Submission No. 1021

(Inq into better support for carers)

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1 July 2008

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

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youths Inquiry into Better Support for Carers.

I am submitting to the inquiry because I am a the Mum/carer of my gorgeous son who has

Autism and Pervasive Development Disorder (not otherwise specified). I also have two other

children, one who has self harm issues and could get a diagnosis of Pervasive Development

Disorder (not otherwise specified). We chose not to go through with this diagnosis as it

would not be beneficial educationally, emotionally and financially. For this child I travel five hours every month to a private specialist speech therapist with no financial support and we are on one income. Without this speech therapist and a psychiatrist '(that we save up to see once a year) my 9 year old child might not be alive. All three of my kids have had speech problems from an early age and this has manifested in learning and social difficulties.

As a Carer, I feel that my role is extremely undervalued. We live in a rural area and have

limited government funded resources. I get \$52 for helping my son. This doesn't even scratch the surface on all the educational supplies, I love him dearly but I get overwhelmed emotionally and financially. My husband has had to get a casual job as well as his full time employment. While this helps financially, it is causing far more conflict by him not being around. For me as a Mum this has meant I have not been able to go back into the workforce as I am constantly on call being a safety warden, speech therapist, psychologist and occupational therapist. I work daily with my autistic son to provide life and educational skills. Our house looks a preschool rather than a home. I also have to fit in helping my daughters as they obviously require extra attention and strategies.

I face the following problems living in a rural area. My son is a Department of Ageing

Disability and Homecare client. His diagnosis was horrendous. The paediatrician is a five hour round trip we had to take the three kids with us. We were told if we wanted a speedy diagnosis we should pay for it all privately. We paid for a speech and an occupational therapy assessment travelling five hours respectively, taking time off work and finding care for our other two children. When we ran out of money the DADHC then sent us on a six hour trip to the psychiatrist. The only joy we had was when the psychologist came to our home to assess our son. This whole process took six months! The worrying thing for me was that the paediatrician told us that with a lot of early intervention there may be some hope for our son. Basically we had wait over six months to receive a piece of paper from a psychiatrist to say he is autistic and needs intervention. IT TOOK SIX MONTHS BEFORE WE GOT ANY KIND OF HELP! I've got to tell you that the amount of paper work involved in looking after someone with special needs is ridiculous. We were grieving and broke.

He gets one hour of early intervention a week thats all.

There is no special school here in Deniliquin. I put him into preschool early, I found we could only afford two days a week and that is with his wonderful Grandparents assisting us financially.

The DADHC supposedly supply us with Speech therapy, Psychology, Occupational therapy and Psychiatry. These are all consultants and do not work one on one with my son. The Psychiatrist is based in Melbourne and is extremely hard to contact so I just don't put myself through the stress of dealing with him. The speech therapist is a part time worker who covers a very large area, she has visited once in the last six months. When I am at my wits end I have to go to Community health to try and see a speech therapist. The Psychologist is available by phone from Albury we have only seen her once since his assessment 3 years ago. The Occupational Therapist is a wonderful person who works for both DADHC and Community Health, she helps when she can, but is very time poor as she also has a large work area to cover.

I need help with regular/weekly speech lessons, occupational therapy, some on-line

psychiatry and psychology for our whole family. I know in a rural area this is not possible, so special needs kids from Deniliquin should get preschool for should be free and should be offered four days a week with a full time aide at any age. Subsidised broadband internet to make lives easier as we can not easily leave the home and also it helps to provide education.

In rural areas the DADHC should be able to work with Community Health professionals when

dealing with special needs kids, so the kids and their family get the resources they require. These `departments need to be flexible in these circumstances. You employ professionals let them use their judgment in a case by case approach.

We have chosen a private primary school for our son next year as they are offering him a full time aide (two part-timers as he needs a lot of help) and also technologically based help. We kept getting told by the education department who hadn't even met our son that a full time aide would be highly unlikely. I don't want my son to have an aide for his entire school life, he just needs one to keep himself and the other students safe for hopefully the first couple of years of school.

The government needs to realise I am doing a full time job. The days my son is at preschool I make up lessons for him on his boardmaker, make pecs pictures, helping at the schools and I am actually able to go to the shops. I can not shop at night when my husband comes home as he goes straight out the door to his other job. I can not take my son places as he has meltdowns and can become unsafe while I am trying to drive.

I deserve more financial help and our family as a whole also needs helps both financially and psychologically.

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

Yours sincerely

Leesa