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Submission No. 881
(Inq into better support for carers)

To The Secretary

Inquiry into Better Support for Carers

Part i) Brief background

Part ii) Acknowledgement of assistance currently received

Part iii) Concerns for future support – Superannuation

Author

Part i) Background

I am the 59 year old single mother of a 21 year old severely disabled daughter.

My ex-husband and I separated 12 years ago, and I have no other relatives in Australia. I rent a Department of Housing cottage, and have a part-time job, but am still in the 'low income' bracket. I manage financially, but only just.

Twenty two years ago, before my daughter was born, I fully expected to have reached a certain level of comfort by this stage of my life. At the very least, I expected to be a home owner, with adequate financial preparation for my old age.

However, with the birth of my daughter, everything changed.

I had to become a full time carer for my daughter, and was therefore unable to return to my profession as an IT trainer at the end of my maternity leave. At that point, it had been envisaged that my salary upon return to work would be used as living expenses, and my husband's salary would pay a mortgage. But it was not to be, and my husband's salary was not quite enough to cover everything at that time. We hoped that maybe a couple of years down the track, we could look again at buying our own home.

Unfortunately, this was in the late 80's to early 90's, when the economic climate in Australia wasn't too good. My husband had his staff reduced from five people to two, and therefore had to work extremely long hours to compensate. He finally succumbed to exhaustion, and had to resign from his job. We were not able to receive Unemployment Benefits, as the superannuation payout and our savings made us ineligible. Needless to say, we had to live off the money which was supposed to be for our future home. Due to his age, it took about 18 months for my husband to find another job, and that was at half his previous salary. We were never able to recover from this setback, and with the added stress of coping with a disabled child, we finally separated.

So I became a 'Single Parent' on the Parenting Payment, but was very lucky to be allocated a DOH cottage near my daughter's school. (At the time of application for government housing, I was told the wait was approx. 8 years, but I only waited 4 months, as a vacancy came up due to the death of the previous tenant).

I have been at my present address for 12 years, working part-time all along, while my daughter attended the special school nearby. She transitioned to an Adult Day Care facility at the beginning of 2007. We live one week at a time, every week almost the same, and every Friday, I am always relieved to have made it through another week.

I only go out at the weekend about 3 or 4 times a year, as looking after my daughter and working, leaves me far too tired to do much more than attend the odd birthday lunch. Holidays don't happen, and I need to work 50 weeks a year to manage financially. My ex-husband has been diagnosed with terminal cancer, so in the near future, I will be in the precarious position of having no one to look after my daughter's needs, should anything happen to me. This is only one of many things, which often keep me awake at night.

The above is a summary of how I came to be where I am today, but there are no two stories the same. There is such diversity in the situations of carers, and there is also a huge range of different disabilities. Two disabled people with the same condition, can differ enormously in their presentation of symptoms and degree of dependency.

Part ii) Current Assistance

I am very grateful for the benefits I receive from the Federal and State Governments, and count my lucky stars I don't live in Romania for example, where the care and treatment of the disabled is next to non-existent.

I receive a great deal of assistance, and know of many others who also receive these benefits.

Eg. Carer's Pension and Allowance (includes pharmaceutical and phone allowance)

Subsidised Housing through DOH

Discount on Electricity and Phone Bills

Exemption from Vehicle Registration fee

Health Care Cards for my daughter and myself (allows subsidised medications and

Reduced or bulk billed doctor's fees)

A new quarterly bonus to help with electricity bills

Disability Pension (daughter)

Travel Allowance (daughter)

DADHC funded Day Centre package allowing 5 days care from 9.00am – 3.00pm

For 49 weeks per annum, approx. \$46k per annum

PADP (Program of Appliances for Disabled People) through Hornsby Hospital, has

Provided several customised wheelchairs at approx. \$10k each, suctioning equipment

At approx. \$2k, a hoist at approx. \$4k, an oxygen concentrator at \$100 per month,

And continence aids at approx. \$1000 per annum

CAS (Continence Assistance Scheme – Federal) \$470 per annum allowance

Carers' Bonus \$1k pa (*please* continue this bonus, it pays my insurance policies)

The above adds up to quite a substantial amount, but it **does not** equate to the cost of a person in full-time residential care. So while I am grateful for all this assistance, I am still saving \$1000's for the State and Federal governments. I would be devastated if I had to put my daughter into full-time care, as I love her dearly, but I thank the government for their help, which allows me to keep my daughter at home, with me, where she belongs.

Part iii) Future

One of my biggest concerns is that I have no superannuation.

I left the workforce long before it became compulsory, and my employment is on a casual part-time basis, which is all I can manage, as the majority of my time is taken up with being a carer. If my daughter dies, I will become almost destitute immediately. I am not getting younger, and while we survive with our current benefits and my part-time wage, should I have to give up work for any reason, there is nothing to supplement whatever pensions apply.

I firmly believe that being a 'Carer' is a legitimate occupation, and should attract a compulsory superannuation benefit from the employer, in this case, the government. It could be argued that carers are de facto government employees, as we keep our children and elderly parents etc., out of residential facilities for which the government usually provides funding. I once heard a figure of \$7k per month to keep a person in care, about the same as keeping someone in jail, yet benefits paid to carers are nowhere near that amount. So why doesn't the government, State, Federal, or both, create a superannuation scheme for carers who meet certain criteria eg. Single, or married but neither person able to work, or being of a certain age etc.? The carer could also be a contributor to the scheme, however much they could manage, and it would encourage saving.

There **must** be something which can be done to allow carers and their charges to be able to continue living in the community with a reasonable income over and above the pensions. A superannuation scheme will also allow some peace of mind for a carer who loses their child, parent, sibling etc. for whom they are caring. We sacrifice a normal working situation in most cases, yet there is currently no scheme to give us the dignity of providing for the future. I would be happy to make a contribution of some sort, to any scheme which gives me some peace of mind, but anyone who is unable to contribute, should not be penalized. Carers should have the right to be treated with equality to all other workers in mainstream Australia, with a fair and equitable Superannuation Scheme.

There are many other issues I could raise, such as help with wound care dressings, which currently do not attract any funding. However, I feel that the one common factor for **all** carers, is the need to feel some security for the future. I trust a suitable superannuation scheme will be part of the outcome from this inquiry.

Yours faithfully