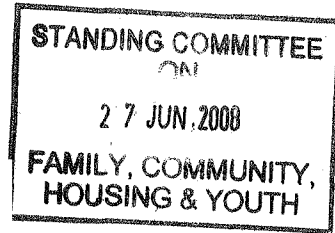


23rd June 2008



Submission No. 505
(Inq into better support for carers)

A.O.C. 7/7/08

Secretary
Inquiry into Better Support for Carers
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 a Carer for my 15 year old son with Asperger's Syndrome, Oppositional Defiance Disorder, Tourettes, Depression and some ADD. He has been having problems at school since day 1. He is now in Grade 10 and has just had a 3 day suspension for dismantling a brick wall because he was bored.

He is over 6ft tall and 125kg and can be extremely difficult to handle at times. I am his carer, but obviously his 10 yr old, 32kg little sister needs a lot of intervention between them, and she is now quite anxious and afraid to be away from me or alone with him.

Add this to the fact that I am on a Disability Pension myself for chronic back problems and at times my daughter has to be my 'Young Carer', by helping me avoid hospital by dressing me for e.g. during my bad days, my son also has to help me get into the shower which, although he is used to and it doesn't bother him, it bothers me a lot.

My caring role affects my life significantly. I have developed a Major Depression Disorder, Anxiety Disorder and have recently started having panic attacks. Unfortunately my medical options are extremely limited as I have a severe Anaphylactic Reaction to any pain killers except paracetamol, and I have had psychotic reactions to many anti-depressants. Therefore I must rely heavily on organizations such as Carers Queensland for counseling and emotional support, not just for myself, but for my children as well.

An area which particularly stresses me and the children is when I am admitted to hospital (and I will only go when I cannot move at all) is the lack of appropriate In-Home Respite. This has been for periods up to 4 weeks at a time before I can walk adequately and go home ASAP. My family has become so stressed at taking care of my children during these times, that they have all advised me they cannot do it for more than a couple of

days, even then, it is just my daughter. My son must stay at home although I phone him regularly and family and neighbours do check up on him. He doesn't like to be home alone at night and has often phoned me at late hours to talk about TV shows as he doesn't know/want to express his discomfort. Ironically, he wants to stay at home, no-where else, because of his disabilities. These circumstances have forced me to discharge myself from hospital after a couple of days, so that I can get back home and try and maintain some degree of normality for them. I have been forced to do this on at least 2 occasions over the past 6 months or so.

Our social life is virtually non-existent. My son's ASD has alienated him from most of his family so we cannot visit them as a family, and some members are quite hostile towards us/him because of his bluntness and language. I can usually speak to my sisters on the telephone so to avoid confrontations. Because I side with him, (although I do not agree with him) this has caused much tension in family life.

While we have finally obtained DSQ family funding, this took a few years of stress, time and paperwork to obtain. Ironically, I have funding for a cleaner, yet no-one wishes to do the work for DSQ as they say that payment takes too long, so I continue to struggle with basic housework myself, causing further pain and injury. There is a strong lack of available services within Mackay, in particular a Male mentor/support worker. I wish we had a 'Big Brother' programme offered in Mackay in which older mentors (who are thoroughly screened) take a personal issue with a child and do and teach 'brotherly' activities with him. I am often sent 'new' workers who do not have much, if any training at all. I have seen them arrive with a page telling his name, his disability and address. That's it, no training, advice on his condition. I usually have to provide this myself. I believe the quality of trained, qualified support workers needs to be raised considerably, as most of the workers I have received over the years do not know what to do with him and are working purely for \$40 an hour or so that they are paid. I am not sure how much of this money actually ends up in the pocket of the workers but, I am sure that a good portion of it is gobbled up in administration...the bulk of the money does not result in the realization of services to the carer or person with the disability.

I believe I contribute to society by saving the government many thousands of dollars. Instead of having him in a Special School, he is supported in a Public High School in which I am closely associated with the SEU teachers and am in constant contact with them. However, there is a severe lack of Special Education Trained support teachers at his school. He wishes to be with me 24/7, will not take a school bus due to constant ridicule and humiliation experienced from other children on the bus and will not inform the relevant staff as this only has the effect of making the bullying worse therefore, I must drive him to school.

These types of issues have caused me extreme financial difficulties. As I am on a disability pension myself, my income is fixed and with the extra petrol prices I am forced to pay so that I can take my son to and from school are now quite substantial. He will not tolerate any type of bus transport so when he does wish to go somewhere, I have no option but to drive him. This may not sound like much, but when I am in so much pain,

he has to help me into and out of the car, and I have to borrow my sisters automatic as I cannot change the gears, the extra costs involved are high.

I have been forced to live on credit card to make ends meet as the cost of living in Mackay has skyrocketed since the 'Mining Boom', petrol, rent, groceries for e.g. I have been affected so much by extreme financial difficulties that I have had to declare myself bankrupt.

Thank you for taking my views into consideration as part of the Committees Inquiry. I look forward to reviewing the recommendations you make in order to improve support for carers.

Yours sincerely

MARGARET