

A.O.C. 10/6/08

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Sent: Wednesday, 4 June 2008 11:10 AM
To: Committee, Reps (REPS)
Subject: Inquiry into better care for our carer's

Dear Chairperson,

I am the parent of two children with Asperger's syndrome.

I have tried in the past to access support in helping my children and my family but have found it immensely difficult to do so.

I keep getting refered from one group to another and somehow falling through the cracks to get support.

I cannot get respite on an ongoing basis as my children are not registered in WA with disability services who do not recognise Aspergers as a disability sufficient for me to need help despite the fact that the child have such intense social difficulties that their school attendance has been threatened. My son homeschools and has done so for more then 2 years on the advice of his Pediatrician yet I get no help form the WA state.

I cannot access temporary respite because this stresses out my children so much that it is more distressing to get respite then to not have it. My children cant cope with being looked after by a stranger yet the only respite I can assess is temporary and not ensured to be people trained in the needs of autistic children. The only respite I get is when my mother looks after the children for me and even then my daughter acts out for a significant time before and after my absence.

It would be extremely helpful for me to get someone to come in and do a little house cleaning yet whenever I have asked I have been told that is not available or only a temporary basis which again is not useful as the stress of a stranger coming in to the house negates the benefits of having a cleaner.

To find help I am forced to go begging time after time and then get turned down time after time. I have had several visits to my house which the government has paid for where people have come in and said that they will go looking for help for me yet in the end I have only had very little help from these vists compared to the cost to the government. Mostly these visits end up with people telling me that I have to provide yet more therapy for my kids and this is how to do it. Yet more pressure on me to be superwoman and not really the help I need which is to get a break from the constant pressure and to have someone come in and take a bit of pressure off by giving my house a clean out.

I wonder if it might not be more useful to give out vouchers for the services that may be available to people who qualify for carers payments of anysort. That way the vouchers can be used to provide a few services that would actually help me instead of hurt. Every time I have to sit down and say to people that I am not coping it inflicts more hurt on me and my children and yet nothing ever comes of it. We are forced to beg for help and not get it.

Do I need help? Yes I do. I am currently on Antidepressants and have to homeschool two

children. I have been forced to fight the government to supply my son with an education and they are still refusing to do so. I need help that is not being supplied even when I beg for it. The current system provides a really good income and career to people who are desk jockeys yet provides very little in the way of help to the people who desperately need it.

If you took into account the costs for running the offices, sickpay, superannuation, travel costs etc I doubt more than 50 % of the money spent actually ends up supporting the carers.

I would rather have vouchers for care and respite than to have to explain my situation to yet more people who go away, come back and say This is all we can do for you.

For me and for other parents of autism spectrum children the system provides a career for people who do little to help us provide the support our family needs.

Thank you for allowing me this chance to have my say.