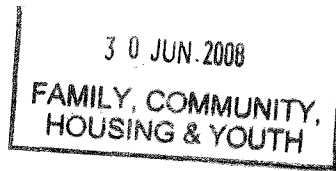


Submission No. 622

(Inq into better support for carers)

A.O.C. 8/7/08

Connie



20th June 2008

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.

My role is to care for my 39 year old intellectually and physically disabled son. This is a 24/7 job as my son also has severe epilepsy and frequently has seizures lasting all night, as well as seizures during the day. I do this because I love him

I contribute to Australian Society by saving the Government hundreds of thousands of dollars by keeping my son at home with what feels like the minimum of help. Until he was 21 I received no help at all and now I suffer from permanent chronic back pain due the amount of times I had to lift him on my own. There was no-one to show me how to work safely.

I face the following problems (to mention only a few of the main ones) and these are also the things that stress me out the most:

1. I am dependent on certain agencies to provide support staff to shower my son and to provide respite. I am therefore at their mercy to provide appropriate workers. I cannot tell you how many times over the years that workers have either not turned up, or they come late or leave early and still expect me to sign their timesheets for the full-time. I have been cheated out of many hours and this is a form of abuse.
2. I have complained about this many times – this has resulted in me being given a bad name and bad mouthed and I am treated with a total lack of respect, particularly by the agency that provides shower and cleaning services. The co-ordinators in charge of the staff invariably take the side of the staff and are very rude to me. The result is that some services are withdrawn or I and my son are treated in an even worse way (if you want more information on the agencies involved, then I will be happy to provide it).
3. I have never had a social worker who has supported me –the current one would not even help me write this letter (I am Italian and cannot write English) and I had to ask a friend to help me.
4. I have no life of my own.

5. I see so much money wasted by certain agencies which could be spent on providing a fuller service for people like me. I am not the only carer in this position and am only writing this letter because I dearly want to help other carers.

It is impossible for me to have any form of social life because when I do have a support worker to care for my son, I need this time to arrange things for him, such as washing, shopping, arranging appointments, etc. or I have to attend to my own health needs. This leaves no time for socialising. At other times I have no-one else to care for him. I have been looking after him on my own since I was 22 and I have never had any substantial time to look after my own needs

I am financially struggling because I have to live on a carer's pension and unable, for the above reasons, to work to supplement this. The pension, which is my only source of income, barely covers my day-to-day living expenses and also has to supplement the living costs for my son as his pension is not enough to cover all his expenses. I certainly can't afford luxuries. I would like to do paid work but I am physically and mentally exhausted every day doing unpaid work looking after my son.

I worry about my future because I am now 62 (feel like 82) and who is going to look after my son if anything happens to me? For 13 years I have not sent him to a respite house because in the past when I was in hospital and had no choice but to do so, he was physically and mentally abused, more than once, and now I am not prepared to risk putting him in a home. At that time, had I had a better understanding of the system I would have sued the home for negligence. Now it is too late. My son was sexually assaulted four years ago at a certain day centre, which is funded by DADHC. I received absolutely no support from Community Services – in fact they supported the Centre who denied it had happened rather than supporting my son. It's only in the past few weeks that a psychologist has been to see him. He has been stressed ever since that incident and you can't imagine the stress that I have endured because of it.

I desperately need more respite as the hours I am allocated are nowhere near enough for me to have some semblance of a normal life. If I had more help I would have more time to look after my own health. I receive only 25 hours a week which is nothing when you consider his needs and mine. I receive no help on public holidays or on the days when the workshop he attends closes in the holidays. My son gets extremely agitated if there is no-one to take him out.

I think the Government could help me and other carers by giving us the money to select and pay for our own workers as, at present, most of the money goes into administration by the agencies, of which there are far too many. If administration was streamlined there would be more left over to provide more services. Often money is spent on running social outings for carers which I am unable to attend because often there is no-one to care for my son. I am sure that I am not the only carer in this position.

As for who currently provides funding, I have no idea. Since last Christmas the respite I received on Mondays was cut-off by a certain agency. I have lost count of the number of phone calls I have made trying to talk to someone to get this reinstated but everyone passes the buck. I am passed around from pillar to post and no-one will take responsibility, including my so-called social worker. Community Services treats me as a number, not a human being. You have no idea how upsetting this is.

The bottom line is my son needs 24 hr a day care. I receive only 25 hours a week respite which is nothing like enough given my state of health and age. I want to care for him at home as long as I can (which you know saves the Government hundreds of thousands of dollars), and the older and sicker I get, the more help I need. I have panic attacks and severe depression from worrying about the day to day care of my son. Sometimes I am in such despair that I feel like killing myself. Then what would happen to my son?

I pray you will do something to ease the burden of carers like myself by the way of more funding and more support and hope that none of you ever have to walk in my shoes.

Yours sincerely

Connie