

Joy

Submission No. 485
(Inq into better support for carers)

A.O.C. 7/7/08

Committee Secretary

Standing Committee on Family, Community, Housing and Youth

PO Box 6021

House of Representatives

Parliament House

CANBERRA ACT 2600

Inquiry into better support for carers

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 a 45yr old female sole parent/carer of two boys who have Autistic Spectrum Disorder ASD. I have been a full-time carer in this role for the past twenty years. I have been in receipt of government payments as my primary source of income for thirteen of those twenty years.

To give you some idea of the extent to which my boys are affected by their autism I have included a brief guide below to allow some understanding of the degree of affect that autism has on them as individuals.

The spectrum of autistic disorders falls within a continuum of mild, moderate, severe and profound. Those presenting with mild autism are generally diagnosed as having Asperger

Syndrome while those affected in a profound sense would present as classically autistic, the degree to which most people in our society are familiar with.

Along the spectrum I believe my eldest son Brenton falls within the mild to moderate level and my youngest son Jayden within the moderate to severe level coupled with a propensity for extreme violence.

I believe that a lot of work still needs to be done in recognising the depth of psychiatric illness associated with Autistic Spectrum Disorder along with the impact that it has on the sufferer, the family and society as a whole.

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

Carers have a diverse role to play in their caring position dependant on the type of disability involved. There can be heavy lifting or restraint management involved, sleep deprivation, endless appointments to attend, medication to collect and administer, behavioural management to implement, adjust and uphold, extra home duty chores such as; more frequent changing of bed linen, cleaning, specialised food preparation and extra laundry.

The Carer's role is constant. The Carer is on call 24 hours per day, seven days per week with most of us receiving little or no relief from our caring role.

Carers should be recognised as worthwhile contributors to society. We go about our job quietly and efficiently and receive little or no recognition or adequate income for our efforts. We sacrifice ourselves in order to fulfil our caring duties and in the process save the government millions of dollars per year. Among the 2.6 million carers throughout Australia a large proportion rely solely on government payments as their only source of income. My income consisted of Parenting Payment, Family Tax Benefit and Carer Allowance. I was not eligible for Carer Payment because it was felt that my son was not severe enough for my claim to be approved however I was forced out of the workforce due to the severe nature of his disability and therefore lost income as a result.

- **How this should be recognised?**

By making it known throughout government departments (especially those who deal directly with Carers such as Centrelink) that Carers *do* work and that they work fulltime.

- By rewarding carers for the contribution that they make to society by increasing government payments so that we are at least living on the minimum award wage.
- By allowing Carers the opportunity to contribute and benefit from a superannuation fund. At age 45 I currently have no superannuation owing to me.
- By raising more awareness of the role of Carers and the range of disabilities through advertising mediums.
- By re-evaluating the criteria pertaining to Carer Payment where psychiatric illness is concerned so that the severity of each case is recognised as an individual case.
- By inventing provision of services conducive to a particular disability. There is currently no provision of service to accommodate children with disability where violence is prevalent, for the length of time needed, in terms of the Carer being able to re-enter the workforce (including part-time) or attend College or University even through open learning. The fact that these children are often excluded from school serves to exacerbate this problem. There is no before or after school care or vacation care facility available to Carers of children like my son.
- By providing more out of home respite care housing so that carers are not forced out of their family home in order to access respite. In the early days before my son became too difficult to manage, I, on occasion, did not access in home respite services because I was unable to access alternative accommodation due to financial constraints whilst my son was being cared for in our family home.
- By allowing carers the same rights as other Australians such as the right to work and or obtain an education. One way to do this would be to re-evaluate the current Education Department policy of exclusion of children with disability from Special Schools or by introducing a closely monitored learning environment staffed by a team of specialist Teachers and Psychologists who fully understand the complex nature of this type of disability.
- By educating all parties working within the mental health/disability field allowing them a sound understanding of the role of the Carer and subsequent affect that the caring role can have on the Carer especially when the disability is related to mental illness.
- **The barriers to social and economic participation for Carers, with a particular focus on helping carers to find and/or retain employment;**

I could not work outside of my caring role due to the seriousness of the disability of my youngest son. As a result I have been denied a reasonable income, superannuation, annual leave and am forced to live just above the poverty line.

The seriousness of my youngest son's violent behaviour prevented me from continuing to remain in part-time employment as he was constantly excluded from educational settings due to Education Queensland's exclusion policy. This aspect also denied me the right to further my education as I could not access a university course due to the lack of provision of service. I could not access open learning courses either as my caring role was so constant that I would not have successfully been able to cope with study without a significant amount of respite assistance.

Some other contributing factors:

1. Being placed on a four year long waiting list to obtain a funding package to allow for access to provision of service.
2. Being denied a provision of service due to the fact that there is no service available to Carers of people with psychiatric illness where violent behaviour is prevalent because the providers of such services do not want to put their workers at risk of injury. I understand the Health and Safety issues and Duty of Care that Service Providers have to their staff but where does that leave me and others like me?

Social Participation/Isolation

The fact that sufferers of psychiatric illnesses such as Autistic Spectrum Disorder generally have a normal physical appearance caused a lack of understanding from the general population including family, friends and some health professionals. This caused a profound amount of social isolation to my children and myself because rather than band together and support me in our time of need everyone turned on me and then disappeared and I was left, for many years, to manage in my caring role completely alone.

The fact that I was living in a low-socio economic circumstance as a single parent only served to reinforce the belief that our situation stemmed from a parenting issue and not a disability issue. As a result I have suffered verbal abuse, have been ostracised, humiliated, defamed,

judged, segregated, have often felt embarrassed and have felt, and still feel, like a misfit in society.

At one stage I was so socially isolated due to my son's behaviour that I could not risk leaving the house with him. I remained indoors only venturing out if it was completely unavoidable. I even resorted to doing my weekly grocery shopping online as a strategy to avoid public criticism as Jayden would tantrum severely in public every time I attempted to access the community with him. My only access to a social life at that stage was the internet and although accessing it caused a lot more financial strain it was my main connection with the outside world at that time.

I have not been able to fully participate in a social life because the pension only covers basic human rights such as food and shelter. I don't have the money to take holidays or even afford an overnight stay somewhere. My income does not give me the means to eat out at restaurants nor to buy clothes suitable to wear to these occasions. Every luxury like this that I have acquired has been through borrowing money, which has resulted in my getting deeper and deeper in debt.

Health and Wellbeing

Not surprisingly the lack of government support coupled with the increasingly serious nature of my son's disability caused my health to suffer immensely. As a consequence I have suffered a major depression and continue to struggle with ongoing affects both psychologically and physiologically. My primary source of income is now the Disability Support Pension DSP. This serves to exacerbate the problems faced above.

Economic participation with a focus on finding or retaining employment.

Unless drastic immediate changes are implemented where serious psychiatric illness is concerned this will remain inaccessible for Carers who are caring for someone within the above circumstance. I know of at least one other woman who is headed down the same path as I. I envisage that she and many more like her will end up on the DSP within the next few years if an attempt is not made to resolve these issues.

Finding employment is virtually impossible due to non existent or lack of government provision of service.

Retaining employment is virtually impossible due to non existent or lack of government provision of service.

Education as a pathway to gaining employment is virtually impossible due to non existent or lack of government provision of service.

- **The practical measures required to better support Carers, including key priorities for action.**

One practical measure to better support Carers would be to increase their income to a manageable level.

To improve the waiting list timeframe to receive funding so as to prevent Carers from feeling so desperate for additional income that they re-finance their home loans or take out personal loans or incur credit card debt in order to meet the ongoing costs associated with their caring role. Before I obtained a package from DSQ I had to find an additional \$140.00 per month to pay for my son's medication as the medication prescribed for him, at that time, was not on the PBS.

To listen to Carers and make a conscientious attempt to implement change needed to relieve the Carer of the strain they experience in their caring role.

To raise awareness and educate society particularly public servants of the true affect that psychiatric illness has on the sufferer and their family.

- **Key priorities for action**

1. Attempt to arrive at a suitable conclusion to the problem of lack of or non existent provision of service.
2. Implement an individual needs based criteria within the current Centrelink application form for Carers wishing to access Carer Payment. (note; my son is so severe in his autism that he can no longer live with me or attend an educational setting for more than 2-3hrs per day, however he was not considered severe enough for my Carer Payment claim to be approved.)
3. Increase Government payments to Carers.

- **Strategies to assist Carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for Carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.**

To my knowledge there is no effective planning for the future available to me. I have lost 20yrs of opportunities in order to maintain my caring role including loss of an education. I chose to be my boys' carer instead. What was I supposed to do? Abandon my children? Because that is what it would have taken in order for me to access opportunities available to the wider community.

I am now transitioning out of my caring role to some degree where my youngest son is concerned as he is no longer in my full time care however I am still legally his primary Carer and still maintain all of my caring duties where he is concerned.

The end result of my caring role is that I am now 45 yrs old, still living on government payments, my income is fast depleting as each of my children grow older yet the cost of living continues to increase. I am at serious risk of having to sell our family home and I am terrified of this prospect when you consider that the pension that I am on pays \$276.30 per week and the average rent at the moment is \$280.00 per week. I am trying to beat depression but I find I am fighting a losing battle considering our dire circumstance.

My youngest son is not sorted. He lives with his 77yr old grandfather who has his own set of mental health issues and is therefore not an adequate solution to this problem.

I have always wanted a reasonable quality of life for myself and my children, yet still, after years of trying, I have not been able to achieve this.

Joy