

Lorraine

Aoe 18/7/08

Submission No. 944

(Inq into better support for carers)

30-06-08

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 feel that my role as a carer is very important to the welfare of my daughter. I am sixty one years old & have been caring for my daughter for the last thirty two years. My daughter had lack of oxygen to her brain at birth. I had two children, my marriage broke up when my daughter was four. My son flew & I cared for both my children on my own, my son left to live with his father at the age of sixteen years. I had no family members as they had passed on so I was the only one there for my daughter. There are a lot more problems as my daughter gets older and as I get older. There are a lot of behaviour problems that get to hard to handle at times this makes problems for her social activities. I don't have any social life as I never know what is going to happen with my daughter from day to day due to her mood swings. I do find it difficult with finances as we rent privately and with living costs and my daughter's social activities it does not leave much over. We are both are on a pension. Being a carer it is very easy to become isolated because most people have their own lives to live. I had a problem last November I went into hospital for a day procedure that went wrong and I had

to have surgery that meant a three week stay in hospital. That meant finding someone to care for my daughter. My daughter was cared for by four different people. My daughter ended up in Sydney staying with a friend of mine. Because she could not see me herself she was very scared and would not talk to anyone. It was a very hard time for everyone involved. This had a bad effect on her it caused a few problems. Her behaviour has been very difficult in the past few weeks she has been verbally and physically abusive toward me. When this happens I have to ring the police and the ambulance for help. I was in such a state that I had chest pain I was taken to hospital they wanted to keep me in because of my heart. My daughter played up so badly that I told them just to let me go home I was getting upset about what was going on. Three days later the same thing happened again. This time my daughter was taken to the mental hospital and she was left there screaming out I want my mum. That was so upsetting to hear and see that happening to my daughter. The guy in the ambulance was telling me not to worry about my daughter just think about myself that is not easy to do as a mother. They did not let me leave the hospital this time. The mental hospital could not keep her there because of her intellectual disability. By the time they brought my daughter over to the hospital we had arranged for my friend at east Gosford to have her for the night and my friend from Sydney to come and get her the next day. My daughter stayed with her until I came out of hospital I had a stent put in a coronary artery. There again my daughter could not see me so she was scared again. There are a lot of stresses involved as a carer when there is no on going support.

I do worry about my future due to my health age and I do not own home I am a renter. My daughter and I rely on each other to survive. We both on a pension

My needs as an older carer with my daughter Belinda who has brain damage at birth now: Bipolar so it is very difficult. When she has her mood swings and gets angry and abusive the only ones I am told to ring the police and ambulance then we go to Gosford hospital and my daughter is seen by the mental health team. They talk to her check that she is taking her medication then we are sent home. Because of Belinda's intellectual disability we are told she comes under Dept of Aging, Disability and Home care. There is a long waiting list for their help. They need more people and more funding for services.

There would be many carers the same as me. I would like to see some type of support were a service could supply a person who could get to know the carer and the one who is to be cared for. This would be so that both would get to know and trust the person. If there is an emergency that the carer would feel happy leaving the one they care for in safe hands. The other reason being it would be good for mother and child to see each other and know all is well.

The other thing is when things get out of hand that there could be some kind of response group that are able to help in these times of stress because it is very hard to have to ring the police each time it effects both of us. There should be more respite places that offer a lot of activities to keep those busy and don't have time to get bored. Also a place for carers to go and

relax and be cared for. A break is needed so we can go on caring for our loved one. Carers give up their lives to care for their disabled child. Who else would show the love that is needed every one needs love. Carers need to be recognised for the dedication they show to the one we care for. I have had many people say they don't know how I do what I do for my daughter. They tell me they would not have the patience to do it. I don't have a social life as such because something always happens with my daughters behaviour and I have to spend time calming her down as she does not have any reasoning power or problem solving skills so it takes a long time to calm her down. Then I am emotionally worn out. I think there should be something in place that carers are checked on to see if they are coping and if they need any kind of extra assistance. Thank you for hearing my views on more help for carers. I look forward to hearing of any improved ideas that will help carers. Enclosed is a copy of report from hospital about some of the problems I face.

Yours Sincerely
Lorraine