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Sent: Monday, 23 June 2008 3:39 PM
To: Committee, FCHY (REPS)
Subject: 'Better Care for our Carers' Parliamentary Inquiry

SHANTY

Submission re: BETTER CARE FOR OUR CARERS

I am a mother of three autistic children all under the age of 11 years, due to this fact my husband is our sole income earner and I in turn am the children's full time Carer.
Being a Carer is not a choice but an obligation to my children and their future status. I cannot seek any forms of employment as my prime responsibility is to care for my children. To improve our financial status via employment would affect and compromise my caring duties to my children and my health, not to mention I would not be able to establish any respite for myself.
In the last eleven years it has been an extreme battle to ascertain and secure federal and state government support for aid and assistance for my children. The government has an attitude on the basis of finding an excuse 'not to give' than granting.
On many occasions my husband and I have been forced into debt just so we could finance support and therapies for our children, a debt which is constantly accumulating due to our limited financial resources. Literally you're fighting for your rights for not yourself but for your disabled children.....your fighting to survive, you fight to exist. Could you ever imagine the physical and mental demands it's effects on a Carer, are immense!
With the Howard government I fought again for my rights to be entitled to the Carer Payment. I was knocked back twice but I never gave up, eventually after pleading and outlining the day to day demands and difficulties to the government via statutory declaration, I eventually won my claim to this payment, I won my rights to be recognised as a Carer! The financial gains were and still are not adequate balanced to my job description as a Carer, who is working 24/7 with no immediate family support being under funded by the government in a position which would be classified as an off shoot to the health system. I don't receive any holiday entitlements, benefits, superannuation or even the safety net of Work Safe. Of course I come under the unrecognised work force of Australia. Who is benefiting here surely not me and my children?
As an unrecognised work force of Australia, who has no choice in their career, who can't change their career path and know that this current job of being a Carer will be for the rest of my life! I have no options and I definitely have no choices. The only thing that keeps me motivated and sane are my children.
The all Australian dream of owning my own home will never happen for us as we could never be in the financial position of attaining that ultimate goal. We unfortunately are not the average Australian family.

I had the opportunity to submit my experiences to last years 'Carer Payment Review Taskforce' and also was part of La Trobe University study in the 'Investigation into factors that influence the health and occupation of Victorian mothers of school aged children with disabilities'. This study is being conducted by Helen Bourke-Taylor.

As you require an insight to Carers personal experiences, I have attached a copy of a presentation I had previously made to Autism Victoria and the City of Kingston's Inaugural Carer Conference in 2003, outlining my experiences and issues I had to initially face.

The presentation attached is titled 'An Emotional Roller Coaster' for your perusal.

I am extremely passionate about this issue and many others in relation to Australia. It's not the first time I have had to challenge local, state and federal governments and it will surely not be my last.

I do not advocate complacency as I do not expect this from my Federal government to the rights of disabled children and their Carers. Words from politicians are one thing, but you've been placed in government by the people of Australia to represent the people of Australia and we expect you not only to do the right humanitarian thing but for it to be the decent thing too! Or am I and my special needs children going to remain another statistic which is once again swepted under the carpet....or should I dare say another charity

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case?

I hope my submissions to this inquiry would be of use to the House of Representatives and that you can draw on one Carers experience in dealing with the constant challenges on a day to day basis.

Yours sincerely

Shanty

AN EMOTIONAL ROLLER COASTER

PARENTS ARE CARERS TOO

SHANTY

FOREWORD

This story was originally presented at the inaugural Carers Conference 2003 for the City of Kingston.

If it were not for the planning committee and the persistence of my husband, I would have never conceived the idea of putting my story to paper and the opportunity in sharing part of my life with you.

What I learnt from this experience, was not only closure, but that we need to swallow our pride and put aside our egos if we are to make a better life for ourselves and the people we care for.

We are all governed by our emotions. But if you can touch people on an emotional level, you not only bring down the barriers, you open the lines of communication and therefore we learn from one another.

Even though we care for children with special needs, never forget that you are also a very special person!

I would like to dedicate my story to Calum, Caitlyn and Shannen. Without them I would have never learnt to read in between the lines. This is my story...

INTRODUCTION

I'm a Mother of three wonderful children. Calum, a cheeky 9 year old, Caitlyn, a real cutie aged 7 and Shannen a tough little cookie aged 5.

I'm also a full time Carer. All of my children are Autistic with Global Development Delay. This means they have severe impaired social and communication skills. They do not understand language and have problems expressing themselves verbally. Their development is not to their chronological ages. Therefore this affects their overall physical and mental abilities.

What I'm about to share with you is my true story to date. My personal account is a profile based on my experiences I've encountered, as a parent, carer and an individual within society. With each account, is a story within a story.

Before I begin, I would like to state that being a Carer to me, is being a mother to my children. I know no difference to compare with. I go through all the normal ups and down's of being a parent. This is made more complex with the demands of caring for my special needs children.

Some days I feel I'm in a rut that I can't get out of, but I do. It's only that as a mother and Carer, I just have to work a lot harder. As a parent, my children are normal in my eyes, but not to society. So my account is based on the issues I've encountered.

DIAGNOSIS

My husband Colin is originally from Australia and we met in the U.K. Our children, Calum and Caitlyn were born there and that's where my story begins.

Family life didn't start off smoothly for us. In 1995, my husband and I unfortunately lost our first baby half way through my pregnancy. The following year, I was initially suspected of having a brain tumour. I was finally diagnosed with a condition, which temporarily impaired my vision. So the expectation of having Calum, safely come into this world, was not only a miracle but also a gift to us. Unfortunately, our lives were to be dramatically altered about two years later.

It was in January 2000 and our first daughter, Caitlyn was only six weeks old, when we were informed of Calum's diagnosis of Autism.

Autism, a disability I wasn't very aware of, but a word, which was, like a dagger to my heart. I wasn't distraught with my predicament. My responsibility was to care for my children, regardless of circumstance. I was just consumed with grief for my son. *I kept on thinking why him? Why my son? Was it my fault this had happened?* I felt like that he'd died, but he hadn't as he was still the same little boy playing in front of me. It was my expectations of his future that had been destroyed. *What future lay a head of him? Would he ever be independent?*

Denial was the easy option, but in reality, I was grief stricken. All I wanted to do was to curl up in a ball and hope this living nightmare would go away. It was only when I acknowledged that it was grief I was experiencing, that I really understood what emotions I was going through. I became vulnerable and uncertain. I knew I needed support and understanding, but I was too proud and frightened to ask for help from anyone. I couldn't even face my own parents. With their self centred lives, I couldn't cope with their reactions and what their overwhelming emotions would be, regarding their first grandchild. I knew I had to come to terms with my grief and to stop beating myself up over whom or what was to blame for Calum's autism. In denying Calum's disability was to deny his rights and our right's for support. So after some deep soul searching and getting the courage to trust anyone, I tentatively accepted help from a support group. The support group was always very patient and understanding with me and I respected them for that. Most of all they never gave up on me even when at the time; I had doubts about most things.

With their help it gave me the inspiration to face the future with confidence. .
The outlook was looking hopeful.

MIGRATION

A couple of months later my Australian visa was granted. This would allow all the family to immigrate to Australia. This was a new life I was embarking on, considering I had never been to Australia before. So even though I was excited, I once became uncertain not knowing what to expect.

We arrived in Australia in October 2000, unfortunately the support and understanding we thought we would receive from my in-laws never materialised and again I headed into despair not knowing where and whom to turn to. *I couldn't understand how they could behave this way?* I became doubtful in trusting anyone.

Unknown to my husband and I, we were expecting our third child Shannen. Then to my amazement the true colours of my in-laws came to light. They couldn't initially congratulate us with our good news. Instead they became critical. It was so hard to believe that my husband's family could be so insensitive. Let alone consider what my husband and I had been through. *I kept on questioning, was there no compassion?* To put it into real perspective, my in-laws never asked me how I was coping and feeling, regarding Calum's autism and not even about the pressures of immigrating to Australia. They would lack understanding, but will prioritise their own wants and needs. They never approached me personally to offer any support, not even regarding the children.

My first Australian summer, I found myself and the children being recluses in our own home, while my husband went to work. For me, not knowing where to go and what to do was extremely frustrating. Not being offered any assistance through the summer holidays from my in-laws was no surprise to me. I knew this is what to expect.

To top it off, the Australian heat didn't help matters either.

BIRTH No. THREE

In January 2001, we were fortunate to enrol Calum on the Early Education program at an autistic school. We were delighted to see him settle in so quickly. It was so reassuring to both of us. By June 2001, the time had arrived for me to undergo my third caesarean section and the birth of our youngest child, Shannen. It was supposed to be a joyous occasion. But the word 'Autism' was to enter our lives again, this time with our beloved Caitlyn.

This déjà vu was becoming all too reminiscent of when autism first affected our lives. The dread of going through the whole assessment process was excruciating. Our family life seemed to be on hold. Being analysed and researched throughout the year, seemed to last forever. We became paranoid and doubtful, especially knowing what the final diagnosis would be. We now realise that at the time we could have received specialist support for Caitlyn via the Dept of Human Services. But being referred to another service provider was not the priority for the child assessment services, but instead for us to be guinea pigs in the name of research. Not knowing what to do and being in a vulnerable situation, my husband and I suffered in silence.

In April 2002, Caitlyn was formally diagnosed with autism. In my heart I felt great sorrow, in my head I kept saying 'No, not again!' We didn't dare share this news with my husband's family. It was too painful to express. Foremost, we didn't trust them to be sincere to us.

Throughout this ordeal, the relationship with my in-laws had become intolerable. For peace of mind and quality of life my husband and I decided it was in our best interest to cease communication with his family and to go it alone. It was so important for us to concentrate and put all our positive energy into bringing up the children the best we could. In response to our decision, my in-laws decided to retaliate, by no longer acknowledging the children at special occasions. This spiteful behaviour was all because we didn't conform to the family expectations and demands. Most of all we didn't consider their feelings.

I suppose the only good thing we had to offer them, was to become the source of the family's '*coffee table gossip*'. This meant being constantly judged and criticised on about everything we did or didn't do. No matter what, they would take every opportunity to discredit me, just because I wouldn't conform to their way of thinking. It's one thing to make detrimental comments behind my back; it was another thing to say it to my face.

Whether it is prejudice or in difference on their behalf, I will never know or want to know. As far as I could see this was their problem not mine.

The whole irony of it is that three of my sister in-laws are teachers and my mother in-law is a retired registered nurse. So you can imagine my lack of faith in the so-called 'caring profession'. *Was it so narrow-minded?* I didn't trust anyone. I had to overcome and learn not to prejudge others whom genuinely wanted to help.

DEPRESSION

Throughout this time, I felt guilty about airing my feelings of frustration and anger. *It was not expected of me to behave in this way!* On some occasions I would feel agitated and defensive for no reason. I was on this emotional roller coaster.

I felt I was being constantly patronised and told what was best for my family and I.

I knew I wasn't paranoid! All I wanted was to be treated as a normal person. To have the choice to decide what is right or wrong for me. Not to be treated as a charity case. Sometimes I was made to feel I was the one with the disability.

At this stage something had to give under all the stress. I started to feel anxious and lack of self-esteem. *I couldn't sleep at nights!* I would find that I would occasionally feel light-headed and then go on to be mentally exhausted. My hair started to fall out. Worst of all was that I couldn't cry. I felt I was trying to fight myself out of a paper bag with no avail! It was suffocating. I needed help and I found the courage to find it.

After gaining the confidence to walk into the Doctor's surgery, to discuss how I was feeling. I was astounded by the Doctor's reaction of being critical and unsympathetic. *This was the last situation I wanted to be subjected to.* So after a long discussion, which led me to break down into tears, I was treated for post-natal depression.

Whether I had post-natal depression or not wasn't the issue. I realised I must have been extremely resilient to cope with all this pressure or very oblivious to my own personal needs.

After some time, my life was starting to get back on track. I was able to feel confident and to look back in retrospect what was and what was not, important to our family happiness. Though post-natal depression played a part to my misery, I knew nobody could resolve my other problems except me. So instead of festering in my own dilemmas, I decided that I needed to dispel the negative aspects and become more pro-active in what was important to us.

I took the decision to come off the anti-depressants. I wanted to be in control of my life once again, not to be controlled by little white tablets.

With the support our childcare centre and the local council, life looked a lot more hopeful.

CHILD ABUSE

Last August, we enrolled Caitlyn for the Early Education Program at the same autistic school Calum attended. But it was only a matter of time that the Principal of the school deemed to report my husband and I to the Department of Human Services for unexplained bruising to Caitlyn's back. All my children possess blue/black birthmarks on their backs called Mongolian Blue Spots and it can be mistaken for bruising.

But once the call had been made, we were under investigation for potential child abuse.

I was devastated having the police question me like a common criminal and having to produce medical reports to sustain my explanations. The worst aspect of this whole scenario was I was led to believe we had a good relationship with the autistic school. Unfortunately the Principal proved us incorrect in this fact.

Of course we fully understood that mandatory reporting of child abuse has to be adhered to, but at what cost to us? We knew as parents having children with special needs, we would be considered in the higher bracket of potential child abuser's.

But it was the circumstance of being guilty before being proved innocent that was hard to comprehend. Forget about our own personal dilemma, as parents with children with disabilities. We would have no say in the matter.

This became the turning point in my life. Enough was enough. I was no longer going to be intimidated by so-called professional's doing their job. I decided to stand up for my rights and to take on the educational system through complaint. All we were seeking was a forthright apology for the mis-understanding. What we experienced was that the Dept. of Education would justify their actions and wouldn't accept liability for the mis-understanding. ***So much for compassion!*** We were just another government statistic.

Maybe if the professionals were trained to deal with real situations, they wouldn't 'jump at shadows' and we would of never been in this dreadful situation in the first place. ***What happened about moral implications? Do we necessarily judge the book by its cover?*** It's so easy to make accusation; it's another thing to admit when there is a mis-understanding. ***Sorry does seem to be the hardest word!***

How could I compare my emotions at the time? Well devastated would be an under statement. This was one of the worst situations I've ever experienced. It was stomach wrenching. The government ombudsman acknowledged our complaint, but deep down we knew there could never be a compromise from the bureaucratic system. My endless list of questions would never be addressed, but swept under the carpet.

However by standing up for our rights we got closure. Gaining the confidence to question and disagree in doubt at any level.

With Autism effecting both Calum and Caitlyn, my husband I wanted to anticipate any imminent complications with Shannen. Unfortunately, as we were so accustomed with the aspects of autism, it was only a matter of time before we would recognise the similar traits of behaviour in Shannen. Shannen was formally diagnosed with Autism, June 2003.

I wasn't distraught, I just felt very disappointed.

SUMMARY

Being a full time Carer is not only physically demanding it is also mentally challenging. You have to be extremely organised, with a good sense of humour to cope. It doesn't help with the added complications of when you have to justify your existence with family, or with the bureaucratic system for financial entitlement and assistance. It always feels like on everyone else's terms.

But it's the sacrifice you make on your own personal life style that can't be quantified. At least I can say I'll have no regrets. Just seeing my children develop gives me gratification that the struggle and sacrifice is well worth it.

Many times I feel just because I'm not out in the work force earning an income that I don't work. On the contrary, I know my full time dedication and commitment as a mother, carer and therapist to my children is un-measurable compared to earning a salary. The rewards I gain are by the progress and happiness of my children.

We are not all given the choice to be a Carer. We do it because it's our obligation and responsibility. I don't think anyone can perceive the ramifications of full time caring until they are put into a similar situation. Their life, the person you care for becomes your life. It's only when your life changes, that you see the difficulties and obstacles you face. Caring and disability doesn't necessarily start at birth and at aged care. It can happen and affect you at any stage of your life in any capacity. As Carer's, we are and always will be at present, the unaccounted for and in many cases unpaid work force.

I know I'm not the only carer who faces these kinds of issues and pressures. I know that there are other Carer's in far worse circumstances than I can imagine. I know I'm not alone.

CLOSURE

It's been difficult at times to complete everything I want to achieve. However, I've learned to prioritise and make time to full fill my goals for my family. The love I have for my children always keeps me motivated. With all that is constantly happening in our lives. My husband and I have managed to acquire the right kind of support for the children.

We honour the hard work and dedication of the staff at Yarrabah special development school, Patterson Lakes childcare and our respite carer from the City of Kingston.

Without their support and understanding we wouldn't be where we are today. It's so gratifying that we can all communicate to work to the same goal, our children. I thank them immensely.

Colin, my husband has found it hard to understand at times, but he is honest and very hard working. At one stage he was working three different jobs to support us financially. Unfortunately not all employers are fair and compassionate when they are aware you have children with special needs.

There is discrimination and indifference within the work force and the employment laws do not always protect you from this. They only give the advantage to the employer. These employers are not the first and will not be the last that my husband will face and endure.

However, his best quality is that he is tolerant, so I'm grateful for that.

With all my experiences, it has changed my life and my views. It doesn't matter what dilemma's I face. I will always rise to the challenge. I've found being patient and being resilient has been a virtue.

I'm not always looking for support, just understanding and being honest.

To me, to understand is to listen, not to understand meant you never were really listening in the first place. It takes an instance to destroy trust; it can take an age to rebuild it.

I've learnt to compromise, to question if I'm not satisfied and to fight in what I believe is right for my family.

I'm learning to find the light at the end of the tunnel. I'm not afraid anymore.

I'm rediscovering my self esteem.

I don't only represent my children now. I represent myself.