

Sue

26th June, 2008

The Committee Secretary,
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family
Community Housing and Youth
P.O. Box 6021
Canberra act 2600

Dear Secretary,

Re: Inquiry into better support for carers.

I am submitting to the inquiry because of the complete lack of services available on the ground. There are services on paper, but if you attempt to get services for either yourself, as carer, or for person/s with a disability, you will find that you will get the run around, and or placed on the waiting list, to which there is a list for everything.

The ever growing role and contribution of carers in society starts with advocacy, at this time there is no advocacy for the disabled either in local government, department of human services, child protection, relevant state Ministers are at best apathetic. One must go the office of public advocacy, again there is the waiting list, it seems that the plight of the disabled and their carers, is not a priority. This is indicative of what carers face every day. The only time you will get attention, is as some associates have, threatened to harm either themselves or their children. It is no wonder why such a large percentage of carers are on anti depressants.

Carers have long been thought off as willing martyrs, this is not the case, there simply is no other choice. You are often made to feel guilty for asking for services. The services and the criteria for getting services can change within twelve months making *gaining/maintaining services all the more difficult.*

Just imagine, if you will, having three autistic/intellectually disabled children such as myself, only one child has a case manager, (on the waiting list for 6 years for other two) only one child received a funding package, so all the funding is divided so that all the children get some service. (again on waiting lists). Only one child is entitled to respite, 4 hours per fortnight. We are forced by family law to live in rural Victoria, I cannot go to the nearest cinema and watch a movie and be back in time. I don't use this service, as no qualified carer will look after three special needs children on their own for \$16.00 per hour, the job is just too demanding, the risks are too great.

...2/.

...2...

Because post 18 years of age, there is very little services, sheltered workshops, day care available, most carers are torn, forced to live in poverty, without services. We will not stay young forever, we loose the ability to drive, we loose the ability to physically care for the children, but there is nothing, nothing, we can do, so we struggle.

There is a broad based theory among some unenlightened, that all carers are unqualified, uneducated, probably as disabled as their charges, unable to get "meaningful" employment in mainstream society, is this why we carers, are treated as second class citizens ?. What is the moral justification behind this rationale ? - financial.

Dr. Jane Curtis, founder of the Mansfield Autistic centre, was forced to provide care for her own autistic child, this was her motivation for the centre, so she could work in her chosen profession and help thousands of people. Not all of us have the financial backing of family or the ability to be constantly pro active in order to have our children and ourselves cared for. The Mansfield Autistic Centre is the only one in Victoria with 8 beds, helping 32 people per year....there is a waiting list just to get on the three year waiting list. The traveling teacher attached to the centre costs \$50.00 per day.

All services must be paid for, unfortunately, most carers are on a pension, which is in real terms, is below the poverty line, how are we able to fund services, when most are struggling to keep a roof over our heads and put food on the table ?. The main difficulty for most of us, is the fear of death, not for ourselves, this would be a relief, but what will happen to our children, this is the number one concern.

Practical measures are simple, let us care for our children/relatives, without all the other stresses, we know how to do it, we are the best people to do it.... let someone else mow the lawn, do whatever needs to be done inside/outside the home. We should not have to be concerned about financing services, medicals, getting to fro appointments, most would welcome sheltered workshops, so people have ability to socialize with peers, earn money, gain confidence, in a secure, safe, welcoming environment were people are treated with respect. Instead of the current ideology of being socially acceptable.

There are far too many disabilities, to lump all carers in the same basket, we have different needs, socioeconomic, ethnic, religious backgrounds for such easy fix. So here it is, when applying just add one more question....how can we help you. This should be reviewed every six months. But most of all be honest about what services you are likely to get....for us there is nothing worse than being told such service is available, but not in reality, or in your district, or there is such a waiting list, the persons needs have changed significantly, or they no longer fit the criteria. Build the infrastructure needed.

Yours faithfully,
Sue