Response to Inquiry on Provisions and Operation of the Carer Recognition Act 2010 by
[redacted]

In relation to the House of Representatives Standing Committee on Social Policy and Legal Affairs inquiry into and report on the provisions and operation of the *Carer Recognition Act 2010* (the Act) in relation to unpaid carers, with a view to reform through legislative amendment – please find my submission below to different elements of the Act.

1. Limited to the Objects of the current Act, the inquiry will have regard to:

- the effectiveness of the Act and the associated Statement of Australia's Carers in raising recognition and awareness of the unpaid caring role, including its obligations on public service agencies

In response to this condition: The Act excludes the very people that provide the majority of care provision from being named as carers simply because of their association with the person who is receiving care as below:

Section 5 Meaning of *carer*

(3) To avoid doubt, an individual is not a carer merely because he or she:

(a) is the spouse, de facto partner, parent, child or other relative of an individual, or is the guardian of an individual; or

(b) lives with an individual who requires care.

In fact, a person who is in any relationship with another person on a long-term basis provides differing levels of care continuously. When you try to exclude this, you are removing from the scenario the very people that you are supposedly trying to recognise. This section should be written to either explain why these people are not a carer or to identify that the meaning relates to financial gain in the caregiving relationship (which already happens if they are named a Carer for Carer pension) or for whatever other purpose this phrase was put in.

- developments in the policy landscape at a Commonwealth level since the Act's passage in 2010

I can't answer this as I am not across all of the policy developments in relation to this area since 2010.

- the effectiveness of existing state, territory and international recognition of unpaid care (statutory or other practice)

Everyone around the world recognises the unpaid care status of carers. What do you mean by effectiveness? If you mean honouring them with one of the thousand special days on the calendar – no one wants this or cares about it.

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If you mean by providing means for respite for carers through state and territory agencies, I welcomed the SA Carer site for information and assistance with counselling and direction for services. Since this has become a "Carer Gateway", it seems it's remit is more towards assisting carers to find nursing homes and other acts associated with the end stage of caregiving.

Also, the publications produced by these agencies seem to treat everyone as though they are either 10 years old or over 90. The majority of carers are between 50 – 70 years old; educated; have left some part of their working and social life behind to provide care. Treating them as though they have been retired for ages and need to be spoken to simply is demeaning.

- how to better identify the role of unpaid carers in Australian society and the role of a reformed Act, with regard to:
    - understanding the value of unpaid care,

To understand the value of unpaid care, you need to ask how much the carer was making before they left their work, social life and other means of financial assistance in order to provide care. For example, when I retired as an academic and researcher, I was making $75,000 - $100,000 per year. I retired because my husband wanted my companionship – he knew that he was ill before we had an official diagnosis. Therefore, providing me with a $256 per week stipend from a Carer Pension would have been ridiculous considering the amount of money that I was making before. We chose not to apply for it because other people needed it more than me – but that didn't mean I didn't want my sacrifice to be recognised.

- the needs of specific cohorts such as young carers, First Nations carers, LGBTIQA+ carers, or culturally and linguistically diverse carers

No comment other than the fact that it should be clearly stated that carers for people in these categories should come from that category to provide the best type of care.

- the meaningful role that flexible workplaces play in unpaid care, and

I did not have a flexible workplace once I became a full-time carer for my husband during his illness. If I had continued to work as an academic and researcher, I would have had time points and expectations to meet. I would have had to put the needs of other people ahead of my husband's. If you are talking about flexible workplaces for a time point when elderly people gradually begin to deteriorate, that would be great but others in the workplace would become very resentful. The carer would be tired, stressed and have limited ability to concentrate on the work at hand. There *would be constant disruptions every time a mini-crisis arose or a doctor appointment had to be done.*

  - the Government's broad agenda in relation to the care and support economy, the importance of employment participation, and a strong focus on gender equity, and

As you already know, the majority of caregiving is done by women. The Government recognises this but hasn't really done anything to acknowledge the sacrifices being made by women. Instead, attention is brought to male carers, young people carers, carers from different lifestyles. Doing this diminishes the highlighting of the role that women play. If women leave the workforce to provide care for someone, they should be recognised as a hero, like we recognise our military veterans – many of whom have not had to kill anyone (thank goodness) and have not had to care for someone.

- any other related matters, noting that the adequacy of payments for carers is out of scope for this inquiry.

In Part 4 – Other matters, the next section is nonsensical and doesn't need to be in the Act:

10 Act does not create legally enforceable obligations etc.

. (1) This Act does not create rights or duties that are legally enforceable in judicial or other proceedings.

. (2) A failure to comply with this Act does not affect the validity of any decision, and is not a ground for the review or challenge of any decision.

. (3) If a public service agency, or an associated provider, is required by another law of the Commonwealth, or by a law of a State or Territory, to consider particular matters, or to comply with particular requirements, in the exercise of its functions or powers, nothing in this Act is to be taken to require the agency, or the associated provider, to act inconsistently with that law.

If it can't do any of these things – what is the point of saying so – just remove this. It seems as though the Act was created to shut people up without having to really do anything or hold anyone accountable for their actions.

In Schedule 1, the following should be removed:

Schedule 1 – The Statement for Australia's Carers

. 1 All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.

. 2 Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential. ☐

. 3 The valuable social and economic contribution that carers make to society should be recognised and supported. ☐

. 7 Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers. ☐

The reason these should be removed is because:

1) Item 1: Carers already have the same rights, choices and opportunities as everyone else in Australia because they are Australian citizens first, carers second. Putting this in this schedule makes it seem as though carers are second-class. Remove this.

2) Item 2: Children and young people who are carers are no different to any other category of carer – they make sacrifices and should be rewarded for doing so, including having their education continue and the same respites that other carers have. Since children make up a small proportion of carers (and they are in a relationship with the carer, aren't they!!!), then they shouldn't be treated any differently. People often defer to younger people when the issue with older people gets too hard. It's easier to feel good about helping younger people – but they don't provide the bulk of care and aren't sacrificing financially for the support of the person being cared for. Remove this.

3) Item 3: It's great to recognise the social and economic contribution of caregiving – but just telling people about it is demeaning without actually providing hard facts. If you really want to recognise this, then have an employment category called "Carer" – remunerate it appropriately and advertise this role as heroic rather than a drudge job. Specify in this Item how you are going to do this or what it is comprised of.

4) Item 7: This distances the actual Carer from others who are providing care by saying they are in a partnership with others in the provision of the care. No one in the care provision is better or higher than the Carer - not the doctor, nurse, nursing home, social worker, government agency – none of them are providing the 24/7 care of the Carer. Remove this.

Finally, I would like to take you down the path of caregiving for older people.

Parent/Spouse/Partner reach the age of 70. Males begin to deal with prostate cancer, knee and hip problems, back problems and cardiovascular problems. They go to doctors at the insistence of their "other" and begin the treadmill of doctor appointments for the myriad things that ail them. Their mental health begins to deteriorate because they are going deaf and, by this time, are mostly wearing glasses. They lose their sense of purpose having retired and find meaning in life diminished so get depression and anxiety.

Females from the age of 70. In their 50's and 60's women go through the horror of menopause which is only now being recognised. Yet, they put the needs of their partner/spouse/parent/children ahead of their own. By the time they are 70, they wear glasses, are beginning to have deafness as well, may be experiencing some mild cognitive impairment from the after effects of menopause. Many will have been told they have breast cancer even though they could live with it and it wouldn't kill them (*in situ ductal carcinoma*). They will undergo treatment which will diminish the quality of their life whilst still caring for their partner/spouse/parent. They, too, will get depressed and anxious.

Parents of the above are usually in their late 80's and early 90's. They have been receiving assistance from their children for the past 10-15 years in relation to grocery shopping; house maintenance; doctor appointments; social activities. In their 80's, if they haven't had the knee/hip replacement yet, they will have it then which will make it even harder for them to get around, so the 70-year old carer will also have to add gardening and house cleaning to the list of chores they have to do for this person and perhaps showering, toileting and medication management.

Meanwhile, the 70-year old male and female carer/partner/spouse is being asked by their children to babysit the next generation and to fit in these activities with the care for parents because, after all, the 70-year olds are "retired". Due to all of this stress, the immune systems of the 70-year olds deteriorate so that not only do they have the conditions identified previously, they can now add diabetes, obesity and a deteriorating immune system to the list.

At some point, the 70-year old carer(s) decide they can't handle things anymore and begin to pressure the 80-90 year olds to go into a nursing home. Except that as of this year, there aren't going to be that many nursing homes for them to go into and at such great expense that it won't be worth it.

The next suggestion will be that the 80-90 year olds move in with the 70-year olds but the 80-90-year-old will rebel against this suggestion regardless of whether they still have a partner/spouse or are now widowed. They will rebel because for the first time in their lives, they actually have an entire house to themselves to do with as they please; they have money to travel and do the social things they have always wanted to do; and they don't want to be around screaming babies and young children from the other generations.

The 80-90 year olds do however still require care. They still aren't able to do a lot of house maintenance or heavy gardening. They have lost their driver's license due to poor eyesight or the fact that they can't move their legs appropriately to drive. They still want companionship so will call their 70-year olds multiple times a day to see what is going on.

At the same time, everyone wants each other to have choice in the way they live, but the choices aren't really working out and are impacting on the carers far more than on the ones being cared for.

Finally, by the age of 90, half of the people reaching that age will have early-to middle stage dementia of one type or another as their brain cells shrink and age. This is when the 70-year olds really start to feel stressed. Do they keep the 90-year old at home until it is no longer safe? Do they start with Assisted or Stepped Living and give up all thoughts of an inheritance? Do they force the 90-year old to live with them? Do they buy a house next door? Do they try to find someone/anyone who will provide day care for the 90-year old in their home or outside of it? Who pays for it? How do they manage the care when the 90-year old resists?

Much of what I have described can and will be happening at earlier ages with the Baby Boomer generation because of their use of drugs and sexual activities at younger ages.

It may seem hopeless, but if we do make heroes out of our Carers, provide them with financial support and respite, have each family case managed so that when the stresses arise, there are ways for it to be relieved, and FORCE people to realise that nursing homes are not the answer and can't be relied upon in the future, then we may be able to provide much better quality of care for all concerned earlier and for longer periods of time.

As a person who has helped to care for members of my husband's family (3/6 had dementia, including my husband), the most important aspects to their care is routine, feeling safe, and providing emotional companionship. This needs to start early, they need to get used to strangers (such as the cleaning lady) early so the strangers aren't a threat later on.

Subsequent generations should be admonished about making their elders become babysitters out of convenience, especially now that the Federal Government is investing heavily in child care.

Then, there are those of us dealing with older parents in other countries where the sacrifice is even greater when we leave our adopted home of decades to go to our home country to try to support the older person. The financial disruptions are huge –

and as a country with over 35% of people from another country, this situation is becoming quite a brewing crisis.

The Act as it stands is shallow and meaningless. Please put some oomph into it – identify what you will really do for carers; don't categorise caregiving; create penalties for external agencies that try to take advantage.

Thank you for the opportunity to respond to this inquiry.

Kind regards
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