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STANDING COMMITTEE

1 - JUL 2008

FAMILY, COMMUNITY,
HOUSING & YOUTH

Committee Secretary

Standing Committee on Family, Community, Housing & Youth

P.O. Box 6021

House of Representatives

Parliament House

CANBERRA ACT 2600

AUSTRALIA

Submission No. 626

(Inq into better support for carers)

A.O.C. 8/7/08

17TH June 2008

Dear Secretary,

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

Thank you for taking the time to read through my letter & also for looking through the many topics which I hope you shall take into account which I have placed within my brief to you!

I am the mother of 4 disabled children, & briefly I shall explain about my children, & their daily needs & requirements that I face each day with! I shall start by going through from the eldest child until finally I shall get to my last child, & hopefully with that in mind, I shall be able to give you a better understanding of my daily life, & the daily requirements of my 4 children & the way our life is.

- Shaun is a 16 year old boy with multiple handicaps, which include blindness, cerebral palsy, spastic quadriplegia, asthma, epilepsy, heart defects, severe brain damage, gastrostomy fed, scoliosis, & so much more, with the fact that due to an accident that occurred a few years ago, the doctors at the children's hospital had to operate upon his left hip & leg, & he has been left with 6 inches that his left leg being shorter than his right leg. Had proper care & supervision been in place at the school he was attending, I feel that this would have been avoided! The sadness of children with disabilities face each day, just survival at times, becomes a struggle that most never see in life! I can't change what has happened in the past, but I can always hope to make the future safer not only for my own children, but for all children overall, for all children should be allowed to know they are safe & that they have as much right as anyone else, to live in a safe environment, where we all are caring & warm individuals in life!
- Shane is a 15 year old boy with intellectual disability, sight & hearing defects that sadly will grow worse as time passes! He suffers from asthma, epilepsy, & a tantrum seizure disorder, that at times sadly can be very difficult to take, for you can never predict when the seizures will take place, all you can hope for is that the child does not hurt themselves within that moment of time, for it is something no one should need to go through in life!

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- Sharona is a 13 ½ year old girl, who has an intellectual disability, asthma, she also has a very bad bleeding disorder, & has lymphomatic malformations which sadly was with her at her birth, but were diagnosed wrongly at birth, & she has undergone a few head operations when she was only 7 years of age, sadly they could not fix the problems, & she still suffers many headaches, & the loss of her right eye's vision, & little vision is left in her left eye, which sadly is just a matter of time, till we will know the outlook of what is ahead for her with her vision, & the little that is available to children with disabilities. Sharona has problems with her legs, her bones always crack no matter how much milk or milk products she consumes, she is always complaining of problems with her bones & the pain that goes through her continually!
 - Sharid is my youngest at 12 years of age boy, who has an intellectual disability, with severe sight & hearing problems, asthma, epilepsy, & problems with his feet, his legs, and his feet need bracing, but sadly on waiting lists for years, & nothing will be done to help him, for what should have been attended years ago! Are always sadly someone else's problems they say! Medically he should be catered for a lot more, but sadly all he receives is more pain!

That is a brief profile of my children, but sadly it goes deeper than all that, but as this is just an inquiry upon how to better help with the carer's side of life, I wanted you to at least know a brief side of the children as well! Sadly I can't give you all the medical side of the children, as some things remain a medical file which is confidential, but to help you understand our life, I had to explain more in detail what is our life!

- Regarding my own health issues is too complex, but I'll try & break it down for you, so that you can get an idea of what my life is like! I am a 44 year old sole parent of 4 disabled children. I have asthma, kidney problems, hypothyroidism, bleeding disorders, spondilitis, spondiletithes, and defects within my bones that make life hard to handle at times, especially go through a lot of pain upon a daily basis! I have many medical problems, too many sadly to place in this letter, but I do my best as the sole carer of my children, plus the fact that no matter what I suffer in life myself, I shall always strive to give the best to my children, no matter what happens in life!

Now it is time to address the topics that would help make our lives easier & possibly the lives of other carers & their families throughout the communities of Australia.

- All carers should be entitled to the bonus that is given to the carer payment recipients as I have 4 disabled children & could totally benefit from the carer bonus that is given! Instead I get the smaller payment that is given to carer allowance holders only, which is not fair to the life we have, & to all the sacrifices that we face upon a daily basis just for survival!
- As carers we should be entitled a receive a clothing allowance to help with buying all the extra clothing, blankets, sheets, medical supplies that don't always get covered by the allowances that are given by the payments that are received!

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- As carers we should be provided with grants to be able to give the needed items that are not supplied by the different organisations to help with all the things needed, such as beds, chairs for the handicapped, a therapy bed, or a day bed, a comfortable sofa for the severely handicapped to be able to sit with the family!
 - As carers we should be entitled to receive funds that will cover the costs of sheepskin mats, etc that help alleviate the pains of bed sores etc, because these are not provided by the organisations & are told for the parent to come up with the costs of all the expensive things that are required, but sadly too costly for the parent to afford!
 - More wheelchair disabled bays should be made available in shopping centres, doctors surgeries, hospitals, etc, for when you have a hoisted vehicle which is designed for the wheelchair, to find parking it is almost impossible, for most parking places are taken by people who hold a disabled sticker but don't require the actual disabled bay as they can walk further than just that spot, yet I need to park a long way away, as all the close bays are always taken!
 - As carers we should be acknowledged we are doing good by taking care of our family members, making more services, more provisions available so that the carer can maintain the family member always, instead by not having information available, sadly most carers have little choice but to resign the fact they can't continue with their caring, all because the needed services & equipment are never available, or even been told to the carers!
 - Housing for the severely handicapped & their families should be designed better to suit each lifestyle, & homes should be made to make life easier for the carer & the family to live comfortably! A house is only a home when the lifestyle is looked within, & made safe & happy for all members of the family.
 - Communities should adapt ways that the disabled can be made to feel welcome, no matter where they may be from!
 - Main topics that need to be addressed urgently:

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- All carers should be entitled to all carers bonuses!
 - All carers should receive bonus equipment payments to cover all the extra needs that are not met by the different organisations.
 - All carers should have available services that will aid their lives as well as the lives of their families.
 - All carers should have surprise bonuses that show the carer they are not forgotten, yet are appreciated in the community.

I have a lot more to say, & will gladly talk more upon this & other topics if you ever care to hear my views, but for today, I feel this is enough to at least get what I am trying to say over to you!

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

Yours Sincerely

Soffia

Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing & Youth