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Submission No. 260

(Inq into better support for carers)

A.O.C. 30/6/08

Thursday 19 June, 2008

Secretary

Inquiry into Better Support for Carers

Standing Committee on Family, Community, Housing and Youth (FCHY).

PO Box 6021

House of Representatives

Parliament House

CANBERRA ACT 2600

I wish to make a submission to the House of Representatives Standing Committee on FCHY Inquiry into Better Support for Carers.

1. Who am I and what is my role? I am an aging 63 year old single, life long, full time unpaid family carer of my son 35 with high support needs requiring total care. I also have two other adult children with disabilities. My youngest son was born with disabilities and has developed complex medical conditions related to his disabilities. This places extreme pressure on me 24/7 each day of every year. My role is to care for all my son's needs to ensure he has a quality of life that is his right as an Australia citizen. My day is totally taken up with providing meals, medications, suctioning (my son has a permanent Tracheostomy to enable him to breath), changing bibs/towels (my son is unable to swallow), giving my son fluids through his Gastrostomy PEG ( my son is unable to eat solid food), bathing, doctors appointments, ensuring that my son is moved in his wheelchair to prevent pressure areas, checking that he is not uncomfortable in any way, too tired, hot or cold; in any glare or bright light, as this brings on seizures, both Petit and Grand Mal. I also have to empty his Urine bag regularly (he has a urine diversion due to Kidney failure). My son also requires chest Physiotherapy twice a day to ensure that his lungs remain clear due to a 50+ scoliosis. Once a day my son also requires 30 minutes of stretching exercises to prevent further contraction of his limbs. In addition to the issues metioned above I am often called by my eldest daughter 42, who has Mental Health problems, some of which manifest in her having Panic Attacks. When this occurs, she phones me to assist her to reach a level of composure, thus enabling her to sleep or resume whatever she was doing.

2. How do I contribute to society? I believe I have contribute considerably to society be caring for my youngest son 24/7, and being there to support and care for my eldest daughter and elder son, saving governments untold amounts of dollars each year. I have and still am contributing my time and knowledge to others. Over many years I have been a member of Management on various committees in the hope, that my experience will assist others. On some of the committees I have been involved with, the involvement has been in assisting policy direction in relation to Carers. I make myself available for interviews, have been asked, on several occasions, to take part in various types of research through Universities and have spoken at numerous Forums and Conferences. I have also been invited to speak and give lectures to classes of students at Universities and TAFE.

3. How does my caring role impact on my life? My caring role has impacted on my life in many and varied ways. My marriage of 25 years came to an end and outside my immediate peers, all of whom are unpaid family carers I have no friends. I do not have any social life. What time I have on my own is mainly taken up with housework, shopping, and importantly, advocating on behalf of my son. I have little or no physical contact with my extended family as they find it difficult to relate to my son and thus I may see my family once or twice a year.

I also have three grandchildren who also have difficulty with the concept of my son and his wheelchair so my contact with them is spasmodic. My physical and emotional health has, over the past 35 years, deteriorated to a point where I now need assistance myself at times. This assistance is given by my daughter who is not always in a position, mentally, to give me all the support I require. I have undergone surgery, having had major spinal surgery in 1994, in 1997 had a bad fall, shattering my shoulder which needed to be reconstructed, and last year I had a total knee replacement. I also I suffer with Osteoarthritis which makes caring for my son extremely difficult and painful.

I am currently on anti-depressant tablets to enable me to get through each day. I am so tired at the end of the day that all I want to do is go to bed. I will admit there are mornings when I wake I really don't want to get up and have concerns about getting through another day, but who else is going to care for my son?

My son also requires suctioning through the night which leads to sleep deprivation and at my age this is not ideal. I do not dare go out at night, even if my daughter is available to sit with my son, as she may have a panic attack and I cannot afford to pay for someone to sit with my son as they do not know how suction him or cope with a Gran Mal seizure in the event he has one during the night. I cannot remember the last time I went to the movies and my last holiday was in 1990. I am tired both physically and emotionally and am

simply worn out; at the moment I am depressed hopefully this will soon change, I do hope this is the case. So I would say that the impact of caring has considerably altered my life. My life is not what I envisioned it would be. I have been isolated from friends who no longer call, I get frustrated at the amount of time I have to spend Advocating for my son and like now my caring role has become overwhelming.

For me to have a break this would mean having paid support workers come into our home; however, I have to provide transport, petrol, food, a bed - mine, clean sheets etc and must comply with legislation as our home becomes a workplace.

If the support worker takes my son out to the movies or shopping for example, I must provide money for their ticket into the movie, pay for drink and snacks as well as pay for my son's ticket. If shopping is the order of the day then I must also provide money to allow the support worker to have a coffee and something to eat. My home must be in good order, clean and safe, having all appliances working properly and I must also provide all necessary health supplies all of which takes money.

When I have done this then I can think about going away. I have to arrange and pay for my own accommodation, meals and transport and when I sit and think about the cost I say "why bother as I don't have the money to go anywhere anyway". Result, it has been eighteen years since my last holiday. In fact I can tell you exactly how many days I have had for holidays since my son was born in 1973, in total I have had 72 days holiday in 35 years. Again I can only stress that the cost of having a child with high support needs is prohibitive.

4. How has my caring role impacted on me financially? I have already intimated at the cost of taking time off under the previous heading and how it is beyond my financial capabilities. The cost of having a child with high support needs is unaffordable. Although governments provide funding for equipment, wheelchairs and Continence Aids, subsidised respite, for my son, as well as government rebates etc, all of which is greatly appreciated, however, these monies do not cover all that is required. For example; if special modifications to any equipment are required the cost of any and all modifications must be paid for by the consumer, me.

In addition, the cost of medications has also reached crisis point. This year medications cost more, and more money has to be spent before we reach the Safety Net threshold. The Safety Net will be beyond our reach this year. Last year, 2007 we received one (1) months free medications. The Carer Payment

does not allow me to save any money and I stress again that the costs associated with disability is beyond belief.

I did have some monies invested however; the cost of having a child with high support needs is prohibitive. I paid for both my surgeries out of my own finances, depleting my available funds considerably. In addition, I was forced to pay for outside support workers to assist with my son's care after my surgeries, all of which came from my personal finances. Further, in 2001 I had a decision to make; I could either sell our home of 27 years or keep my son as I could not afford to keep both. I chose to keep me son. The home I bought needed to be modified and all of the modifications I also paid for out of my own money. I managed to buy a second hand modified van in which to transport my son. This cost me over \$30,000 again, this money came from the sale of our home and after the modifications and the Van I was back to having no spare cash. Nevertheless, due to the overburdening cost of having a child with a disability and the ongoing and ever increasing costs associated with disability my funds have now diminished to the point where I fear my finances will not be enough to see me and my son through till one or both of us die. I am constantly pulling monies form my meagre funds to top up our combined Pension and Carer Payment.

4. Finding Work: In 1998 I felt that I should try to return to the workforce. In so doing I further decided after being turned down for several positions, purportedly due to the fact I didn't have a degree, I decided to go to University to obtain a Degree. This I did and graduated in 2004. In obtaining my degree I have also accrued a HELP debt greater than the national debt. Since that time I have applied for many positions and although it has not been said, body language is very clear and speaks volumes. I believe prospective employers find that I am too old and that my caring role would be a disincentive to anyone who would even think of employing me. I have applied to Advocacy Agencies as well as employment in a managerial and coordination positions as well as other positions within the Disability Sector. Thus far I have not been successful. My conclusion is that employers see me as being:-
  - a). A Carer first – that is my role and position in life.
  - b). To old – given that I have years of experience is of little value it would seem, and;
  - c). The perception, from the people I have seen thus far, I believe, see my caring role as one of inconvenience in relation to any work I may obtain.

5. What practical measure would assist me care for my son?
- a). I strongly believe there should be Uniform Carer Legislation in place throughout Australia, in this way Carers will be recognised by governments.
  - b). The Carer allowance could be increased for Carers who provided not only full time care, but are in reality providing nursing care to their family member with high support needs.
  - c). Carers, who do have some funds, should not be penalised by having their Carer Payments reduced because they are over the allocated amount they are permitted. We save Governments Millions of dollars each year, please consider this point seriously. Remove the obstacle of asset testing incomes of Carers who are, in my opinion, among some of the most in needy groups in our society. Carers are not out to steal anything from anyone we are simply asking that government(s) departments discontinue penalising carers unnecessarily.
  - d). There needs to be specific services in place to assist Carers return to the workforce if they so desire.
  - e). Implement a Superannuation fund for Family Carers, after all we do work very long and difficult hours without any reasonable compensation.
  - f). Entitlement to Flexible and Quality support that is overreaching and should be the main criteria of service provision.
  - g). Suitable age appropriate Respite for Young Adults with high support needs – not based on a Medical Model of Service.
  - h). Supports and Services must be accessible when and as they are required for families caring for a person with a disability.
  - i). Carers/families who have paid support staff come into their homes to assist with the person with a disability should be indemnified from liability for in-home support. I do believe however, there should be a degree of responsibility taken by consumers. Nevertheless, carers having to meet Occupational Workplace Health and Safety Legislation and Health Legislation places additional stress and costs onto the Carer/families and consumers.
  - j). One point of entry for Carers in crisis or who find themselves diagnosed with a dependent disability themselves.
  - k). Advocacy for Carers is, in my opinion, a major issue. Advocacy services should be funded to ease some of the burden from families as well as give them voice in matters that affect them and for those for whom they care.
  - l). Keep the Carer bonus payment as a lump sum each year and increase the amount. The payment is of major benefit to all carers who receive it and it is not wasted. This year I need to buy four new tyres for the Van to comply with Service Policy and OWHS legislation. A full service on the van is also required. I have overdue bills that need to be paid and I will be able to see my dentist.
  - m). There needs to be serious consideration given to increasing the Carer Payment to meet the ever increasing costs associated with disability. This

does not include the additional costs of living, eg food and petrol, which has made front page news for several months.

n). Subsidised areas of respite for Carers. For example, arrangements could be made with some Hotels or Motels where Carers could go and not have to pay the full price for accommodation with possibly one main meal a day at a reduce cost. This could possible be modelled along the lines of respite in nursing homes or hospitals currently in place for the elderly and people with disabilities.

o). Carers who provide Nursing, Physiotherapy and Occupational therapy as part of their caring role need to be recognised as contributing at a higher level and therefore need to be acknowledged in a more practical way.

Yours sincerely  
Valerie