

A.O.C. 30/6/08

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.

I am submitting to the Inquiry because I have been caring for my disabled son for 30 years. I was 23 yrs old when I started my caring role. I am 53 yrs old now. My son suffered permanent brain damage at birth, which left him suffering from Cerebral Palsy. This is a physical disability, which has left my son with a life long dependency on a Carer. A Psychiatrist diagnosed him with Schizoaffective Disorder and Depression, approx. 2 years ago. In 2005, my son was given an IQ test (Wechsler Adult Intelligence Scale-Third Edition (WAIS-111) that placed him in the Intellectually Disabled range. In all, his brain damage has resulted in a physical disability that affects his speech, fine motor skills needed for writing, shaving, and personal care needs, drinking and eating. It affects his mobility, intellectual capabilities and mental health. He was diagnosed with Cerebral Palsy at 18 months of age. He was diagnosed with borderline Intellectual Disability at 28yrs of age. He was diagnosed with Schizoaffective Disorder and Depression at 29 yrs of age. He is now 31yrs.

More information is attached on a separate sheet

1. The role and contribution of carers in society

As a carer, I feel that my role is to provide my disabled son with assistance to allow him to live as normal a life as possible. To ensure he receives the medical help he needs and accesses services that are available to him. Help him to achieve the best level of independence to enable him to pursue his goals and allow him to participate in social activities and live his life fully.

In practical terms his disability means he cannot live alone. He needs a full time Carer to shave him, help with personal hygiene. Prepare food and drinks, manage medication, take him to doctors, fill out forms, and manage his finances. He needs Speech and Physio Therapy. He needs a personal shopper. He cannot drink hot fluids. He can only drink with the help of a straw. It is not safe for him to use a knife to prepare food, or use a stove. He needs to be monitored to ensure that he is wearing clothes appropriate for the weather. He needs to be monitored to ensure he showers, is groomed and wearing clean clothes. He does not adjust to moving or other changes well and this must be managed carefully to minimise his distress. Any problems that arise will cause him to become distressed and agitated, which easily leads to violent or abusive behaviour. He can be up and down all night turning his light switch on and off, checking the door is closed, checking the front door is locked, checking the back door, checking draws in his room, and many other "checking" he does. This is one of his mental health problems. Photo albums have to be placed in a secure place or he will rip up photos of people who have angered or upset him. I have lost many precious photos. Phone calls are difficult and he needs someone to

interpret for him because of his speech impairment. The Caring role covers many everyday needs and might be described as performing the role of Nurse, Private secretary/Assistant, Financial Manager and Therapist. This is an overview of my role as a Carer.

Carers and their families are carrying a very heavy burden that would otherwise be the responsibility of society. If Carers were to abandon their role to allow them to live their own lives, fulfil their own goals and earn an income society would be faced with a huge financial burden.

More information is attached on a separate sheet

2. The barriers to social and economic participation for carers

As a Carer, I face the following problems that create barriers to social and economic participation. My son has been physically violent and verbally abusive since he was 14 years old. When the violence started, my daughters were very young. As a family, we endured 15 years of domestic violence and verbal abuse. We lived in constant fear. I lost contact with friends, as my son would become violent if I even talked with them on the phone. My daughters could not socialise at home for the same reasons. We became socially isolated and extremely depressed. We lived with this problem daily and did our best to keep it from escalating to the point where we had to call the Police. We were a family unit constantly on the verge of collapse. Family and Police intervention didn't help. The only way the police could help was if I pressed charges. Our only other avenue of help, a support agency for the disabled, Care Connect advised us to ring 000 – so we continuously went round in circles. There is nowhere a Carer can go to get help or protection from violence. Calling the Police is not the best way to resolve domestic violence involving someone with a disability. This is a medical problem not a criminal problem.

There are long-term negative effects caused by the need to find a coping mechanism. I have survived on Valium since 1991. I found myself resorting to alcohol as a way of coping. After many years of violence it finally became so unbearable that my teenage daughters and I were considering suicide as a way out. I had no idea my daughters were suicidal too. We started talking about it one day – the violence etc. and that's when we realised we were all feeling the same way. At the time I had returned to work for financial reasons but I had to make a choice to either abandon my son or make one last effort to get him help. So I left the work force. My income went from \$31,000+ to around \$15,000 p.a. The impact on us financially was devastating.

The failure to get all of my son's medical problems diagnosed early in his life prolonged our misery. It was not until Care Connect provided funding for a Neuropsychology Report in March 2005 that his intellectual disability was diagnosed. He was 28 years old. This important fact changed the way I treated him and my expectations of him were adjusted. As a result there was an improvement in his behaviour. I applied to the Department of Human Services for him to receive help. They assessed him as "borderline intellectually disabled" which made him ineligible to receive their help. So he fell through the gaps in the system. We were left again to deal with this problem on our own. We remained a family, isolated and in crisis.

Despite the fact that I sought help continually over the years from GPs, my son's violence was not brought under control until very recently. It was not until I took him to see a psychiatrist (that bulk billed as we had very little income) that we finally saw some results. He prescribed medication that did help my son. It should not have taken so long to get a correct diagnosis. The help was always out there but we were left floundering in the dark. If your GP doesn't know what to do – you are in a hopeless situation.

My son's disability was a major factor in the break up of my first marriage. My second marriage also broke up. These are the major repercussions. Family break-up that escalates to financial distress that guarantees social isolation.

I am on my third marriage. When I got married in November 2007, Centrelink severely reduced my Carer Payment through "means testing" my husband's income. He is 59 years old and before he married me was laying aside savings for his retirement. He is on a very basic wage of around \$750 per week gross. Centrelink expects him to support me with his wages, assets and savings so I can continue to be a Carer. He has been forced to dip into his savings so we can survive. My husband has a 12-year-old son from his first marriage to support. He is feeling the strain both emotionally and financially. The pressure on him to support me so I can be a Carer to my son is a great concern to him. I could go back to work and earn a good wage, which would put an end to our financial woes and take the pressure off our marriage but my son would have to find alternative care.

While I am saving the government a small fortune performing my caring role, it is costing us dearly. I have given up a career and a good paying job that would have provided a comfortable and secure life and retirement so I can be a Carer. Being a Carer is now my job.

Government does not value my role as a Carer. I receive \$79 per week Carer Payment and \$100 per week Carer Allowance. Centrelink means tests the Carer Payment to every last cent of income my husband and I receive. To improve our financial situation I need to go back to full time work. I could earn around \$700 per week if I abandoned my son to whatever provisions government has put in place for his continued care. Why am I means tested at all? Why are we forced to deplete our savings so we can survive?

Prior to my marriage, I received the full Carer Payment of around \$300 per week plus \$100 per week Carer Allowance. I have spent 30 years performing a caring role that would not pass Work Cover laws. My Centrelink payments are a slap in the face. This role has all but destroyed my health. Any stress will put me in bed with a fever for days. What happens to a Carer, who after 30 years can no longer perform their caring role because it has taken its toll? Do they go on Newstart? Do they apply for the Disability Pension? Where has government legislation drawn a line to recognise the contribution Carers make to society? To recognise the financial savings government can attribute to their caring role. Where is government legislation that elevates the role of a Carer from that of a single mother and the unemployed? The heavy personal price paid by Carers (financially, socially, physically and emotionally) and the great contribution they make to society should place Carers in a different category to single parents and the unemployed. If the Caring role we provide is of value then this should be reflected in the way government supports us financially.

Currently we are treated like beggars and thieves. The meagre financial provision Centrelink gives us ensures we do not starve to death while we care for the disabled and the means test makes sure we don't have any extra money to make our lives more bearable.

The barriers to social and economic participation for a Carer are:

1. The inability/great difficulty to access respite facilities in order to have a break from the caring role at the time needed or for the time needed

2. The lack of support to deal with domestic violence

3. The lack of finances available to the Carer

4. The failure of current agencies to provide referral to appropriate services in a timely and correct manner.

5. The failure of agencies to properly follow up on problems that have been identified as placing the family unit in danger of collapse.

More information is attached on a separate sheet

3. The practical measures required to better support carers

If government want to know how to better support Carers then it is important that the issues are viewed correctly. The Carer and the disabled person are each affected by how well the other is faring. If one is neglected then neither will make it. You can't support the Carer without also supporting the disabled person being cared for.

A Carer cannot care for a disabled person without being given certain support and assistance. A basic and fundamental part of that support is to provide the Carer with reasonable financial support. It should reflect the important role Carers play, the financial cost/loss of wages to the Carer, Spouse and family, the associated negative effects upon health, pressures placed on the family unit, the loss of social participation and the contribution to society.

To participate in society you need to have the financial means to do so. Carers cannot participate in society on current Centrelink benefits. At present, Centrelink provides Carers only with a way to survive. Means testing ensures that Carers cannot improve their financial situation without returning to the work force. This reflects government's expectations for Carers to be full time carers and work in order to have the finances to live and participate socially.

Government should be viewing Carers in realistic terms. Carers are providing an important service not looking for a free meal ticket. We have given up employment and its rewards in order to perform this role. Full time Carers are not looking for work - we are working. Caring for the disabled is not viewed as work that deserves remuneration for a service provided. Rather, Carers are viewed as providing a charity and despite the fact that being a full time Carer means you cannot earn a wage as you once did, government support leaves us in poverty. Government

financial support should be more in line with current wage figures. The caring role often is not temporary in the same way as unemployment/single parenthood may be. Their state has a hope of a better future and financial improvement but the Carers role may last a lifetime.

Government should not depend upon a spouse to financially support a Carer wife/husband. This may have been reasonable in 1954 but in today's economy the wife/husband Carer is needed to provide additional income to support the family unit. If the wife/husband is needed to act as a full time Carer it should not be used by Government as an opportunity of securing that Caring role at a severely discounted rate or at no cost at all by "means testing" the Carer's husband/wife's income. The lack of choices available to Carers most likely means that this role has been forced on them and the opportunity to earn an income taken away as a result.

Another practical measure seems obvious when we know we are trying to care for someone who has medical problems. Ensure Carers have access to a "specialised knowledge" base that can provide referral to the correct medical specialists. Ensure that funding is provided to enable Carers to access these services on behalf of the disabled person in their care. This ideally would be made available via a centralised Agency that specialises in all major issues that affect the disabled and their Carers. The knowledge base should include all medical issues (physical, mental/intellectual), violence and behavioural management issues, assisting families/Carers at risk of collapse, respite, physio, occupational and speech therapy. These are just a few of the major issues Carers and the disabled need to have addressed and gain easy access to.

I am now aware that a Cerebral Palsy victim should undergo an IQ and psychology examination to determine if these areas of their brain have been damaged. The physical damage suffered is obvious but the rest can be camouflaged by symptoms that make no sense until diagnosis. Diagnosis will give the greatest assistance to both Carer and disabled if identified as early as possible. In our case, we suffered needlessly for most of my son's 30 years before we received the medical help needed. I say "we" because whatever affects him also affects immediate family members and me. The current services failed us as a family and we suffered for lack of knowledge.

If current services such as Care Connect are retained they need to do more than just hand out money and book respite accommodation. The high turnover rate of case managers is a huge disadvantage. It is so frequent that by the time you get used to one case manager they are moving on to a better job. You are continually bringing new case managers up to speed. How can case managers make real progress when they are there for only 6 to 12 months? It means you have a hit and miss thing happening. The difficult problems never get addressed and are always there. The next time it reaches crisis levels it gets looked at by the current Case Manager and they may hit the problem on the head and point you in the right direction or they may not. Case Managers should be locked into a contract to provide their clients with case management for a minimum of 2 years. More transparency is needed so that Carers know how much funding has been allocated to them. Timely and correct referral, assistance and follow up should be provided to address issues that have been identified as placing the family unit at risk. Agencies should be made accountable by government consulting with clients to assess the quality of the service being provided. To assess if goals set for clients by case managers are just words on paper or are actively pursued and achieved. To assess if goals set by a departing case manager are actively followed up by the Agency to ensure the new

case manager continues the goal plan. The Agency should be held responsible and accountable to ensure the client gets results. One case manager visited regularly; talked about what options could be looked at to help but I never saw any results or even a goal plan on paper. What a waste of time!

The Department of Human Services might achieve their budgets by making sure people like my son, who are diagnosed "borderline intellectually disabled" are not allowed to access their services - but someone will pay the piper. There needs to be a sea change in how government provides services to the physically and intellectually disabled. We were a family in crisis caring for a disabled person with an intellectual disability unable to get help from anyone - including DHS. A practical measure would be for a government department who is supposed to assist a person with an intellectual disability to give that help - even to someone who is diagnosed as "borderline intellectually disabled". "Borderline intellectual disability" does not translate in real terms as normal intellectual ability. There remains a disability to be dealt with and the symptoms are very real and capable of destroying a whole family unit.

Respite facilities are supposed to provide carers with a break from caring. Many times I have not been able to access respite because a homeless disabled person was using the respite services. So the Respite facility has been taken away from Carers in order to provide a temporary home to disabled homeless people - ironically *who no longer have a Carer to care for them*. If this trend is not rectified, this vicious circle will continue. Respite is the only way a Carer can recoup so they can continue their caring role. Carers are on call 24 hours, 7 days a week. If you do not provide adequate places and take this absolutely essential support away - Carers will eventually break. The Respite facility will become home to the disabled - not a Respite facility for Carers. Government needs to provide adequate respite places.

When we, as a family were in crisis, suicidal, at risk of becoming addicted to prescription drugs and resorting to alcohol as a coping mechanism, we were told by Care Connect that there was nowhere for my son to go. We were left without any kind of help whatsoever. We were forced to continue to live with the daily abuse and violence. Today, we suffer the consequences as a family unit. It has resulted in long-term damage. I am not broken but I have been burned out. My health is damaged. I am sick for 1 to 2 weeks out of every month but continue to provide care. I need sleeping tablets most nights and Valium. Stress will make me sick with a fever for days. My daughters have suffered emotionally and both have difficulties. As for my son's future care, if we had found help earlier my son may have received care from his sisters after my decease or inability to continue his care. However, the damage caused by his long-term violence towards them makes that extremely unlikely to ever occur. The failure of government to provide the support needed today will mean society pays the price in the future. Government needs to investigate ways of providing emergency support and solutions/management options to Carers and the disabled person they care for when the disabled person is the cause of domestic violence.

There are hidden, abnormal financial costs Carers and their families pay. Extra costs are incurred because someone with a disability lives in the home. Besides the extra medical expenses there are costs for repairing/replacing household fittings and doors that are damaged due to my son's disability. The car gets damaged. The toilet gets damaged because he collapses onto the seat. Doorknobs fall off doors. The flyscreen door gets damaged because he leans heavily on it for support. Towel rails are ripped from the wall, plaster and all because he has leaned on it too heavily.

Then there is deliberate damage caused by violence. Carer Payment and Carer Allowance does not allow for any of these hidden costs. These things should be taken into account when legislating how Centrelink financially support Carers.

It is not unreasonable for Carers to be remunerated for their roles in a similar capacity to what they would otherwise receive in the work force. It is unreasonable for society and government to expect Carers to carry such a demanding burden for remuneration that is at or below the poverty line. It is unreasonable to expect that a Carer should continue their caring role and receive a greatly reduced Carer Payment or no Carer Payment at all because they have savings, assets and/or can be provided for by a husband or wife.

1. The Carer has lost a full time income. The spouse is expected by government to support the Carer so they can perform their caring role instead of earning an income. The government in fact expects Carers and their spouses to make as many sacrifices as possible whilst providing minimal support. The loss of an income results in the inability to participate in many social activities. There are no family holidays or luxuries. Financial difficulties are a daily concern placing extra pressure on marriages and family units.
 2. The spouse has lost whatever income the Carer could have earned. But in addition to this, he has lost his Carer wife/husband to the caring role 24/7.
-

Government should introduce legislation that recognises the unique role and valuable contribution made by Carers. Legislate to ensure that Carers are rewarded rather than punished for the work they do and the sacrifices they make. Legislate to remove means testing on assets, savings and spousal income. Ensure that Carers are not abandoned to a life of poverty. Legislate to ensure that the role of Carer is given the respect due from government and society by elevating it from that of the Unemployed and Single parent. Legislate to ensure Carers continue to receive the same support (financial and health) at the end of long years spent in the caring role. Taking into account the physical and emotional toll that may have affected their ability to return to the work force if they are below retirement age. The benchmark used to determine humane and just levels of support that government should give to Carers should not be the same as those used for other Centrelink beneficiaries.

More information is attached on a separate sheet

4. Strategies to assist carers to access opportunities and choices

It is difficult for Carers to access respite. To organise respite for my son so I could go on my honeymoon was a nightmare that spanned months of frustrated planning. I needed respite for 13 days. I was not able to get all the dates I needed as they had been allocated to someone else despite it being a special occasion and requesting these dates well ahead of time. So an additional care plan had to be organised and funding sought. Then after having done all of that, I was informed by the Respite House that they had decided to give me those days too. Provide adequate Respite places so we can access the facilities on a regular basis and we will have the choice to take a break from caring to live our own lives for a little while and participate in social activities or simply rest.

Provide dedicated supported housing for the disabled. The supported housing should be designed to provide care for the needs of those with different **levels** of disability and care needs. Allowing for those disabled who have a level of independence, which should be encouraged and maintained. Placing my son in supported housing with people who are severely intellectually disabled and violent would destroy him. This was the kind of housing available to us when we were in crisis.

At the moment we cannot place him in supported housing. There are a number of reasons. Firstly, the long waiting list which we can only bypass by tossing him out onto the street and making him homeless. Secondly, the supported housing available has been described as not good for him. There is no suitable alternative for someone with his level of disability and independence. He has goals and a desire to live as normal and independent a life as possible. He needs to be provided with the level of support that allows him to achieve this. He should not be forced to endure living in a stressful violent environment or live in a nursing home because he has a disability.

Provide suitable Supported Housing that enables the disabled to live in a safe, peaceful environment that allows them to exercise their level of independence in a reasonable way and you will give us a choice to live normal lives. A choice to continue to be a Carer - or not. To live our own life or not. You will also give us the choice of returning to work and earning an income.

Provide real help to Carers and their families to resolve domestic violence that is caused by a disabled person in their care and you will give us a choice to either endure violent and abusive behaviour or find relief from it. We need more choices than making the disabled person homeless or bringing criminal charges against the people we are caring for.

Provide a basic wage to financially support Carers to do their job and remove "means testing" from spouse's income and assets to allow Carers, their spouses and children to do more than just survive. We will have a means by which to exercise choices and opportunities and participate in society.

Government should legislate to ensure Carers continue to receive the Carer Bonus. The bonus has provided much needed financial relief to Carers who have made many sacrifices that have saved the community, government and society greatly in financial terms.

More information is attached on a separate sheet

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

Carmen

Print your name

Carmen

Date

8th June 2008
