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(Inq into better support for carers)

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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

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 have only been made aware of the closing date for this submission in the last 24 hours and respectfully request that my submission is included in the Inquiry. I would appreciate being advised if this is not possible.

The Committee is seeking a better understanding of the situation for Carers in Australia. Use any or all of the following starting points to help you write your letter:

I feel that my role is undervalued, not understood and not supported, both within the community and state/federal government systems enough to make me feel that society cares about the intense challenges we face every second of the day as full time carers to our child, and the ramifications it has on the social, personal and financial aspects of life.

I contribute to Australian society by being socially aware of what is happening in our communities, informing myself of what services are available, being politically aware and ensuring I have a broad understanding of world issues. This enables me to make informed decisions when voting at elections to ensure I am voting to help those less fortunate, rather than how it will just effect me/us and to help others understand how to access services and understand issues facing the community. I also contribute by being a full time stay at home mum, scarifying increased family wealth for a number of years until our children are at school. I also consider we contribute by not living beyond our means and causing ourselves un-necessary financial stress. I am now also a full time carer to our son who has a disability who cant not be cared for by anyone else due to extreme feeding issues with his gastrostomy tube., I feel this role leaves me dimished choices about many aspects of my life, however in saying that I have a friend who is single with a 3 year old profoundly disabled daughter who has absolutely no choice but to be on welfare and live in state housing accommodation - if this child was born typical she would not be relying on the government for any aspect of her life.

I face the following problems. I seem to be a carer stuck in the middle...not on welfare but not a high income family. At this stage in our sons life we only qualify for carer allowance and yet in a few years time when his disability becomes more apparent (according to criteria) we might qualify for the carer payment. I have a typical child also (age 4) who has missed out on 2 years of fun with her mum due to the immense stress our 2 year old sons life has placed on us, this intern causes guilt at the quality of her life.

I cant look after myself properly and this impacts on physical and mental health. We have extremely limited family support cause everyone is so busy and consumed with their own lives. Another problem I have is the stress of being responsible for every aspect of his physical, social, and cognitive learning and development, as well as running a household, looking after another child and generally providing a good family environment for everyone. This is all very the same for parents of typical children but the stress increases when weeks are consumed with Specialist appointments, therapy, early intervention and rehabilitation appointments. Its great that these services are there and I make

sure I access everything I can to help me with Spencer, but it has a major impact on doing anything else with my daughter, for myself, socializing or returning to work.

I can't fully participate in social life because the feeding regime and extreme problems we have with feeding spencer does not allow us to just take off to the park with others, hire a baby sitter, or even ask a family member to look after him. Spencer vomits violently at every feed and we have to feed him every hour. To do this requires training and understanding of the management of this feeding tube, this places pressure and responsibility on others...if a medical incident was to occur in someone else's care then we would never forgive ourselves. We have hired paediatric nurses to care for him so we can attend social events (twice in 2 years). My partner has given up all his/our recreational activities to stay home on weekends to help me look after our kids and accepts all overtime opportunities in increase our finances. We have just started to go camping again but have had to purchase a device that will enable us to charge his feeding machine while we are away.

I am financially struggling because of the increased cost of living generally and the extra money that is required to feed our son. He has a feeding pump machine that is battery powered and requires electricity, the machine uses disposable feeding sets that we have to purchase from the hospital at \$80 per box every 2 months, and then we purchase special food/formula (which is his sole nutrition) from the Hospital at approx \$100 per month, which we have to order and pick up from the hospital. He will also need nappies for significant years, which cost a small fortune; I worry about the financial stress from this.

I would like to work (full-time or part-time) but have the following issues to deal with – noone else at this stage in Spencer's life can care for him as we feel they can not feed him. There are so many appointments I choose to attend, such as early intervention...which is the key to helping kids like Spencer...that I cant return to work, if I did these appointments would have to be sacrificed and you don't get early intervention and specialist teachers, physio, OTs and Speech Therapy in child care. I can not afford to limit his learning during these early years which are crucial to his development.

I worry about my future because I am not able to maintain any skills for re-entry into the work force, I cant contribute to my superannuation after working for 15years full time, I cant contribute to the wealth of our family to help place us better financially into the future, eg for our children's educational needs. I cant study cause I cant physically attend the uni.

The things that stress me the most about being a Carer are not being able to fit everything general and extra into the week/day. Never being able to trust anyone to care for Spencer because people, even nurses find it very hard to understand his feeding issues. If we were to fully train someone within the system there would never be the consistency of care or the one to one care he needs as these things are not funded or operate this way. The little financial support I get for caring for him 24/7. \$50 per week. Being so responsible for his whole wellbeing and development - having to implement everything to experts tell me and fit it into our daily routine. The impact this has on wanting another child, we want another child but can I possibly do it with the care I provide for Spencer...will I be too old by the time he has some physical or feeding independence.

Remember that it will help the Committee to understand your point if you can support it with examples from your own experience.

The Committee would also like to hear of any ideas, solutions or strategies that will support you in providing care. Use any or all of the following suggestions for getting started:

I need help with [insert problem or issue here] and think that [insert idea] would be the best solution for me.

I need to have someone dedicated to looking at all of Spencers needs such as case management (such as a nurse from the Hospital) and this would help me because it would enable me to live without the constant stress of trying to advocate and ensure that I am doing everything possible within every aspect of his care.

I think the Government can better help Carers by ensuring that good quality respite services in the home and out of the home are provided by highly trained and qualified medical people/nurses with complimentary support workers. To get a weekend off or just a night/day and have the confidence that your child is being cared for to your standards would alleviate a lot of pressure on families who have a child with a disability in their care. Better support parents living at home with a child who

has complex medical needs. Not means test things such as feeding equipment and medical formula, just because we are not on welfare payments doesn't mean we can better afford the medical things we need on a very average one income family. To assist with the cost on incontinence aids from a much earlier age, the current restriction is outrageous, age 6 or something.

To ensure that all carers receive all the information about services and entitlements that are available to them as soon as they are identified as someone who is considered to be a carer. There are many people who go years without anyone telling them they are entitled to a carer allowance. Someone needs to have a data base of people who are carers so all the information can get to them, such as this inquiry - I should have been told about it a long time ago.

To ensure that kids are not left on waiting lists for years to get their disability package, purpose designed wheel chairs, lifting equipment in the home, educational equipment etc etc. Ensure that enough funds are supplied for inclusion support programs in child care centre's and allow for those kids that need 1:1 care to get it until they don't need it anymore.

I acknowledge that this is a bit of a 'bla' but I simply don't have the time to reread and edit this information to ensure it's a well structured document covering all the issues I see facing us and the other carers I know. I do hope that the above does help in some way.

I used to work in the Department of Premier and Cabinet; I also used to work in Ministers offices including a former Premier. I am on extended leave without pay from my full time job under special circumstances due to the caring role I now have. I doubt I will ever be able to return to work. I consider myself lucky that I have knowledge about government services, how to find out about them and therefore how to access them. Many many people I meet don't have this knowledge and it causes them stress, frustration and then negativity about services that are out there, that they have not been told about, or could have been accessing some time ago.

Thank you 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

Karelle