies

New legislation should provide for better instructions to be supplied at the time of assessment on our to access the system. It is called 'care' but to access any services an aged person has to be able to navigate an array of providers with their slick sales rhetoric in a undisputed shonky industry. Many people eg myself do not understand the fraught public/private funding and are misled by the word 'care' thinking that would mean they would not be lied to

and ripped off. The only pain greater than that of ageing is the pain of disillusionment caused by the use/abuse of the word care. I know this from many as well as my own experience.

The other word that is constantly confusing is 'provider'. Sometimes it refers to an accredited business to manage government funds for a HCP recipient. At other times it refers to those providing services eg cleaners etc. It is also refers to allied health businesses.

The 'provider' that is an accredited business managing funds for a HCP recipient does not in fact provide. For many this term leads to the assumed posture of superiority and they even believe the are providers. The reality is they are administrators or facilitators – not providers. This might seem minor but it is not. Words are powerful and in the osmotic process of words/thoughts/ actions/ anything that leads to an inappropriate attitude of a business that harms the aged and causes government to incur unnecessary costs and loss of funding is not minor.

I hope someone has read this and I am happy to discuss it with anyone.

Denise Abraham

