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Submission No. 753
(Inq into better support for carers)

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June 28, 2008

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
PO Box 6021
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 wife is an educated woman with Cerebral Palsy who led an independent life and saw it as a privilege to teach young children. In 2000, she underwent the last of a long line of surgeries to assist her maintain her mobility. Out of hospital for 2 days on her way home from rehab she was hit by a drunk disqualified driver doing in excess of 100kms an hour in a 60 km zone. He later left the scene of the accident and went into hiding. Yet the courts were prepared to do a deal with this man, who was well known to police. He would plead guilty to the more serious assault charges pending, provided her accident went away. He wanted his license when he finished his jail term.

This accident caused devastating health problems for my wife which has required frequent hospitalization and exacerbated her disability. She is now plagued with more spasming externally and internally causing a great deal of pain, decreased independence, mobility as well as chronic back pain. For years I have been juggling a young family and a full-time job single handed. Her ill health, loss of independence and mobility cause me great sorrow and stress. Life was difficult enough for my wife. None of us were ready for the hell TAC put us through for 5 very long years.

As a Carer, I feel that my role is to support and assist my wife maintain a good quality of life. A life that allows her to have the same choices and opportunities as any other person. Due to her special needs she requires an accessible home to ensure she remains at home with her family and can function as independently as possible.

I face the following problems:

Our service provider does not cater for my family's needs. They are not concerned with the level of service they provide to their clients. They are more concerned about following their own inflexible business practices. The organisations representatives have resorted to using intimidation, harassment and bullying and threatened to withdraw services if my wife did not allow them into her home to make an assessment whether the home was safe for the carer. We had moved from a rental property to our new home. She was forced to sign their blank action plan at a time she was vulnerable and ill (she was hospitalised that night). We are unable to change service providers because they hold the contract with our shire.

They have shown they are an organisation that does not understand the needs of people with disabilities. They have rigid inflexible rules that do not allow carers who come into the home to carry out everyday household duties during a respite shift. The result was my so called respite leaves me with a mountain of work to do when I get home at 11pm after playing night tennis. The Manager of our service provider told my wife a round table conference, where we could discuss our concerns would be organised after Easter 2007 and we are still waiting.

After numerous phone calls my service provider has sub contracted my shifts to another company. The carers who attend my family now are wonderful so I hope they do not leave. They all say we need more home help and said the same thing to their employer.

Our service provider was given funding to provide transport to medical appointments for disadvantaged members in their region. The only problem was once again those responsible were inflexible and made this valuable service useless; by stating you must be out of the city by 3pm or you could not use this service. As you are aware specialists tell their patients when they are available not the other way around. You take what you can get or face lengthy waiting periods.

My wife found another organisation who offered transport for a donation. They were funded to provide a coordinator on Monday and Wednesday mornings for a few hours. This made it near impossible for this service to meet my wife's needs. My wife usually had the same driver take her to her numerous appointments. He witnessed first hand that one appointment quite often resulted in a further appointment being needed a couple of days later. He on occasion would instruct my wife to leave a message for the coordinator that he was available to take her due to the time restraints. This practice resulted in my wife receiving a letter from the chair of the board stating my wife would no longer be allowed to use this service if she continued to organise a lift without going through the coordinator. The volunteer driver went to my wife's defense and attempted to explain the importance of this essential service and that we were trying to assist the coordinator not bypass her. Once again due to a lack of funding a service provider was unable to meet our needs causing a great deal of stress.

Being a carer is a daily struggle and often leaves me with no time for myself or my daughters. I would love to attend my girl's special events and spend quality time with them but, am unable, due to work commitments and my carer's responsibilities. The reality for our children is they regularly miss out on having a parent present and have spent many hours in care, with deep regret on our part. Both my wife and I are extremely proud of our daughter's who often act as young carers for their mum. Caring for a person with a disability is a demanding job. I work 24/7 and I have little energy or time for a social life. My service provider does not allow respite hours to accumulate. The result is I am unable to go away for a few days by myself, so I can recharge the batteries. For many years I have had to use my Annual Leave and ADO's to care for my wife and family as I have used up all my Sick/ Carer's Leave. As a result if I fall ill, I then also have to use my Annual Leave if I have any left.

Since caring for my wife and family I have become diabetic. I am convinced this is partly due to the stress associated with holding down a job while trying to meet my carer responsibilities eg taking my wife to regular specialist appointments in Melb during work hours. I have been subjected to discrimination and victimization even though I work in the disability field. My employers have not always been aware of their responsibilities (I appeared on the 730 report June 2007 re discrimination by my employer). Battling TAC and my employer, as well as a building dispute re lack of wheelchair access has taken its toll, resulting in the near breakdown of my marriage.

Participation in regular exercise is near impossible due to my carer responsibilities and the unpredictability of my wife's health. Therefore, I am extremely anxious about my own health and wellbeing. What will happen to my family if I became ill?

I must work to pay the mortgage and bills. Due to a lack of funding and the classification tools used by funding bodies, my wife who is 46 has been unable to get a package resulting in her isolation. Even though she is a fall risk she spends her days alone at home unable to get out. Over the years I have come to dread phone calls from her because it usually means she has fallen and unable to get up or she has taken ill and requires medical attention. I am in a constant state of worry and guilt. She has been told on more than one occasion she would have a greater chance of receiving assistance if we separated. Her lack of socialisation is of great concern to me and certainly reduces the quality of her life. She suffers from depression and high levels of frustration due to loneliness, a lack of stimulation and I cannot deny chronic pain plays its part.

- I need help with finding a **permanent** position of employment in the disability sector or training. A job that will allow me to meet my carer's responsibilities and financial obligations. This would involve paying the disability sector a higher income in recognition of their skills and the valuable job they do. It is a well known fact that the disability sector is poorly paid in comparison to other career sectors. I need to pay the mortgage on our accessible home and for my wife's medical treatment, physio etc. She has a good team of specialists who all say regular physio with a neurological physio and hydro are essential to reduce pain and spasming and to keep her mobile. However, I cannot be in two places at once and are unable to afford regular visits. Transporting my wife to medical appointments and hospitals also costs extra money in fuel, parking tickets and Citylink passes.

Secondly, I require help to get my wife out into our community to enjoy what is often taken for granted making friends, shopping etc.

Thirdly, I need help to find an accessible and affordable holiday destination because my family and I have been unable to have a relaxing, much needed break away from home for years.

Fourthly, I need more support to assist with meal preparation and general household duties such as washing, shopping etc so my children get to bed at a reasonable hour and my families' quality of life improves.

Finally, I need help to manage my wife's complex needs. My wife is very capable advocating for herself but, often is dismissed. I on the other hand find it extremely difficult advocating for my wife and family during working hours. Many hours are spent on the phone by my wife and/or me speaking to many different people and not getting anything resolved. This adds to our frustration, stress and my workload.

I think the Government can better help Carers by:

- finally recognizing the very important role carers play within our communities and paying them accordingly. The carer bonus and carer allowance is simply not enough. At present I must inform Centrelink when my wife is hospitalised (mostly in Melbourne). For the record my workload tends to increase during these times. Travelling to and from Melbourne takes at least 2hrs. She tends to have more washing and it is difficult to keep up. She often requires me to advocate on her behalf because staff don't understand her needs and/or don't listen. For example, my wife was in hospital for 5 weeks longer than she needed to be because the continence nurse would not get her a variety of appliances to trail. It's hard enough to cope with having to wear a bag for the rest of your life. My wife told them repeatedly that she could not use the hospitals standard appliance. My wife's close friend decided to take the girls to visit their mum. My wife wanted to be dressed and dry when the girls came but, instead she was swimming in her own urine. My wife lost it completely and what do you know the continence nurse presented her with a different appliance with a lock the next morning. It worked and later she was discharged. While all this is happening I still have to organise my daughters, run the household, meet my carer's responsibilities which now involves travelling to Melbourne regularly and work.

- Providing Community Centres with the funds to employ specialized staff who can provide treatment for people with complex needs eg neurological physio etc.

We moved from Traralgon where my wife had access to hydro and physio 3 times a week at the Community Rehab Centre (CRC) run at Latrobe Regional Hospital. She received this level of treatment for approx 3 years. We are aware that patients do not receive treatment for this length of time usually. Those responsible for her treatment saw the decline in her ability to walk each time they instructed her to take a 2 week break. Due to the level of her commitment and her complex needs, a decision was made to allow her to attend CRC 3 times a week on a regular basis.

In September of 2002 we moved closer to Melbourne to reduce travel to specialists which my wife attends regularly. We constantly are looking for ways to strike the balance between work and family. We chose Beaconsfield because our research indicated that Casey was going to get a new hospital with a hydro pool. Unfortunately, costs needed to be reduced so the pool was cut and the hospital run CRC did not eventuate. Now my wife receives no treatment because the community centres in this area cannot cater for her needs. The result her mobility has declined while her pain has greatly increased.

- Providing better education and training for service providers to ensure client needs are being met. The rules and regulations for respite need reviewing. Paid carers should be able to complete daily household duties if that is what is required to assist the unpaid carer receive a much needed break. I was shocked to hear an ill friend of mine being advised by carers, to become a carer and do the night shifts, because you don't have to do anything (easy money). Funding bodies should be able to stop or decrease an organisations funding if they are not performing and providing a good level of care. Shires who sub contract out HACC funded services should be held accountable if the organisation of choice is not meeting the client's needs. We have been with this organisation for 4 years and not once have we been asked to complete a quality of service survey.

- providing more respite hours that can accumulate.

- providing carer support groups that meet out of working hours to cater for those who work.

- Improving access though legislation; even though the Disability Discrimination Act makes it illegal to discriminate; large scale or Systemic discrimination happens to people with a disability on a daily basis. People with disabilities try to work, play and participate in the community, but can't because of inadequate access into and around public buildings. Housing from the design stage, should be built to anticipate all potential users of the house if communities are truly to become **inclusive** for all. The lack of disability access impacts on me, our family and friends not just my wife with the disability.

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,

Wayne

PS. As I write this at quarter to midnight, I am also helping my wife pack to go to a rehab hospital in Brighton (over an hours drive from home). It is the start of the school holidays and once again she will miss out on quality time with her daughters. Her sister and nephew are flying down from Darwin in the second week of the holidays She had a fall two weeks ago, just before her daughters birthday and now is in a great deal of pain and unable to use her right leg, making walking near impossible. She was hoping things would heal without intervention. Unfortunately, for our family this is not the case. She saw her neurologist on Wednesday (his first day back at work) and was given time to organise care for our children. She is getting admitted this Sunday June 29, 2008.