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

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.

As a Carer, I feel that my role is a stressful one with no end in sight. If our special children were not Cared for by us, the financial burden to the government and the wider community would be unfathomable. I do not wish to institutionalise my child, nor do I expect pity or thanks for Caring for my Disabled child. However, support for my family and I would assist me more than words could ever express. I feel that I don't know what the future holds for my Disabled Son. I need to know that the future of my Disabled child is taken care of and that he will be provided for long after I have gone. If I can have that, then that would allow me to have greater piece of mind and less stress when I think of his future.

I realize that as a Carer I am faced with a multitude of problems, these include:

- Illness / Depression: I am susceptible to falling in and out of severe depression because of the mammoth stresses that a Caring role does bring. I am sure you would agree, dealing with depression is difficult for any individual, but it is amplified for those in a Caring role. As a Carer, you can't afford to get sick or unable to cope. If you can't be the "Carer", then who is there to take over for you?
- Stress: The stresses we face as Carers are many and these are on top of the every day pressures that general society faces today. Things such as rising petrol costs, rising interest rates and the rising of general living expenses. If you have the extra Care requirements that go with Caring for a person who needs tube feeding or medication then you have even more financial stresses. It is not like food and medication items are luxuries you can do without. I am betting there are not that many Carers that have any or many luxuries they can afford for themselves. In order to keep some sort of balance in life, we all need a little "me" time on a regular basis. We Carers are people too, we need a break too. Just like everyone else, we like to feel the sunshine on our faces and wind in our hair, but do we get to do this as often as we should? No we don't. Why? Because we don't have anyone to take over the Care of our special people for us. So we seek out organisations to help us get some respite and help. What we get told is that there is nothing available due to lack of funding or you will be put on a waiting list or someone will call you back and our call just isn't returned. And if we are lucky enough to get put on a waiting list, do any of these people bother to check up on us to see if there is anything else they can do to help? No. Do any of these people refer us on to someone else who can help us? No. Do any of these people make some enquiries on our behalf because we are clearly in need of help and completely stressed out? No! A build-up of stress usually evolves and develops into depression, this might mean treatment such as counselling or intense therapy and or medication. This all costs time and money. This extra financial burden coupled with having to find the time to do the therapy all adds up to..... yep you guessed it.....more stress!!! And here we go stuck on that revolving door again!!!!

- Understanding: I wonder if the people that make the decisions for us Carers, as well as those we care for even understand what it is like to be in this position. I mean, do they know what it is like to repeat yourself all day every day for years on end, the same thing? You end up feeling like you are getting nowhere after years of the same thing? It's a bit like a broken record. It is frustrating and can wear you down when you are stressed out with all the other daily things you have to contend with. Imagine Caring for someone all their life but it takes 5 or more of their years to make up for 1 developmental year of a "normal" person. "Brush your teeth, wash your hands, you are in quiet time for behaving badly, get ready for school, you need time out, don't hurt the dog – you need to be nice to the dog, take your fingers out of your mouth, you need time out, eat your dinner with your utensils, clean your bottom, use soap to wash your hands, you are in quiet time for behaving badly, your shoes are on the wrong feet, your clothes are on back to front or inside out, don't hurt your Sister – you need to be nice to your Sister, you are in quiet time for behaving badly, concentrate on what you are doing, you need time out, speak clearly, use your manners, you are in quiet time for behaving badly....."

Think about all the therapy a Carer needs to do with the Disabled person to ensure they have a better life / a better future. Has anyone even looked into the different challenges that face Carers today? I watched a Four Corners ABC1 program called "In My Shoes" on the 12<sup>th</sup> May this year (I don't understand why it wasn't on a bigger commercial TV station for more people to see??). It was a fantastic look into the world of Carers and the challenges that face us. (see attached program introduction information) I was left feeling nothing but empathy for the people in the story. I also reminded myself of how very blessed I was that my beautiful special needs Son did not currently need any medication, or have any fits and nor did he require tube feeding. Take a walk in our lives. Feel what we feel, see what we see, deal with what we deal with and I bet that you will see that we Carers are not getting the understanding and support we need and deserve.

- Not being involved in the decision-making, having important help taken away: I feel as though the government organisations out there have a lack of genuine care for the Carer. When I was first put in the system as a Carer, there was such a person as a "Social Trainer" through Disability Services. (see attached document that was provided to me early on) Wow, how I loved those visits, I learned how to be a Carer to my Disabled child, being taught invaluable skills as well as having someone to talk to and confide in without any prejudice. These Social Trainers had compassion and a great understanding of what it took to be a Carer, they were such a huge link for the Carer. I don't believe that we have anything like that now. A huge shame in my opinion, it was such a beneficial union. DSC (Disability Services Commission) no longer has its "Audiology" hearing services for our children now either. I found this out by calling up to make an appointment for my Son. Why are all these decisions being made without consultation or consideration into the needs of those who need them and use them?
- Respite: I believe that the biggest reason there is very little or no respite is because there are not enough funding resources for respite. We can't rely wholly and solely on our families and friends to give us respite when we need it. When you are a Carer, quite often it is difficult to have and maintain friendships because you don't have the time or energy to invest in them and or friends just simply don't understand the Disabled person you are Caring for and or they don't want to be or even be considered to be a Carer for your Disabled person at any time. Without respite our link to general and healthy community involvement is limited or null and void. No respite usually = stress and this usually evolves and develops into depression. And here we go stuck on that revolving door again!!!!
- Lack of Organisation: This is a difficult one, while I am grateful that there are groups out there who want to support Carers, I just don't think the Carers are benefiting as they should be. I am sure there are many reasons for this. One main reason is financial backing. I think another main reason is a lack of guidance/leadership. If there were better control of the finances, more financial support from the government and better fundraising efforts, then more could be done for Carers and the Disabled People. If the organisations had a better structure, then in my opinion, more could be done for Carers and the Disabled People. So many organisations so little organisation! They should all be lumped together under one umbrella to better serve the "Cared For" as well as the "Carers". It is hard enough being a Carer without having to sort through all the different agencies, groups, organisations, charities, government departments etc etc etc. It is left up to us as the Carer to find out what is out there for us as well as our Disabled People.

Lack of Organisation (continued): Our Paediatrician initially referred my child for early intervention to Princess Margaret Hospital and they were fantastic for the first 2 years. When my Son was about 15 months, friend of mine (that was not a Carer) told me about the DSC LAC (Disability Services Commission Local Area Coordinator) and told me to contact them for support and services to help my Son and I. I made contact with them and was told that it was their job to ensure that I was given information on what services were out there for my Disabled child and I. They told me that they were my link to everything we would need and that they would assist me as much as possible. When you first get into the system you are inundated with information. In the early days, you already find it difficult to cope with the trauma of dealing with your special child as well as dealing with the physical and emotional stresses. Now, I get inundated with many different newsletters, emails and articles. At first I tried to keep up with reading them all. I read them hoping that there would be something in there to help my Son or I. Often trying to read each piece of mail that I receive from various organisations becomes too time consuming and impossible to do. You end up filing them or putting them in the bin. As a consequence they don't have any benefit to the Carers or Disabled at all. As Carers, we don't have time to go through each newsletter and it's not because we don't want to, but we are busy trying to be Carers, Wives, Mothers, Fathers, Sons, Daughters, Friends, Physiotherapists, Speech Pathologists, Occupational Therapists, Teachers, Cooks, Cleaners and the list goes on.....

Lack of Interest: This is a very recent story. Craigie Leisure Centre is run by City of Joondalup and they have a program for Disabled Children called "Sportslink". I thought my Son was at an appropriate level to join in such a program and sent him along for the last term of 2007. He absolutely loved it, so of course I enrolled him for the first term of this year. Unfortunately though, there was only one other boy participating. I tried to encourage the centre to seek more interest and to advertise. I gave information to our school but by the end of term there were still only the two boys. I think it is disgusting that this program was left to its own devices without any advertising in the appropriate areas. There are plenty of disabled children who would love to do the program. Maybe it is financial reasons keeping people away, I don't know. No advertising was done upon my request and as a consequence, the program was not run for second term. They have told me they are going to advertise to gain more enrolments for term 3. In the mean time, my Son has been very upset that he is missing out on his sport. He doesn't understand why it has been taken away, no matter how much I try and explain it to him. I think it is a disgrace that this was allowed to happen. Why do our disabled get second rate service and attention? We have to fight for every bloody opportunity and every bit of help our kids need, it's ridiculous and disgusting. In my opinion, the program being stopped for all the wrong reasons just stinks! How would the government cope if the majority of people had to put up with the same crap we do. Letters like this would be so many and so often that the government would admit defeat and retire. The government should be ashamed of how it and its organisations often treat the Disabled community and its Carers.

Lack of Support: Let me tell you of a recent account with regard to my contact with my LAC (Disability Services Commission Local Area Coordinator). I emailed my LAC earlier this year and in the communication I informed her that I had been suffering from severe depression and was struggling with things but trying to get my head above water. I have not had any follow-up from her with regard to my health and well being. Nor has my LAC offered any respite or other help. Nor has my LAC checked to see how I am coping with my special needs child because of the depression. My LAC simply suggested that I should contact her if there was anything she could do! I reached out the best way I could and got that as a response. Not really good enough now is it? How the bloody hell would I know what she can help me with? Isn't that her job? She definitely went above and beyond to help someone in need – NOT!

While I am a firm believer that we should help ourselves, I must say that I understand why situations get way out of hand sometimes. Mental illness is a very daunting illness that has a life of its own, amazing moments of feeling great and shocking lows. I have seen the stories of people that have been faced with very similar situations to that which I have been going through. In their situations, there has been diabolical consequences. Situations where because of no support or care, the consequence was Disabled children being abused in horrific ways (sometimes causing death). Situations where because of no support or care, the consequence was the Carer resorting to self harm while trying to suicide and sometimes succeeding. People do this because they are desperate and their illness and situation has become too overwhelming and out of control. They simply can't cope on their own any more. It is purely just not good enough.

Lack of Support (continued): I consider my Son and I to be two of the luck ones. Lucky, because I know that if I didn't take myself off to get all the help I did (no thanks to any "Carer" or "Disability" organisations) things could have ended disastrously for us and they almost did on quite a few occasions. You simply feel pushed to the edge. The help that was meant to be out there for me as a Carer did nothing but fail me, very sad, but true! Moreover, the help that was meant to be out there for my Son did nothing but fail him, also very sad, but true!

- A future for our Disabled: The person whom I Care for has a few more years of school, however I am gravely concerned about his future after school ends. I have spoken to Carers with 17+ aged people to Care for who are gravely concerned for their future. Support to Carers and the Disabled drops even more once the Disabled child leaves high school. So, if the Carer was lucky enough to have been getting respite before their Disabled child turned 17, then they got even less or nothing after their child turned 17 or left school. As a Carer, you wonder; where will my Disabled child work?, where will my Disabled child live?, how will my Disabled child support themselves? and what happens to my Disabled child if I (their Carer) am no longer able to take care of them? Carers should not have to worry if their Disabled child will have what they need to survive in this world of ours. There is clearly a lack of planning for the future of our Disabled children and this creates more stress, more anxiety and more depression for Carers.

I need help with building a valuable and comprehensive overall home program for my Son, so I would like to feel as though I am contributing as much as I can to his progress. I have loads of work here I have put aside for him and I to do and I would like to build a program for him, but at the moment I find it an overwhelming task to tackle. (I am still recovering from depression and slowly getting my life back on track.) I need help with ongoing and regular respite services so my Husband and I can re-connect and spend some quality time together. I need to get help with dealing with the stresses and how to avoid depression. I need some ME time to help me get "beyond the blue" of depression. I need to know that the future of my Disabled child is taken care of and that he will be provided for long after I have gone.

I think the Government can better help Carers by gaining a better understanding of what Carers are dealing with on a daily basis and actively finding ways to help Carers. I have outlined some issues and given some suggestions above. I think the Government needs to take this far more seriously than it currently does. If the Government has not watched the "**In My Shoes**" – on **Four Corners** ABC, then it most definitely should. Ask us to be part of the decision making processes, put us on committees and for goodness sake **listen to what we have to say**.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I strongly urge you to read the attached information and get access to the television story "In My Shoes" by Four Corners on ABC. It is a total eye opener for anyone wanting to seek some understanding of what Carers are faced with. I look forward to reviewing any recommendations you make to improve life for Carers in Australia.

Yours sincerely

**Donna**