Submission No. 370
(Inq into better support for carers)
A.O.C. 2/7/08

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23 June 2008

Committee Secretary
Inquiry onto Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
PO Box 6021
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 submitting to the enquiry because I am a carer of an adolescent boy with multiple disabilities, an active advocate for carers in my community and I am employed in the disability services area.

1. The role and contribution of carers in society.

As a carer, my role involves 24 hour a day care and responsibility. As a carer of a person who cannot speak or act on his own behalf I am responsible for the ongoing supervision and monitoring of every aspect of his life and the people who work with him including his support staff, teachers, specialist care, medical and continence supplies, support funding arrangements, transport, finance, personal care, communicating his needs, maintaining and monitoring his medication. It is my responsibility to keep up to date with funding arrangements current expenditure, policy and procedure affecting his daily life including ongoing changes to medication administration laws and policies, respite policies and availability, local, state and federal government policy that impact on his life. Most importantly it is my role to advocate for my son's needs including his safety and wellbeing.

2. The barriers to social and economic participation for carers

As a carer I have faces numerous barriers to economic participation. This has happened in three stages.
Stage 1. The disability occurred due to an assault. At the age of 7 months my healthy baby boy was shaken and left with global brain damage, cerebral palsy, left side hemiplegia, intellectual disability , loss of ability to speak, and blindness due to retinal detachment in both eyes. For the first 3 or 4 years I was mentally and emotionally incapable of caring about anything other than my baby. He needed ongoing specialist appointments, hospital procedures and intense early intervention. I lost any sense of what my life was about and only prayed and hoped for a miracle. The legal processes and conviction of the offender took three years and during this time I obsessed over every second of the day he took my sons life looking for an answer, trying to understand why this had happened. Remembering the last time my baby could see me.

Stage 2 . I tried to get my life back on track. I tried to study and gain new skills but I was constantly running from appointment to appointment and getting calls from the school about his my sons behaviour. I was always taking him to the doctor and Department of Human Services (DHS) tried the behavioural intervention services team, but nothing helped. Not long after his 9th birthday, he had still not yet slept for more than 2 hours at a time in his whole life and the high doses of antipsychotic medications given by doctors with no answers was not having any effect. He cried he growled he screamed and kicked and pinched. All I could think of was making him shut up.

I had not slept properly in years. I would turn up the TV really loud, ignoring my poor daughter and putting earplugs in just to block out my sons screaming. I started thinking the only way to make it end is to shut him up, on more than one occasion I put my hand over his mouth to shut him up for just a minute and I would think what if I just held it there, the nightmare would be over, he wouldn't suffer anymore and I could go to sleep. I knew I was in a dangerous state and I had to get him away from me. I was a single mother and would have no contact with my sons father.

I woke up one morning realising what it had come to and the guilt of not being able to protect my baby again (the first time when he was assaulted) and now again because I was the one who could hurt him was over whelming, I cried uncontrollably. I couldn't stop the pain felt worse than anything I have ever experienced in my life. I left him in childcare at a local school holiday program. I refused to collect him for his own safety. I was inconsolable and continued to cry for hours and hours I couldn't control the crying anymore and I was afraid.

I had been begging for respite, we had a case manager, but we had received no help. The doctor called the case manager for help, but still no respite, no child protection services nothing was available to protect my son.

Stage 3
Department of Human Services managed to find money when they realised I would not collect my son from care. Then my life changed. A Department of Human Services worker started looking at my son's behaviour and suggested a child psychologist. There was one meeting with seven different professionals all keen to find an answer to his behavioural problems. It turned out to be something as simple as temporal lobe epilepsy, he had been having seizures continuously for years and no body recognised it, not even the medical professionals.

It is really important that you know about what I went through because sadly I have not met a carer that hasn't been through the same emotions and the same lack of support when they have cried out for help. I have heard at least 12 stories like mine just in the circle of carers that I know. Try to imagine what is going on in the homes of all those families with a child with a disability that cant get the support they need

Once my son got the proper treatment he started sleeping though the night so my daughter and I did too. He got respite on the weekends and I start working part time.

That was seven years ago, now I am married I have a 3 year old and I work full time, I have completed another diploma and I support other carers in the community. But I'm waiting again because at 16 my son has no care available in the school holidays. It's a week before the holidays start and I have to work, I have asked Department of Human Services for a school holiday program in the area for teenagers for the past 6 years and I'm still waiting. I cant afford to not work, I have a mortgage and a family to care for. Because I am not getting the support I need to care for my son I again have to make a decision between caring for him or caring for everyone else I love.

2. *The practical measures required to better support carers*

As a carer I need help with care for my son during the school holidays so I can keep my job. There is no program for teenagers with a disability and he cannot care for himself.
There needs to be a strategy to address accommodation services. When I die I want my son to have a home he can live in for his life where he is cared for. I am happy to sign over whatever I can earn and save in my working life to care for him when I no longer can.

RESPITE RESPITE RESPITE!!
Having a time on the weekends were I get the freedom to do what I need to do and what I want to do for a few hours has made a huge difference to my life. I can see things more clearly, I can make better decisions for my family and my future.

Current DHS respite services are ridiculous, days and times are restricted, inconsistent and infrequent. Parents have to do the drop offs and pick ups and the running around to sort out medications and forms and this makes the whole process far too stressful and impractical.

3. Strategies to assist carers to access opportunities and choices

I think the government can better help carers by providing intensive support at key developmental times in the child's life. Early intervention is so important to get the correct diagnosis and early adolescent is a really challenging time that requires reassessment of supports.

It is hard to deal with a future that means you will be stuck at home for the rest of your life caring for a disabled family member, it's soul destroying. Not enough money for even a hobby. We need adequate care before and after school and school holidays so that we can contribute to the future financial needs of our disabled family members.

Thankyou for taking my views into consideration as part of the committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for carers in Australia.

Yours Sincerely

Sally