Sent: Thursday, 26 June 2008 4:27 PM

**To:** Committee, FCHY (REPS)

Subject: FW: Submission: Better Support for Carers

Sent: Thursday, 26 June 2008 4:01 PM To: Committee, Reps (REPS) Subject: Submission: Better Support for Carers

Clerk Assistant (Committees) Inquiry into Better Care of Our Carers House of Representatives Standing Committee on Family, Community, Housing and Youth. Parliament House CANBERRA ACT 2600

26 June 2008

RE: Inquiry into Better Care for Our Carers.

Dear Sir/Madam

Thank you for the opportunity to make a submission.

I would like to offer you information about our personal family situation related to being Carers.

I am the mother of two young boys, 12 and 8yrs. Both our boys had Autism Spectrum Disorder diagnosed at 2yrs 8 months. The older child is severely affected and also most likely has a significant intellectual disability (due to the severity of his Autism we may never be able to accurately assess his IQ) and attends an Education Support Centre. The younger child is in a mainstream classroom and his teacher has the support of an Education Assistant 0.6 of the time and he requires significant modifications to his curriculum. The everyday care of these boys is huge compared to "normal" children of their age. Most people do not realise the extra work of showering, toileting, mealtimes, supervision, medical appointments, therapy etc that is required for children with disabilities even for children aged 8 and 12 who are usually much more independent than the younger ones. Our two boys will both require constant supervision and care for the rest of their lives.

Due to the assessed LACK of severity of our children's disabilities compared to the criteria

we only receive \$50.30 per week for each of them in the form of a Carer Allowance from Centrelink. This is supposed to assist us with our daily EXTRA expenses due to our children's disabilities. It is not to replace any income potential I have as the second income in our home. The two boys have a Health Care Card - I don't - luckily for us my husband and I are rarely sick. Luckily the boys are rarely sick either.

 $^{*}$  I am a Level 3 Head of Learning Area employed by the WA Department of Education and Training. I have the capacity to currently earn \$85540 with my current employer however this is impossible with the caring role I have responsibility for. I was working part time until the end of Term 1 2008 and even this was too much for me - my doctor has placed me on sick leave. I am stretched to the hilt. I am very likely to resign in the near future s I can not do it all and survive - I am barely surviving now let alone returning to work part or full time. It is almost impossible to get carers for before and after school care, for when I have professional development and school work commitments on school holidays, after school, in the evening and on weekends. On school holidays when I should be able to have some respite getting carers is almost impossible. I have one family member who I can call on occasionally, who already works full time and has a family herself. We have no-one else! Other than this one Angel, I am then begging organisations like ACTIV or Commonwealth Carers Respite Centre for help. Often this doesn't lead to any respite as their recruitment of carers has become more and more difficult in recent times. Having two children with disabilities means I need one very competent carer to care for both of them or two carers which becomes extremely expensive.

In addition to this caring role I am also the primary carer for my 70 year old pensioner mother who lives with us full time. She requires help with medications, personal care, meals, doctors/hospital appointments and her financial affairs as well as social/emotional care. I am not prepared at this stage to force her into care accommodation as she is gaining physical and emotional support from our family that she wouldn't get in such a facility IF we could find a place suitable. I receive the same pittance of \$50.30 per week that I receive for the boys to assist me with caring for her. Again this doesn't replace my possible income.

That's a grand total of \$150.00 per week to replace my salary of approximately \$1250 a week I could earn if in full time employment as a teacher. Not a very fair trade is it??

Of course, me not having an income will make our lives more difficult financially but we have no other option at this stage. My husband and I have refinanced our home twice over the last 10 years just so we can survive. Due to early intervention commitments for both children I was unable to work for 6 years from 1999 to 2005. I have received the \$600 Carer Bonus payment each year over the last few years which has been used to pay urgent household bills - not for recreation I can tell you!!!

So what will our government - both federal and state offer to make my life better as a carer?

I would value an appropriate assessment of my "capacity to earn" and a suitable replacement "income" be offered to me - I am, after all saving the government a lot of money looking after these three loved ones in my home rather than in state funded facilities. I would appreciate special recognition of the contribution I make as a primary carer by having my mortgage interest rate held at a much lower level - our family will never have the capacity to pay this off on one income. I believe it is essential that increased funding be given to large organisations such as Disability Services Commission, Autism Associations (and other large organisations supporting disabilities/syndromes) around Australia, CarersWA, ACTIV, IDentity and Commonwealth Carers Respite Centres. Grants

should be made readily available to other not-for-profit organisations for local community activities and projects to support families like ours. These organisations and many more give outstanding value for money support and respite opportunities to thousands of familles every week - they keep us from falling apart.

A couple of other strategies that do not affect us but we see as URGENT: funding is urgently required to support the Royal Flying Doctor Service throughout regional and remote WA; heavily subsidised, payments or FREE accommodation and transport for families with loved ones requiring medical treatment or therapy services in Perth or larger regional centres; counselling services and early intervention provision urgently required in regional and remote WA, respite services and respite accommodation in regional and remote WA.

Significantly inter-related to this issue is the priority the government gives to diagnosis and early intervention for children's intellectual and physical difficulties, schooling priorities, hospital and medical funding and the care of the elderly. For our family these factors have significantly affected my ability to function as a carer.

So many of our family, colleagues and friends have loudly commented how they wish the current Rudd Government would realise that they would rather their taxation payments be used to support families like us than to give money to people here from overseas and those BLUDGING on Centrelink payments.

I hope you have the time to listen to individuals like me. My life is on a knife edge, tip me over the edge by not increasing the support you offer and you risk being 100% responsible for looking after these three special people for the rest of their lives.