

Submission No. 452

(Inq into better support for carers)

From: Sonia
Sent: Thursday, 26 June 2008 2:17 PM
To: Committee, FCHY (REPS)

A.O.C. 2/7/08

Subject: Carer submission

Sonia

26th June 2008

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am one of the 2,800 people who receive the Carer Payment (child). According to National Welfare Rights (2007) this payment is one of the most difficult to obtain yet it was given to myself and my 18 year old son, without question, so does this not highlights the degree of need my child with a disability has. Yet presently there is absolutely no support for me. I have been unable to gain any respite yet I am a single mother with no extended family support and four children to care for. I look after a profoundly disabled, high medical need nine year old child called Alec and can only do it with the help of my 18 year old son.

I am just like everyone else in the world, I wanted a baby. I don't smoke, drink, take drugs and eat well. I am educated, intelligent and there was no reason why but the pregnancy just went wrong. It could have happened to anyone of you. Twins were born, one of which had a profound medical condition causing a cascade of events that have changed my life forever. My husband left, my sustainable wage decreased to the measly Carer Pension (child), I had to give my ex-husband a 40% property settlement no allowance could be made for my child's disability in the court, my new \$300 a week mortgage was now more than my Centrelink payment, so I needed to cash in all my assets such as my superannuation, shares etc to help pay for all the house and car modifications, medical equipment, therapist and specialist appointments medications, aides etc, etc. But this list is forever growing and very quickly after 20 years of working I am struggling to make ends meet.

You may say to yourself, what do I do all day? My son requires me to care for him 24/7. You can never shut the door as he relies on me to manage his airway. His bed is right beside me. I get very little sleep as I am up hourly, and am very tired all day and now after nine and a half years I would call my tiredness, chronic. If I need to do something big such

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as go to the shops I get what the doctor calls a tension headache (very similar to a migraine, vomiting etc) that can last for 5 days and is very debilitating so my 18 year old son takes over. I don't go out socially and the thought of a holiday is only a distant dream.

What I find very interesting, despite that my son, Alec can not speak, vision impaired, tube feed, breathes through a tracheostomy, confined to a wheelchair, reliant on me for all his activities of daily living, **he is not considered disabled by DADHC**, he is medical? Yet I have not even yet begun to mention all his medical problems as I thought that the above would be enough. Due to this label, we are not entitled to any help. We are not entitled to any respite either as he is considered not having an intellectual disability yet he cannot read. I live on constant red alert as what makes his disability different from many other disabilities is **I can never close the door** as it only takes 3 minutes for irreversible brain damage or death to occur. The cynics may say why don't you just let him go, but this is a moral judgment on your behalf and no-one has even won in a court of law that their birth, caused a wrongful life.

I do however realise that the lay person cannot look after Alec as it requires special training such as a registered nurse to maintain his airway, but does not this exaggerate the need for help as the neighbours, friends etc cannot mind him. It is well documented that caring is physically demanding and a determinant to health (AIHW. 2004, p. 16) so without help the only other option would be to place this financial burden back onto the tax payer and surrender his care?

I have tried extending myself beyond the welfare system but the work force is very limited as you become very unreliable, tired and the constant role of caring makes your own health suffer. I thought I would try and do some more study online to gain access to a more appropriate field of employment where there is need for workers for a limited period a week such as nursing. Yet the only way I can leave my house and do anything, is to get my older son to mind Alec. However, firstly, is it ethically correct to put this burden on an 18 year old child, depriving him of his own plans and dreams, and secondly, what if in-eventable mortality occurs while in his care, could an 18 year old live with the possible feeling it was his fault. But if I do not put him in my older sons care my attempts to attend the needed exams and later work, is hindered as no other help is available. Plus will working a few hours put me in a deep sleep where I won't hear changes in Alec's breathing and fail to administer oxygen, suction or reposition placing his life at risk.

As there is no help available for me I will just have to learn to cope with burnout and living in poverty. There will be no opportunities for me to gain assets, advance in a career, or contribute to a superannuation fund. Instead the long hours and high costs associated with caring forces me into a life of stress and financial burden.

I would just like to add the need and importance for the continuation of the Carer \$1000 and \$600 Bonus as this is a form of recognition and empowerment to us that the country does appreciate our hard work and the government actually recognises what we are saving them. The Australian Institute of Health and Welfare (2004) estimates it is around \$19.8 billion per annum. I would just like to share where my \$1000 went. On Christmas Eve, my fridge full of food blew up. It is only now, because of the Carer Bonus of \$1000 I purchased a new fridge last Friday. All I ask is, could you live like this?

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for carers in Australia.

Yours sincerely
Sonia

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Reference:

Australian Institute of Health and Welfare 2004. *Carers in Australia: assisting frail older people and people with a disability*. AIHW Cat No. AGE 41. Canberra: AIHW (Aged Care Series) Retrieved from April 9 2005 from www.aihw.gov.au/publications/age/cia.pdf

National Welfare Rights. (2007). Submission to Carer Payment (child) Review Taskforce. Retrieved June 1. 2008 from <http://www.welfarerights.org.au/Policy%20papers%20%20submissions/lf4607.doc>