Submission No. 518
(Inq into better support for carers)
A.O.C. 7/7/08

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

STANDING COMMITTEE
ON
26 JUN 2008
FAMILY, COMMUNITY,
HOUSING & YOUTH

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 submitting to the Inquiry because...

I would like you to know what it is really like for me at home with my two disabled daughters.

I adopted my girls so I went into it with my eyes wide open and I don't regret a minute of it.

I'm a single mum as is 'normal' if your child has a disability.

My problems are accessing appropriate services. It takes a lot of time, energy and frustration to try to find services only to be told there is a waiting list (we have been on a respite waiting list for 5 years).

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1. The role and contribution of carers in society

As a carer, I feel that my role is...

To care for all my daughters' personal care, medical care, equipment needs, As well as cooking, cleaning, washing, shopping ect ect . These needs are for a lifetime, my eldest daughter is 25 and I am still changing nappies, cleaning up the mess she has made, trying to work out what she wants, putting things away so she doesn't break them, as well as bathing, dressing, cutting up her food, cleaning teeth, doing her hair, putting her shoes on again and again, putting on music in the hope she may stay still for a few minutes.

My 16 year old has a physical disability so I do most of the same for her but with more lifting. Then there are appointments with doctors, specialist, dentists, physios, schools, case workers (who keep changing), to arrange and attend.

An other role is to advocate for my daughters and to find services that meet their needs this takes a lot of emotional energy and time often with very limited results.

2. The barriers to social and economic participation for carers

As a carer, I face the following problems …

I no longer work. I receive the carer's payment and allowance, but this doesn't go far with the added cost of disability.

I do manage to go to the gym a couple of time a week (only during school terms) to keep fit.

As I get older it get harder to stay fit enough to handle the physical demands of caring.

What makes it hard to get involved in community or social activities is the time my daughters are out home during the day at school and 'Day Placement".

My 25 year old daughter is picked up after 9am and is home again at 3pm.,

Her centre tells me they *are funded to run programs* from 10am. To 2.30pm. plus transport.

This is not long enough, if I go out I am always watching the clock. An adult placement should be more like 8.30 to 5pm. which would allow more opportunities for me to work or socialize and my daughter to lead a more adult life.

I went to a meeting the other day where we were told that we end up receive only 30% of funding. The other 70% is leakage as it comes through the system to us. Surely this can be done better and more efficiently.

Retirement is something that I don't even think about, it can never happen as things are.

There would need to be a massive improvement and availability in housing for the disabled both in respite and permanent care. I worry what will happen to my girls when I die.

3. The practical measures required to better support carers

As a carer, I need help with …

Funding is like winning lotto, some people seem to get plenty while others with similar needs miss out. There has to be a simpler and fairer way to receive funding. I will not beg or go into crisis or become the 'difficult' parent to get what I need. It needs to be easier to receive adequate services.

Funding should meet the needs of the family, my daughter love the rhythm of driving. It calms her down and keeps her happy. I can get respite which I don't need but I can't get petrol for our van which would be a great help. The cost of a wheelchair accessible vehicle frightening.

4. Strategies to assist carers to access opportunities and choices

I think the Government can better help carers by …

Funding services that run good program for people with disabilities eg. Yooralla.Noah's Ark.

Carers allowance could be increased on a sliding scale depending on the needs of the child's disability, this would allow parents to better meet the needs of their severely disabled person.

Better access to respite houses (a lot of beds in respite are full of people waiting for permanent places. (They call this the respite shuffle.)

Availability of permanent housing (for when I die) !!

Day placements for adults with disabilities to run from 8.30 to 5pm.

Incontinence aids funding to cover the real costs. At present it only covers about ¼ the cost.

Funding for vehicles modifications.

JUST MAKE EVERYTHING EASIER AND FAIRER PLEASE !!!

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for carers in Australia.

Yours sincerely

Print your name

Kerryn

Date

23/6/08