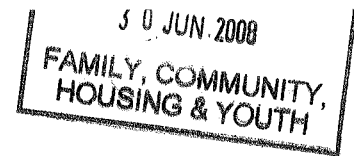


Submission No. 620

(Inq into better support for carers)

A.O.C. 8/7/08

Committee Secretary.
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
P.O. Box 6021,
Parliament House
CANBERRA ACT 2600
26TH June, 2008



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.

As a Carer (Mother), I feel that my role is very demanding after 26 years of looking after my son on a daily basis, I feel tired and worn out, with a sore back from all years of lifting and carrying my son and his wheelchair before I received a lift. He is very intelligent but physically disabled. He communicates with a talking device. I have to get him out of bed every morning, toilet him and prepare his breakfast for him. Since several bouts of aspirated pneumonia. He has needed to have all food and drinks thickened to the consistency of yoghurt. I then have to spoon feed him his drinks and food, which takes quite a lot of time. He then has to be toileted again, teeth cleaned and be dressed for the day. If it is a day that he goes out with his carer, I then have to thicken drinks and food which he takes with ice in a bag type esky which hangs on the back of his chair, as the thickened food has to be kept cold. At night time he has to be fed first as with his feeding problems he needs to be fed 1-1 ½ hours before going to bed. On days he does not go out Monday, Saturday, Sunday and Wednesday when the special funding runs out, and on public holidays I am his full time carer. He has had difficult times with surgery i.e. muscle releases in legs and hip, rods in his back, and both his feet have been reconstructed.

I face the following problems, as I also have a husband and a 22 year old son at home, and depending on my daughters fiancées' roster, I can have her 20 month old daughter during the day and older children after school on 3 days in a week and all 3 on a Saturday. Chris my son is doing a word processing course at TAFE at the moment, which he has been doing for nearly a year now as his physical disabilities makes it a slow process, last week his carer was sick as they did not have a replacement carer for him, I had to go to TAFE with him as his carer for the morning. He plays Boccia on a Tuesday afternoon, he plays with a ramp for the ball to roll down. He recently played in the State and Nationals Titles, he got Silver in singles in State and Bronze in pairs in Nationals.

I need help with hours for Chris to go away for Boccia, to have some more outings and carer hours so we could sometimes go out knowing there are spare hours available. I sometimes stay home and mind Chris while my husband goes to the social event. For the last 5 years I have taken my son to boccia titles but when away I have to do all the lifting without a lift and no one to help me it is becoming too much. This year he went with a carer. It takes a lot of carer hours even though the carer and my son stayed the bare amount of time needed to compete, we were given some funding but it was not enough to cover all his hours, as a result we have had to cut back on daily hours on some days he goes out, to catch up on hours we went over while he was away. This means at the moment there are no spare hours for him to go anywhere at night or my husband and I to go out at night. In a normal family a 26 year old person would not be a problem as they look after themselves. We cannot go out some where on the spur of the moment, it all has to be planned well ahead of time, I also have to share taking my father to places at times as he is nearly 87 and still lives on his own at home.

I think the Government can better help carers by giving more hours when the children leave school. While they are at school they are out from 8.15am-3.15pm every day of the week. Suddenly you have got an 18 year old that only goes out 2 or 3 days a week. The other days the fulltime carer (mother) is looking after him the whole time. I can often be woken up of a night to toilet him, because he is too hot and needs uncovering or because he is too cold and needs covering up more. When he gets a cold and gets asthma I can be woken several times a night. I have had four children they are now 33,29,26,22 this year. Having a physically disabled child restricts your chances of employment very much, as he does not go out every day, he goes out at 9am for TAFE on Tuesday and 10am on Thursday and Friday. Towards the end of last year special funding was made available to go out on a Wednesday but it stopped for about 8 weeks over Christmas break. But has started up again this year, I have to take him to this and get him home in afternoon. You do not know when he will be unwell and you have to spend time at doctors and minding him at home, it is very difficult to get employment when you can not guarantee you can come every day.

My son wants to move into shared accommodation. He has his name down at Qld. Housing and DSQ. We have had phone calls for available accommodation, but we cannot get enough funding for him to move. He would like to share with 2-3 people as he would need overnight carer. I am starting to feel burnt out after all the years of minding my son, for the first 12 years of his life we lived in a high block house, where he had to be carried up and down the stairs to go to school, I also had to carry a heavy manual chair up and down the stairs each day. He was 16 before we had a car suitable for him to stay in his wheelchair in the car, before that I had to lift him in and out of the front seat of a station wagon and pull his wheelchair into two parts to put it in the back of the station wagon. His balance is not good, so his wheelchair is specially shaped for him, it is a lot heavier than the standard folding wheelchair. I am 58 this year and my husband is 61. We would like the chance to have some time to travel and do some things together, before we become too old to do so. I feel I have saved the government quite a lot, caring for my son

till 26 years of age. Anyone who meets my son realises he has a great sense of humour and enjoys his life as best he can. He has absailed in a manuel chair at a camp for disabled children when he was 9. He goes in a double tube at Sporting Wheelies Ski Days with his carer. He has rode on a mechanical bucking bull (not real fast) with his eldest brother at a cousins 21st party. He has gone down water slides and large slides at the show when he was younger, but he is now getting too heavy to carry up to the top of these slides. As I am getting older looking after my son is getting harder.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations.

Yours sincerely

Lorraine