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Submission No. 1126

(Inq into better support for carers)

## Submission to the Better Support For Carers Inquiry

My name is Jonathon and I am a carer.

I am 25 years old, and I have been a carer since I was 16, but not officially recognised by Centrelink until I was 18. At that time, I had been carer for both my mother and my younger brother. My mother had an accident in 1999 which left her with a permanent injury, and therefore no longer able to care for my autistic brother. I, subsequently, became carer for both of them. Sadly, in 2004, my mother passed away. For most of her adult life, my mother had been taking numerous medications for various medical issues, and I personally believe that these caused a level of toxicity over many years that her body could not handle. This, however, was never medically verified officially.

Since then, I have been caring for my brother alone. Our mother's death and subsequent loss of Centrelink benefits coming into the household has left my brother and I with a gaping financial hole in our lives, especially with the Queensland State Government almost doubling our rent since November, 2004 (we rent from the Qld Dept. Housing. It's all we can afford, although lately even this is looking dicey). One really sad moment was on my 25<sup>th</sup> birthday, January 9, 2008. It was a Wednesday, and I had received in the mail that day a notification from the Queensland Department of Housing (our "landlords", effectively) that they were raising our rent for the sixth time in three-and-a-half years by \$6.30/wk.

### **The Role and Contribution of Carers In Society, And How This Should Be Recognised**

In spite of the hardship experienced by carers around Australia in similar situations, we save Australia millions of dollars each year. As carers, we choose to take responsibility for the care needs of our disabled, chronically ill or frail loved ones because, if we didn't, we'd be made to feel guilty. There's a stigma attached to being a carer. As a carer, a person is pitied socially, marginalised legally and discriminated against by almost all segments of society. People are afraid to become carers for fear of such treatment, fear that they'll never again find employment, or go to university or socialise with friends. Life plans such as marriage and parenthood are simply not a priority for some carers, for others these things are simply not possible.

Carers should be recognised for their contributions to society by an immediate increase of all Centrelink benefits by 150%. The GNP of Australia is tipped to top 9.5% in 2008, and the surplus is \$21 Billion. We can definitely afford it. We live so close to the poverty line, we might as well be under it. Also, I suggest making it mandatory for all grocery outlets, such as Coles, Woolworths and IGA, to give all holders of a pension card to receive a minimum 25% discount on all purchases. Other goods and services outlets should be made to do the same thing. Stores such as Target, Kmart, Big W, Best And Less, Kingsize Big And Tall, Phelan's Bakery, Myer, Spendless Shoes, Payless Shoes, Athlete's Foot, etc. Also, encourage the state governments to half all rent to public housing tenants with valid pension cards. The current system of calculating rent, in Queensland at least, is totally inadequate. Please, put pressure on the States to help carers!

## **Barriers to Social And Economic Participation for Carers, Focusing on Helping Carers Find and Retain Employment**

The main barriers to social and economic participation for carers are time and money. Many young carers, like myself, simply do/did not have the time or money to go to university or to seek employment. Issues such as payment of fees, transport costs, internet costs, stationary/textbooks and the like are very important issues, as is how to fit study/work around the care needs of their loved one.

### **Practical Measures Required to Better Support Carers, Including Key Priorities for Action**

Many people don't quite understand what it means to be a carer. Doctors, for example, often ask me why I'm so involved with my brother's health. When I explain that I am also his carer, they treat me like I'm his father, and my brother like he's a child.

Also, my brother's finances are under the jurisdiction of the Queensland Office of the Public Trustee, which means that the Public Trust Office make final decisions on how to handle his finances. If my brother wants to buy a new TV, for example, I have to obtain three quotes and tell the PTO which one I think would best suit my brother's needs. I have no help in actually going and purchasing the TV, bringing it home or installing it, I've got to do that myself. I don't have a car, and no family or friends who are willing to help me out for free. I could call Centracare Transport Services to help me get there and back, but I would usually need to pay them money that I don't have, as well as give them a week's notice.

Also, here in Queensland, the State Government Department responsible for supporting families of disabled people is called Disability Services Qld (DSQ). The Family Support Package offered by DSQ provided for a mere \$9 000.00 per financial year. This kind of funding is totally inadequate.

One practical measure that the Federal Government should, and ought to, consider itself with is placing pressure on State/Territory Governments across Australia to cut the red tape and increase Disability Services funding, perhaps by as much as 100%. Also, the Federal Government ought to relax medical eligibility rules for transport subsidy entitlements, such as the taxi discount offered by Centrelink, and make carers eligible as well.

### **Strategies To Assist Carers Access More Opportunities**

For younger carers, tertiary education is an important desire, but an unattainable luxury. We want to go to TAFE/University with our friends. We want the same access to freedoms that our friends get. We cannot afford to pay for the courses we want to do, and we are very hard-pressed to find a tertiary education institution that will allow us the flexibility we need to accommodate our loved ones' care needs. One strategy would be to put pressure on secondary and tertiary institutions to work with students who identify as being carers, allow us the financial, social and educational flexibility we need to learn effectively and work with relevant state/territory and federal government departments to co-ordinate an effective plan for the student/carers to achieve his/her goals.

Also, if the carer no longer wish to be a carer, the carer may feel financially trapped in the situation because of the very little income the carer receives. One strategy the Federal Government could try is to place pressure on financial institutions to provide macro-loans to help carers leave caring and either attend university or find work. Another would be for the Department of Families, Youth and Community Care, through such charitable organisations as the St. Vincent de Paul Society, the Salvation Army or the Smith Family, as well as state/territory housing departments and furniture and appliance outlets such as Retrovision, Harvey Norman, The Good Guys and Fantastic Furniture, to help the soon-to-be-ex carer find somewhere to live (if needed), as well as vouchers for furniture, appliances, clothing and food.

Some new carers are daunted by the prospect of looking after a loved one full-time. At first, the current services and entitlements may seem adequate, but as the saying goes, initial appearances can be very deceiving. For new carers, I propose that Carers Australia receive funding to establish a helpline for carers who require information regarding health and government services, as well as other relevant information.

Maybe I've left a few things off my list that, I have no doubt, some others may be able to suggest. All I know is that carers are the most important people in Australia, saving the taxpayer millions of dollars. Don't you thing that all that money ought to be spent on carers?

Jonathon