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Sent: Friday, 17 February 2006 2:27 PM

To: fths.reps@aph.gov.au

Cc: mail@aafcd.org.au

Subject: WORK/FAMILY BALANCE - AND THE PLIGHT OF FAMILIES WITH DISABLED CHILDREN

Dear Mr Catchpole

I am writing to you as a parent of two children one who is severely intellectually and physically impaired - he also has uncontrolled epilepsy which means he is often raced to hospital or I am called to collect him. To add to my problems I am divorced and my ex does not share custody of the children so I am in the situation where I need to work but have to find care for the disabled child which is almost impossible.

My son is eight years of age and I have been trying to find a service that would take him for years - he went to a daycare centre which accessed SNSS funding which meant the centre was given funding for a person 5 hours a day to assist the group - but my son was in care 8-9 hours a day - I was just lucky this centre was open to special needs children - I was refused by many centres in the local area. That was fine whilst he was able to be cared for there but I also had the situation that he was getting older and he really shouldnt be spending his days with toddlers - how can we expect our children to mature and develop as much as they can if they are not in situations to help/demonstrate maturity.

Finally the centre advised me that Tom could no longer go as he was too old and then the dilemma started! I rang and went to see many organisations - OSHC and finally found that Carina Family Daycare had a mum that would be able to take Thomas on the school holidays as her numbers dropped - this was a godsend. This service is more expensive than normal vacation care in OSHC - I am on the top percentage Child Care Rebate and it cost me nothing to send my daughter before she started high school but it costs about \$10-12 a day after benefit and I have to travel 28 kms per day to get him there and pick him up. This does not solve the problem of before and after school care - there is nowhere he can go I am just lucky that I am working part-time and the other times my mother is happy to have him - but she is getting older and they want to travel like most people do in retirement.

The problem also arises when Tom is sick - no-one to help with care I have to take time off work. I have access to respite 5 hours per fortnight but this is in the evenings and only for social purposes - if I wanted a carer for after school it would cost me a fortune - no subsidy or funding approved for that the service tells me.

I am really facing the situation - that I dont know how long I will be able to continue to work unless there are some systems in place to help with his care. All service providers are stretched and that is what you are told when you contact them. Most single parents that have children with disabilities are at home trying to survive on a carers pension - I dont want that I want to work and give my kids the things they deserve and need.

I hope that your committee will look at the problems that face parents of disabled children - we dont have a normal life - work, let the kids go to OSHC/vacation care because no one wants to help us - we get limited assistance through the government - not that I expect anything handed to me on a platter but I have always worked hard and paid my taxes and want to provide the best opportunities for both my kids and when I see money being handed out to people who have never worked and rort the system it makes me angry.

I would love to see the government acknowledge and start doing something about the plight of families with disabled children - why cant more facilities be set up to provide care for these kids - if there was a monetary incentive for OSHC programs to take these children maybe they might be open to it - or why cant more funding be given to the special schools to set up programs for after school - they have the facilities there to care for these kids but as I know my sons school doesnt have the funding for such a program.

I I hope my letter has given you some food for thought and if you would like to discuss these issues further I would be more than happy to speak to you.

My details are listed below.

Kind regards

Annette Milburn

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