

Submission No. 751

(Inq into better support for carers)

From: Karen
Sent: 1st July 2008
To: Standing Committee FCHY
Subject: Better Support for Carers

The Secretary
House Standing Committee on
Family, Community, Housing & Youth
Inquiry into Better Support for Carers
House of Representatives
PO Box 6021
Parliament House
Canberra ACT 2600

I wish to make a submission to the Inquiry Into Better Support for Carers and thank the committee for this opportunity to provide comment.

I would like to address the committee in relation to my caring role of people with mental illness and psychiatric disability.

Submission Summary

It is a long, hard road for carers to travel when we take on the caring role for a close friend or relative. We, and the people we care for, have long been forgotten members of our society and it is now time to pay tribute to those who perform this role. We are very aware that carers save the government astronomical amounts of money, but we need acknowledgement and recognition by our government and community, in the way of additional funding. I hope I am able to highlight some the issues associated with being a carer, and aim to touch the 'tip of the iceberg' by providing what I see as possible solutions to the problems we face. They include:

- **An immediate review of the rate of Carer Allowance and Carer Payment**
- **Develop a coordinated approach and focus to carer issues at a national level**
- **Initiate a Carers Health Care Plan**
- **Gradual phase-out of the entitlement of the Carer's Payment Concession Card when a carer begins paid employment**
- **Suspension of the Carer Payment for a defined period instead of complete cut-off for those who join the workforce**
- **Increased funding for Community Awareness and Education to reduce stigma**
- **Creating carer-friendly workplaces**
- **Introduction of a monthly transport payment via voucher system**
- **Increased funding for flexible Respite Options**

My story

I currently live in a rented home with my two sons aged 20 and 21. My 22-year-old daughter left home the day after she graduated from high school due to the high levels of stress and dysfunction in the home. She married earlier this year and lives approx 30 kms away.

My second child, and eldest son, was diagnosed with

- Tourette Syndrome
- Obsessive Compulsive Disorder
- Attention Deficit Hyperactive Disorder and
- Moderate Oppositional Defiant Disorder when he was aged just 9 years in 1994.
- In 2002, Gonadotrophin Deficiency
- In 2007, Severe Obstructive Sleep Apnoea and Generalised Epilepsy
- Morbid Obesity - his weight is 192kgs and he has severe Flat Feet.

My youngest son displayed similar behaviours and he too was diagnosed with

- Mild Tourette Syndrome
- Attention Deficit Hyperactive Disorder
- Oppositional Defiant Disorder – Moderate
- In 2004, his ODD diagnosis was reviewed and rated as Severe
- In 2006, he began to have Drug & Alcohol dependency issues
- He also has had Chronic Asthma since the age of 2

The impact of these behaviours on my eldest child and only daughter was very distressing for her and difficult for me to observe. She talked of suicide when she was aged 14 years.

Subsequently, my family became users of a Child and Youth Mental Health Service from 1989 until 2005 when my eldest son turned 18 years of age. At this point he would begin to use Adult Mental Health Services. That is, if he could get in to see them. He was struggling with his anxieties, crying on a daily basis and would not go out in public, but his condition was not considered to be serious enough for intake into the Adult Mental Health Services. I eventually found a private psychiatrist who agreed to see him and prescribed medication that thankfully has settled some of his symptoms.

Although my youngest son has mental health issues, he also has drug and alcohol problems that only make matters worse. His aggression is frightening and often results in broken furniture, damaged walls, doors and windows, a mother wondering what provoked him into this tirade of abuse and questioning if it is safe for us to go to sleep.

I also care for my ex-husband on a part-time basis, with daily phone calls to and from him in Beaudesert when he is not sleeping on my lounge up to 6 days a week. We divorced in 1993 partly left due to an inability to cope with his sons' behaviour, but who suffers from

- Alcoholism
- Severe Depression
- Diabetes
- Atrial Fibrillation and
- Hypertension

I too have health issues including

- Type 2 Diabetes
- Hypertension
- Low Mood (not technically Clinical Depression)
- Obesity (from 70kgs in 1988 to my current weight of 135kgs)
- Sleep Apnoea (suspected)

Let me tell you about my home environment. In 1988, I had three children under the age of 2 ½ years. All three were in nappies at the same time. In those days, disposable nappies were just new and very expensive. So I washed loads of nappies every day. In between that, I had a toddler who threw up all the time with reflux and who took off at every opportunity to look underneath cars. He didn't speak, just grunted. He screamed, cried, ran everywhere, climbed everything, terrorised the family pet, harassed his siblings, broke their toys, disrupted their sleep, was aggressive to them, didn't sleep longer than 20 minutes at a time himself and generally caused havoc. He was expelled from Family Day Care at the age of 2 because the FDC mother could not keep him from 'getting into everything' and distracted her attention from the other children. But I was initially dismissed as being neurotic when I attempted to seek help and answers for his erratic behaviour. I was EXHAUSTED... and still am to this day.

I struggled for years to find support and assistance for my son and on more than one occasion was told that he could get every support he required if only I surrendered him to the Department of Families. But for him to stay at home with his siblings and me, there was very little in the way of support. I know that I saved the government tens, maybe hundreds, of thousands of dollars by having him remain with his family.

Sadly, I never had the support of extended family members and struggled with very little assistance. Many friends and family found it too confronting to see his behaviour and the impact on our lifestyle, and chose to stay away only increasing our isolation.

It costs a lot of money to entertain a child who cannot mix in public, where his funny sounds and strange actions cause people to laugh at him and stare. Keeping him busy was easy when he was younger; playing in our yard was ok until the neighbours complained about him (at this point he had coprolalia – repeated swearing). Today, the computer and electronic games are his friends, but they can cost a lot of money. Thankfully, the carer bonuses come in handy for repairs and upgrades etc. I have also used the money towards car repairs and new tyres. Clothes also cost a fortune for size 7XL. His shoe

size is 16 4E and there are not many of that size around. They cost between \$150.00 and \$250.00. Even a pair of leather thongs cost \$80.00. I don't know how politicians think that it is more expensive to raise a child under 5 years of age than it is to feed, clothe and educate an adolescent, given that the Family Tax Benefit stops when your child receives the Youth Allowance at age 16.

Kids can be very cruel and do not realise the emotional damage they can cause. My son today will not catch public transport because of the long-term harassment from children and ignorant adults who would comment on his weight and how he should be walking not catching a bus or train. One bus driver told him to stand in the middle of the bus so it would not become 'lop-sided'. But he cannot get a Taxi Subsidy because he does not have the right diagnosis.

As a carer, I have an overwhelming feeling of guilt.

- What did I do to cause this to happen?
- Did I not look after myself well enough during my pregnancy?
- Am I too overprotective?
- Am I too lenient?
- Should I take him out more often?
- Am I giving him the opportunities that his peers have?
- Is it unfair of me to want a future of my own?

I also face grief and loss every day.

- I grieve that my son is not going to have the future that I planned he would have.
- I grieve that my son may not meet someone who will care for him in a loving way.
- I grieve that my son may not have the opportunity to raise a child.
- I grieve that my son will probably never learn to drive a car.
- I grieve that my son may not ever find a regular job.
- I grieve when I see my son wave to me and call out 'goodbye mummy' off as I drop him at school in grade 11 with his peers watching on.
- I grieved the day I had to walk into McDonalds with my arms up in the air because that was what his tics and OCD demand that I do.
- I grieved the day I took my children to Lone Pine Sanctuary and it took my son 20 minutes to walk 40 metres from the car to the entrance because he had to stop and touch everything in sight 4 times over or in multiples of 4.

Thankfully I tried to maintain some level of hope for our future and this helped me to get through those terrible days. Now, his tics and obsessive behaviours are lessened and he is slowly growing up. He recently celebrated his Twenty-First birthday, but still has a long way to go. He is a very loving young man, but has very little or no insight into his disability.

The role and contribution of carers in society and how this should be recognised

Carers are mostly undervalued for the work we do, after all, we are mostly caring for our loved ones, so politicians don't consider it to be a 'job' where payment is required. We are also hidden, because we don't get the opportunity to socialise and as humble Australians, we don't often complain about what hand we have been dealt in life. We often do not have the strength to fight government systems and just put our 'head down and bum up', and get on with the job at hand.

Like everyone who works, in whatever field they choose, we as carers want to be recognised for the hard work we do. There is a groundswell in the consumer and carer movement across Australia where consumers and carers are paid for their expertise in particular fields. As carers, we should be paid for our expertise in knowing what is best for our loved ones, for providing the specialised care and attention we do for them, but also for the vast amounts of money we save the government. This should be reflected in the amount paid to us. As it is, we are living below the poverty line, not a good look for the government when you consider the savings we provide.

Given the recent increases in the cost of living, particularly for fuel and groceries, there needs to be an **immediate review of the rate of Carer Allowance and Carer Payment.**

Disability Services Queensland, along with other state governments, have developed a Carer Recognition Policy and there now needs to be a **coordinated approach and focus to carer issues at a national level.** This recognition should be supported by legislation in order to protect the carer's rights and provide them with flexibility and options in their caring role. The Federal Government needs to develop these initiatives in consultation with carers.

Practical measures to better support carers

It is well known that the carers' own health becomes compromised when they are caring for others. It comes well down the list of priorities. In order to prevent this from happening and to protect the caring role we have, thought needs to be given into how this can be achieved in a simple yet practical way. Those who suffer from mental illness can have their GP draw up a Mental Health Care Plan. This allows the patient to link in with services and supports to enhance their recovery journey. My suggestion is to modify this initiative and develop a **Carers Health Care Plan** that can allow identified Carers access to a range of health care options for them. This can assist them to maintain their own health in order to continue their caring role. This could include access to

- Massage Therapy
- Podiatry treatments and
- Psychology sessions etc

I have been working 19 hours over three days per week for the past six years and because of my caring role, I was entitled to receive a Carer's Part-Payment to supplement my income. However, after falling behind with some bills and having my rent increased, I recently took up the opportunity to begin a second part-time job. This put me over the limit of hours I could work and still retain any Carer Payment status. The moment I contacted Centrelink to advise of my new circumstances, my concession card was cancelled and I was ignorant that this would be the case. I expected that to happen at some time soon but not immediately, as I needed to fill my prescriptions for necessary medications. I attended the chemist within 10 minutes of contacting Centrelink and was advised that my monthly medication would not cost my normal \$35.00 per month, but now over \$180.00 per month, money that I did not have as I was not to be paid for my new position for another two weeks. I like many other carers, have no savings to draw on and that left me unable to purchase my necessary medication and going without for another two weeks, as well as suffering from unwanted withdrawal effects of Antidepressant and Diabetic medications. Perhaps a solution to this situation occurring for other carers, would be to **phase out the entitlement of the Carer's Payment Concession Card** not just cut it off immediately. Access to some of these concessions and discounts can be of benefit while trying to 'get back on their feet'.

Sometimes, working full-time may not be the answer and again a resignation might come soon after starting work. Perhaps a **suspension of the Carer Payment** might be in order for a period of 6 months in order to 'test the waters' for carers first before the payment is finally cancelled. This might ease the burden for the carer and Centrelink, where their payment can simply be re-instated.

I work, but constantly worry about the fact that my son is at home alone just keeping himself occupied with the computer. When a crisis occurs, be it real or perceived, and this happens regularly, I am called at work to address the problem. It is difficult to do this on the phone. But it is the best I can do, given that I am the only working person in my household and need to be employed to meet my financial commitments. If my younger son is at home at the same time, my worry is multiplied because of his impulsive aggression. There have been some days when I have had to leave work and return home to deal with the remnants of this behaviour. Every day when I get home, I then have to do a days work in the house, cook a meal, clean the dishes, tidy the house, do a load of washing etc. This workload leads to constant levels of stress.

Many years ago when my boys were still in primary school, I was forced to quit my job that gave me some mental activity, to concentrate my time attempting to find solutions to my eldest son's problems. This took me from being in a stable financial position to then being on or below the poverty line, completely reliant on welfare. This poses a great deal of social and emotional conflict when family members do not understand the impact and issues with mental health problems. Some people do not believe that there is such a problem as 'mental health blah-blah' and that it is just 'a cop out' and the

answer to the problem is just to 'use more discipline' or 'smack them more'. Great support from your loving family members.

Obviously, **community awareness and education** of mental health issues has been addressed in many areas but I do believe that more funding needs to be put into education around children and young people who have mental health issues. BeyondBlue does a wonderful job but this could be expanded to include the YBBlue initiative and increase community awareness into Child and Youth Mental Health. As statistics show, mental health problems often have their roots in the adolescent years and this must be highlighted in promotional campaigns. They suffer stigma too, even more so than adults, as they do not have the capacity to understand why they are targeted and bullied. I am aware of the MindMatters education program being delivered in schools but all too often that is only if the principal arranges this to occur.

This community awareness and education should also be extended to teachers, because they spend the most amount of time with our children after us. They need to be supported with strategies to assist them in dealing with children in the classroom. Quite often teachers are not able to participate in additional training or professional development as there is no other available resources to provide relief-teachers, and those teachers who do attend are usually the 'converted'. All teachers should be required to attend as a mandatory requirement of their professional development and to 'keep current' with up-to-date research and learnings. Funding should be allocated specifically to address this area of need.

Of course, with the need to be at specialist appointments and tests, time off work is imperative to meet these demands. Thankfully, I do work in an environment that respects the need to balance these commitments and I have the ability to use TOIL and TIL. Some workplaces don't and carers must take time off without pay. This impacts on the available funds to meet financial commitments and increases stress for all members of the family. Perhaps thought needs to be given to **creating carer-friendly workplaces** where carers have some protection and allowances in place to help meet the needs of their caring roles.

The cost of this additional transport places extra stress on families, especially in recent times with the increases in the price of petrol. Perhaps an answer could be to provide carers with a **monthly transport payment** to alleviate some of this stress. This could be provided as an additional payment or included as part of an **increase to the Carer's Allowance**.

I fully support the recent promotion regarding an **increase in the rates of pension**, including the Aged Pension, Disability Support Pension and Carer's Pension. All too often I see that discounts and concessions are provided to Aged or Senior Pensioners and Disability Support Pensioners. Never have I seen a discount offered for those receiving a Carer's Payment. Again, community awareness can help raise the profile and plight of carers and highlight the needs of this disadvantaged group.

The lack of resources in the community often leave many gaps in service provision and families who need assistance can miss out, especially in rural and remote areas. This needs to be addressed by way of additional funding to non-government organizations to run long-term programs not just a six-month pilot project and then nothing. Families also need support, for themselves and their family members who struggle to cope with the strains of physical, mental, emotional and financial burden which disability often brings. Too many families are left with no time to attend these critical support systems and therefore, the issue of **flexible respite options** needs to be investigated. Of course, this too will require more funding.

Families who have a child or young person who has a mental illness often fall through the cracks of services where there is nothing to offer under 18's. Many organizations turned me away when I sought respite for my son in primary and secondary school. Sometimes, Queensland Carers were able to source funding and seek workers from local NGO's, but not always did I receive services. One option for the child or young person who is recovering from mental unwellness is to be placed in a hospital setting to give the parents/carers/siblings a break. This is certainly inappropriate for the mental wellbeing of the child, especially when he/she is placed with unwell young people and may be witness to distressing behaviours from those who are still receiving treatment and care for a range of issues, including psychosis, anxiety, self-harm, eating disorders etc. For respite to be effective, it needs to be beneficial for both parties, the carer and the care recipient. When respite does not go well, the child will return home and their behaviour may again deteriorate and this only places additional stress and burden on the parents/carers and other family members.

Perhaps the use of short-term farm-stay holidays, adventure camps, and beach-house stays is something that could be pursued. It would require a significant number of trained staff to operate, but the benefits of activity based age appropriate respite would be invaluable. The carer needs to know that their child is in a safe environment where they are kept busy and interested, in order for them to feel relaxed and feel the benefits of respite. The rewards for the carer and family can be immeasurable.

The above issues are all aimed at reducing the level of burden for the carer and the family. I know that if I receive high level, timely and appropriate services for my son, then I will feel that my job as a carer is being made easier. It is one thing to ask for what the problems are and what we think can help, but it is another thing entirely, for the implementation of programs, resources and supports to be put into place. Please don't fail us by your inaction.

Again, I give my thanks for the opportunity to raise these issues. By having this inquiry, I do believe the government is clearly interested in how I cope and function as a carer. This gives me a feeling of worth and that someone is interested in the hard and tireless work I do. It also gives me hope; hope for our future, the future of my sons, of myself, of my family as a whole and of my community. I love my children and any parent will want what is best for them.

It is encouraging to know that we now have a government who is at least interested in the same thing as well.

I trust that the committee will take on board all the suggestions that we, carers and community members, entrust to them, with the aim of easing the burden and improving the lives of carers.

Karen