

Submission No. 607

(Inq into better support for carers)

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Committee Secretary

A.O.C. 8/7/08

D&S

Standing Committee on Family, Community

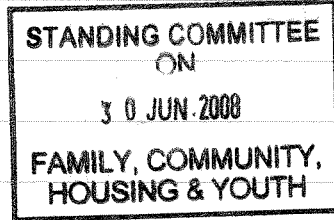
Housing & Youth

PO Box 6021

House of Representatives

PARLIAMENT HOUSE

Canberra ACT 2600



20 June 2008

Dear Secretary,

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

My husband & I both care for our 3 children, all have special needs (2 with Autism & intellectual delay & 1 with a medical condition called Bladder Exstrophy. Our son Ryan, who has the medical condition, has undergone 27 surgeries to date & well over 100 hospital stays because of his condition. Ryan is 11 years old & his siblings Kieran 9 & Eiri 8. I have been in paid employment for 28 years & when I'm not out working I'm assisting my husband to care for our 3 beautiful children.

As Carers, our roles are very undervalued.

We currently face the following problems:-

- uncertainty about our future
- a lifetime of caring for our 2 autistic children who are intellectually delayed
- no time to care for & nurture ourselves
- my husband is unable to work as we need a parent at home to deal with our children's needs. (ie. assisting at school, taking children to appts, looking after children when they are sick, in hospital etc).
- trying to hold down a job yet having to have time off when my eldest boy is hospitalised (sometimes 4 weeks & over and another 4 weeks recovery at home & requiring constant supervision.

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- We also (my husband & I) oversee the care of my elderly father, who had a stroke just before his retirement after 50 years of working.
- Becoming more & more isolated
- Relying on support workers to assist us with our children.

I think the Government can better help Carers by :-

- providing financial support to Carers.
Let's face it, if Carers didn't provide the 24 hr care for their loved ones, the cost to the Government would be enormous (ie. accomodation, clothing, food, schooling & care & constant supervision & medical care)
- provide more flexibility in the workplace for Carers who have to earn a living to pay mortgages, bills etc like me. (Eg. All my annual leave, sick leave, personal leave & family leave (which comes out of sick leave) is utilised when my children are sick or my eldest son is hospitalised. I have the option to take leave without pay - but I can't afford to do that. I have even been in a position where my husband cares for our 2 autistic children at night, both still constantly get up during the night, & I have spent the night by my son's bedside when he has been very sick in hospital & I've showered at the hospital & gone straight to work from there!)
- provide a tax break to Carers who try to hold down paid employment
- valuing carers more, because no-one chooses to become a Carer.
- Provide Business Grants to enable Carers to start up home based businesses that may also help to support their loved one with a disability.
- Provide grants for parents to attend conferences so that we can gain more information & knowledge to better support our loved ones & become more familiar with medical conditions, what to expect in the future etc (Example: I'd like to attend a Convention in the USA that organises specialist Psychiatrists, Surgeons, adults & other children who are specialised in providing care for the medical condition my son has & the opportunity to meet others who were born with the same condition. If I was an organisation - I'd have a better chance of applying for a grant than I am as a "Carer" & the Mother of a son who is living with this condition.

- Provide tax deductions/reimbursements when Carers attend workshops/seminars to better inform themselves. (Example: my husband & I attended an orientation to an organisation who helped you to form a Network to better support your loved one with a disability. There were 3 Carers in attendance & 5 representatives from Non for Profit organisations & Government departments. All of the "staff" attendees were paid to attend, & provided with work cars or kilometre allowances to be there. Us Carers don't receive anything for taking the initiative to attend. In my particular case, I had to work extra hours at work, so that I could get the time off to attend. We are trying to do everything we can to better our future - meaning the future of our children & we are not supported in any way.
- Another avenue that could assist Carers is to provide Direct Funding to them. This is taking place in the UK & strongly supported by a group called "In control". The families involved are actually saving the Govt money by taking over the hiring of support workers who assist with caring for their loved one with a disability. By cutting out the middleman, a huge amount is saved as money is not absorbed in administrative fees, govt cars, staff training etc. I'm not suggesting this would work for every family but some should at least be given an option. Another example I can share about using an agency is - you sometimes don't know who your going to get, & you don't get asked ~~how you~~ to provide feedback about the agency worker - you are expected to be grateful for what you get. When your a Carer - you have to put up with this stuff, because you don't have a choice or a second option.
- Carers also need support when we are sick. We can't afford private health insurance. Last year I had to undergo a hernia operation after enduring pain for many years. My hernia was the result of having to lift my children for many years. I had to take 6 weeks off work & spent one night in hospital. My husband & I tried to advise the surgeon of our situation & I was sent home to recuperate for 6 weeks. No-one cared that my husband had to then try to

look after me too. Well we couldn't do it - so we had to fly my elderly mother in law over from England to try to help us because there wasn't anyone else to help. We couldn't afford the airfare but had to put it on our credit card. The surgeon said to us that we should be grateful that I got to spend the night in hospital because they could have sent me home that night.

- People shouldn't assume that family will step in to help families like mine. My brother for instance is an academic & has a good job & a lovely family. He lives in the Eastern States & has never offered any support to us. Its the same as my husband's family in the UK. They all know of our situation but nobody cares. Its very hurtful & thats how families like ours become more & more isolated. We really have no-one to turn to. In an emergency what are we going to do? In the past, we have been in a position to ask for emergency respite for our 2 children when our eldest boy was hospitalised without notice. There was nothing available for us so we had to organise support (paid support) for ourselves. Sadly - money talks when you need help. ? Carers Emergency Funding - can that be a consideration?

In Summary, my husband & I have worked hard all of our lives. We want our children to have secure futures but how do we give that to them when we can barely look after ourselves. We are part of the Politician Adoption Scheme which is coordinated by the Disability Developmental Council & our adopted politician is Senator Glenn Sterle, Labor Western Australia. We joined this scheme so that we can share a part of our life & hopefully ~~also~~ educate people so that they realise that the life of a carer is not an easy one.

We take one day at a time & enjoy the simple things in life. We thank you for giving us this opportunity to provide feedback on how we think you can better support carers.

Kind Regards .

Dianne