A.O.C. 27/6/09

Submission No. 186

(Inq into better support for carers)

Better Care for our Carers

Parents and carers of people with disabilities have varying experiences related to the person they are caring for in varying levels of intensity. Some parents and carers cope, some cope very well, while the relationships of some family members can be blown apart by having a member in the family with a disability.

The care of people with disabilities is impacted upon by the health of the carers, whether they are a spouse, parent, grandparent or foster parent. In circumstances where the carers are experiencing ill health, the person with the disability can be deprived of the care from the person they depend on. Sometimes this carer is the only one available who can care for this person. This is my situation.

I am 55 years single parent of four children and I work full time as a family worker/case manager for families at risk of breakdown. I am employed by a community service, and the position is funded by the state government.

I am also a parent of a child with a disability. My 16 year old son Michael has Down Syndrome, a Ventricular Septal Defect (congenital cardiac condition), Hirschsprung's Disease (no nerve cells in his bowel requiring surgery and on going paediatric supervision), and a severe intellectual delay requiring one on one personal and physical support.

In my report I will briefly discuss the history of my role as a carer for my son. I will also discuss the barriers I faced as a carer gaining employment, studying, and obtaining after school care for my son. I will describe a brief history of my family situation and the methods I used to care for him and my other children while being employed; and I will also describe what I require to be able to continue to care for my son, while taking care of myself and my other family members as well.

As I discussed, my son was born with a number of medical complications. These were detected when he was three days old. He was transferred from Campbelltown District Hospital to Royal Princess Alexandria Hospital for children at Camperdown and was operated on for Hirschsprung's disease. This was a particularly difficult time for me as I already had three other children, and I was separated from my children's father. My fourth child was not planned, and I had no idea of how I would manage four children by myself, but somehow I was determined to manage them all and survive.

I was glad my son survived birth, operations, and all the interventions. He had many visits to hospitals, doctors, therapists, and specialists. For the first five years of his life he was admitted to hospitals on an average of once every two months for varying conditions. He eventually started school, at Mary Brooks Bank School for Specific Purposes, Rosemeadow. He has survived his frightening introduction to life and has thrived and progressed on a scale I never thought was possible. Raising the family, however, has not been without it's challenges.

In the meantime, I had to make plans. Before he was born I knew I would have a struggle so when I was 28 weeks pregnant, I placed my three year old daughter in child care, and completed a six weeks' full time secretarial course. My plan was to wait three months after the birth of the baby, have them booked into care, then return to work after 14 years so I could support my family. The birth of my son with disabilities, however, kerbed my plans of returning to work. I knew I had to do something so when he turned four years of age I entered him into preschool for one day a week, and I commenced volunteer work with Lifeline as a telephone counselor. I applied and was successful in gaining entry to Deakin University Geelong and completed a degree majoring in Sociology and Women's Studies. I conducted all my studies off campus (externally) and my exams were conducted and supervised through Lifeline as I could not attend examination venues because of the needs of my son.

During this time I gained experience not only through Lifeline but also through sitting on various community management committees. This eventually led to part time work as a casual family worker with Campbelltown Family Support Services. While I worked part time, my son was often in hospital and my other children were attending school so I had to organise my tight schedule to cater for all the families' needs, and customize my domestic situation according to the presenting situation. This took precision timing and contingency planning. No matter how hard I planned or tried, however, something or someone always had to miss out.

I raised my four children mostly in hospital settings, and studied for my degree in hospital settings, often setting up my studies next to my son's hospital bed. I rigidly adhered to my time table and managed to fit most things in, however, my three daughters' education suffered immensely.

As no one could care for them when they were not at school (such as after school when there was an emergency with my son without warning) they were often with me during my son's hospital admissions. As I had no one who could help me with my children, or would help me, I often had to take them with me to hospitals, doctors, and therapists, and as a result, they would miss out on vital parts of their education. Worry over their brother's medical condition and missing key learning components at school led to lack of confidence, lack of motivation and lack of learning opportunities for my three daughters. Teachers at school were made aware of the situation but showed no compassion or empathy for my daughters and were not prepared to make any allowances or provide extra supports for my daughters. Teachers could have concentrated on helping them make up for missed learning by arranging peer supports with other students but nothing was offered to them.

The only respite available at the time was home based host family respite (volunteers) and I would not accept that. Michael had no respite until he turned 7 years when a centre based respite centre was opened. I had limited home care for domestic assistance and when I started work I was informed that I was no longer entitled to any domestic assistance. As a result I continued on doing everything myself, with no domestic help and no home maintenance of any kind. My children's father took the children infrequently, and felt unable to take his son into care because of his complicated medical condition. With limited respite and no assistance, I would often succumb to exhaustion.

I was unable to find any before or after school care for my son. Child care centres were unable to cater for his needs and would not take him. I had to rely on a friend who still cares for my son after school until this day as there was and is no before and after school care for him. In addition he is also 16 years of age so no institution will cater for him and his needs in a day caring situation. He requires one on one care, supervision and assistance. There is no care of any kind for him other than my friend and if she stops caring for him I will have no help to allow me to continue to work.

The care of my son also depends on my health. If I am unable to care for him I have to rely on my three daughters. There is no one else available. My children's father was killed in a horrific truck accident two years ago so my daughters not only have their concerns about the welfare and well being of their brother, they have also lost their father.

Weekends are used for domestic "catch up", as well as taking my son to swimming and dancing lessons to improve his low muscle tone. His weight and muscle tone needs to be constantly worked on.

In order to lessen some of the demands made upon me I referred myself to Home Care of NSW hoping to get some domestic help. I was hoping Home Care could assist me even though I am working. I was also hoping Home Care could provide me with some respite to take my son to his weekend activities. My hopes however, were dashed. Home Care sent a male carer for my son who had a water phobia and appeared to have a physical disability himself. He walked with a limp and he was a gentleman over the age of 60 years. My son is 90 kgs and needs to be assisted in and out of the pool. Although the carer was the only one available, he was unacceptable. As for the domestic help, I have been waiting for 12 months now and have heard nothing.

Recently I have been experiencing severe pain in my knees, especially my left knee. I have had X-rays done and have to have physiotherapy to enable me to walk and continue caring for my son. I cannot have an operation as the post surgery confinement will be six weeks off my feet, an impossibility in my situation. My doctor and I both agree that surgery for me is impossible because of my caring responsibilities.

I am very conscious of my health as a carer, and I do not smoke and drink very rarely. I work very hard to fight any illness and most of the time I am successful.

In addition, I have ongoing concerns involving my financial issues. Although I am my son's carer, I do not receive any benefits as a carer. While I am told I earn too much to be entitled to Centrelink benefits, I do not earn enough to afford private health care cover. With care of my son always a priority, I am unable to plan my son's care if I go through the public health system as the dates of hospital confinement are out of my control.

Ideally private health cover would mean I could have more input into creating a schedule of care for my son around my confinement if I ever need to go to hospital.

I am disadvantaged in accessing adequate health care because of my domestic and financial position. One of my biggest fears is becoming ill and the recovery period being interrupted by my caring role. It has happened once when I developed pneumonia three years ago and was confined to hospital for one week. During this time my children cared for my son, but when I was discharged I was left to care for him while I was extremely ill and trying to recover. I am hoping I never have to experience this situation again.

The inadequate amount of respite available does not help reduce the intensity of my role as a carer. The limited amount of respite available only helps to meet the care needed for my son during school holidays. I am still dependent on my friend to care for my son after school, and use the respite I get to work during the school holidays. I receive an average of ten days every three months' respite. I save my annual leave for emergencies but occasionally I have to take time off from work to avoid extreme fatigue. I have to keep healthy and fit and often work out, exercising and maintaining my health to avoid illness. I still have to care for my son if I am ill, no matter the extent of my condition. At this stage of my life, my only real threat to my health is exhaustion brought on by my inability to access adequate opportunities to have a break from my combined responsibilities as main bread winner, carer and home duties.

When I do suffer from ill health I am unable to access private health care cover, including private access to hospital and allied health care. In addition as a carer to a child that is totally dependent, because I am a public patient I cannot recuperate in hospital; I have to recuperate at home. As recuperation at home is impossible my health is difficult to maintain with lack of needed social supports from the community. My health is unnecessarily at risk.

Various institutions may feel they are saving money by not putting assistance in place, but such a practice shortens the time that I will be able to care for my son independently, meaning who takes over when I can no longer care? The government departments will have to pick up if my health breaks down.

In conclusion, it makes social and economic sense to look carefully at ways to preserve the health and well being of all carers. Carer breakdown equates to increasing state and federal debt to the economy.

Recommendations:

- Provide more supports to single parent carers to enter the workforce, eg, adequate care for their child with a disability. Where are the supports for working parents of children with disabilities? They do not exist. This creates even more stress for these families, impacting in psychological health, financial independence, and career opportunities. Think more on this one. No thought has been given to it at all.

- Assistance for study for these parents, supports in the home in the form of domestic care and help,
- Access to private health care coverage for immediate medical attention of carers and an extended range of recovery supports.
- Access to alternative health care systems such as gymnasiums and workout classes to improve and maintain health of carers.
- Support systems (individual supports) for parents of carers trying to access employment, perhaps a separate group of employers seeking to employ carers (see department of commerce project – the encouragement of employers to employ mature aged carers who have proved their capabilities of planning, and contingency planning, strategies, and scheduling abilities, handling responsibility, and developing their own networks for support and interventions).
- Ensure options for home recuperation for carers.
- Increase options for domestic help. Services such as Baptist Community Care and Home Care of N.S.W. are supposed to provide help but are inadequately staffed and do not follow through.
- Increased respite available so that families can access monthly respite.
- Consider accreditation for young carers' and their experiences as being a valued contribution to society and the community. Their role needs to be rewarded through education institutions, rather than ignored and treated an invisible personal problem. Support the Education Department to come up with ways of supporting students who are young carers for siblings or other family members with disabilities. There could be many ways that the Education Department could help without going to extra added expense. Perhaps provide teacher telephone support and/or a responsible peer student to help the student catch up on missing learning components. Written detailed explanatory information in hard copy as well, and an adjustment of learning outcome requirements, as well as assessment adjustments, and perhaps recognition of young carers' roles as recognized in learning curriculum. Reports from the young carer about their experiences can count towards assessment marks. These experiences are social learning experiences and should be recognized as such.
- Increase opportunities for access to weekend respite for carers.
- Increase respite options for working carers.
- Measures to be put in place to preserve the health and well being of carers by providing increased access to free or nominal cost private health care.
- Ensure extra options for recuperation of carers after medical intervention.
- Assistance to access a model of private health care ensuring immediate and adequate intervention and hospital recuperation.
- Immediate respite during my illness for confinements, recovery and recuperation.
- Caring centres for people with disabilities of all ages for before and after care.
- My employment opportunities are directly impacted and dependent upon the flexibility of my son's care options. At this stage he has no care available with the excemption of private arrangements I have been able to make with a friend.
- Consideration needs to be focused on developing and expanding on care of the person with the disability so carers can continue to work uninterrupted.

When my son finishes school I want to continue to work, both for financial reasons and personal reasons. Working and concern for our future also impacts on my health. I need assurances that my child leaving school does not mean the abandonment of my ability to keep working. For the financial upkeep of my family and my own choice to keep working, I need to continue working to be financially independent.

Carmel