

To Whom It May Concern

I am writing in submission to the inquiry into the recognition of unpaid carers.

I am mother to two young adults, one of whom has complex diagnoses that impact his cognition, physical abilities, and social functions. He is 27, but according to psychologist reports, will be forever 6. I want the committee to understand that disability and the care of someone with a disability has profound limitations, which include social impacts, employment impacts, relationship impacts, psychological impacts, and socioeconomic impacts to name a few.

When my son was 3 and a half, he was diagnosed with [REDACTED]. Age 8, [REDACTED], and on being assessed to go to high school, [REDACTED]. We are grateful to be in receipt of NDIS funds as we are slowly working through complex issues in the goal of having my son become somewhat independent.

When he was 7, my husband checked out. I think you will find that the ratio of single households that include disability are much higher than those without. I read somewhere that the rate of divorce amongst families coping with a disability is 85% - I have not checked this fact, however I know many single mothers with disabled children in their care. My extended family structure is non-existent so I have little help from outside my small family.

My submission welcomes the recognition of unpaid carers, but I truly hope it is being heard in a view to recognising that unpaid carers require equity. I say equity, not equality. In the 20 years I have cared for my son (and daughter) alone I took the initiative to turn my BA into a teaching degree. This took me four years to accomplish part-time, as my son's needs rightfully took precedence. I did this degree and took on additional debt in the view of being more able to provide for my family. This whole process was incredibly challenging. At every opportunity for employment, I had to measure my commitment to both my son, and the job, so as not to let anyone down.

After 6 years in daycare teaching, as I could not commit to the hours required in a primary school, I fell upon the opportunity to teach a part-time load in a discipline I actually loved - the arts. My son attended a social program three days a week while I taught. Please realise this means I got no respite other than going to work. The balancing act that came with juggling my son's needs, my school and 630 students' needs, and my well-being, finally took its toll in 2019 when, on attending the GP, I was diagnosed with 'carer fatigue' - the GP's terminology, not mine. I caught a virus from a student and went down with pneumonia.

Before I say what I am about to say, I acknowledge the inquiry is not focusing on the adequacy of remuneration for carers. My opinion does not center around the amount carers are paid by the government, merely the inequity that ensues when the government treats a carer as a 'welfare' recipient.

On the introduction of the NDIS, services providing respite or household assistance started to appear. The amounts the agencies asked for these services seemed very high to me, as a carer who was given an amount per fortnight that would amount to 11 hours pay if I were a carer in an agency's employ. This is not where I take umbrage, though. I take absolute offence at the idea that my job as a teacher somehow cancels out my job as a carer. What other second job affects a first job to the extent of fifty cents in every dollar? When sitting down and looking at my workload and the amount of energy it took to supply 630 students with an arts curriculum, and calculating that I was only \$260 a week better off for my hard work - work that took more from me than what it gave, even though I loved it. I realised there was no way 'up'. I realised that I was killing myself and that my work as a carer, even though I was still providing the same 24/7 care for my son, was diminished, because I had taken the initiative to get a teaching degree and to strive for more for myself and my family.

I would welcome the recognition of unpaid carers as having a job - they care. They do not receive equitable remuneration for their labours of love, because the assumption is that their familial relationship to the person being cared for diminishes their right to equitable remuneration. I am not arguing the adequacy of the carer payment, I am arguing for a carer not to be penalised when they work themselves into positions of employment outside of their caring role.

Each fortnight I had to declare my income and hours outside of the home (no more than 50hrs a fortnight), to Services Australia (formerly Centrelink) and each fortnight my wage from my first job (caring for my son 24/7) was impacted 50c in the dollar for every dollar over \$170 (approx.). Now, there is a push to get carers back into the workforce. There is no incentive to be in the workforce. One cannot work harder to move themselves up because of the inference that a carer pension is a handout, not a wage. Yet, the government relies heavily on the unpaid carers of Australia and has created a wage structure (that is inequitable) for paid carers.

The government spends money on supporting carers through the "Carer Gateway". Since leaving my employment to care for my son, I have had counselling and been supplied a clothes drier by the Gateway. As much as I am grateful for the assistance I have received, it leaves a bitter taste in my mouth, because had I been 'allowed' to keep my payment and my wage, when I was doing the work in both areas to earn the money, I would have not needed assistance from the Gateway. I would not have been stressed financially to the point of feeling hopeless. I would not have been overworked because I could have afforded services to lighten my load. I could have afforded holidays to refresh, I could have afforded to live within the community my children were raised in rather than having to buy a ramshackle house in a small country town.

The system deemed me a charitable case, but even when I used my initiative and tenacity to raise my family up, I was confined by rules imposed on me that were made under the assumption that the carer pension is a 'wage support' payment, when in fact, it should be a wage full stop. Carers are further impacted with the inequity of watching someone come into their home and be paid upwards of \$35 an hour to care, when they are not afforded that opportunity because of their familial links - the assumption that your life should be impacted on all levels because you are related to the person with a disability is offensive, because the government has it both ways!

The inference that they don't have to pay the carer an equitable wage because somehow their blood connection punitively infers an unpaid servitude, and that this servitude restricts them from earning the same rate of payment as a paid carer is highly offensive, demoralising and destructive. Then to see the push to get carers into paid work befuddles me! So you push the carers who are doing most of the caring (unpaid) into the workforce, where presumably the carer payments will go down due to the impact of the 50c in every dollar rule, whilst replacement carers get \$35+ an hour to do the same work. The privatisation of the caring role and the building of the caring industry negates the value of the familial carer. At all angles, the familial carer is devalued and diminished, while the care industry - which, might I add, is severely flawed in standards of quality and education - only grows, and negates the role the unpaid carer is fulfilling.

It would be only right if the inquiry could make the following recommendations that:

- i) A carer payment be made in recognition of the work unpaid carers do and the invaluable contribution and sacrifices they make to ensure so many Australians are cared for in loving, caring environments
- ii) The work done by unpaid carers is indeed work which deserves equitable remuneration
- iii) The carer payment be no longer affected by any secondary employment if the carer stays within the less than 50 hours outside the home stipulation currently attached to the reporting of income
- iv) Carers must still report the hours outside the home (as this would ensure that true carers receive the payment)
- v) Unpaid carers be recognised as valuable in terms of their familial role and connections to the person being cared for
- vi) The unpaid carer be afforded the ability to earn carer hours from their charge's NDIS package - even if it was a limited amount
- vii) Some sort of scheme be instigated to ensure that long-term carers have a form of superannuation or a guarantee of a pension in recognition of their service

I would like every person on the committee to ask themselves the following questions:

- i) If I were to become a carer by necessity, would I like to be valued for my contribution?
- ii) If I were a carer, would it be equitable to me if I was prevented from earning the money I earned?
- iii) What other second job subtracts 50c in the dollar from the first job? If this were happening to me would it feel punitive?

- iv) Would it be equitable to me if someone could enter my house and be paid far more than me because my caring role is punitively not deemed worthy of equitable remuneration, simply because of familial ties?
- v) Is it reasonable to rely on an unpaid workforce while limiting their earning capability?
- vi) How would it feel to not be allowed to earn an equitable wage from my employment?

As a carer who has worked hard to try to rise above my situation and failed, I need you to know that any 'help' the government supplies to carers is valued, but would be far less necessary if carers were allowed agency over their working lives.

I thank you for the work you are doing to inquire into the unpaid carer and hope you are being suitably paid for your endeavours.