

Submission No. 1185

(Inq into better support for carers)

Asc 4/8/08

I have struggled to get this submission in, but feel this is an opportunity that I should not let pass. A Personal Assistant would have been handy! I started this a fortnight ago (as soon as I heard about it) and the 4th has come and gone.

I have been interrupted to clean up faeces, settle disputes, calm a distraught autistic child, answer business calls, go to the physiotherapist (for me), speak to the School Principal, speak to the other School Principal, take Oliver to the podiatrist, to the Naturopath, shadow Oliver so he is safe, shadow the sibling so that Oliver is safe, spend some one on one time with Sarah, (the sibling), so I don't feel so guilty, prepare the gluten and dairy free diet that I know has helped him speak and that she refuses to eat, put in some time for fundraising, find time to have that blood test (the request has been on the fridge for 4 months), go to the physio for a follow up, fit in some work around the kids school hours, see the school counsellor about the sibling with the issues, try and get the exercises done that the physio recommended, set up the house so

7/07/2008

Oliver's auditory issues are a bit easier to deal with, try and fit in my session with my counsellor to deal with my stress load, ahhh. I am so tired. And all I want to do is put it into words how I feel and what I need.

And how should the role and contribution of Carers in Society (are we really "in" Society?) be recognised?

*Possibly a medal? Acknowledgement is a great thing if all of your other needs are met.

*I haven't been "in" society since I stepped into the world of Autism. It is so isolating and often I am too tired to be able to deal with "normal" people when that is the most important need of my young family. I struggle to sort out work commitments with the needs of my family and you guessed it, I put my family first. One of the ways of this world right now in acknowledgement and recognition is of a monetary sense. This would also enable the carers to better provide the services and therapies that our "cares" need, or at least give us a better choice. Who else could care for my son as good as I do but his mother.

What are the barriers to social and economic participation for carers, focusing on helping carers to find and/or retain employment?

*I haven't participated successfully, economically or socially since before Oliver was diagnosed at 2 years old (9 years ago). I am self-employed, so have one of the most flexible employment situations, but this did not meet the criteria for Centrelink's welfare to work, because I could not provide the volume of hours needed to produce an income after the expenses were taken out. I actually go out to work as therapy and as an escape from my commitments at home. I went through a horrendous 8 months dealing with different staff at Centrelink all telling me something different each time I went there for an interview or depositing forms, sometimes waiting up to 45 mins with Oliver and Sarah in tow. Autism doesn't "do" waiting.

What employer would tolerate workers to leave at a moment's notice to support their autistic child on a regular and ongoing basis. In today's economic climate who would expect them to without some financial compensation. Again it comes down to the dollar.

And what about the practical measures required to better support carers, including key priorities for action?

*Would you be able to give us Hope? This is one of the most important factors in my daily life and each day hinges on totally relying on God for hope for myself, my son, my daughter, for the present and future.

Practically, I need financial support to provide services that I know would benefit Oliver. The key priority for action for supporting me individually would be to make my caring role easier by enabling me to support Oliver in every way that is best for him, whether it be by diet, supplements, speech, OT. All of these choices are very expensive and when my earning capacity is so challenged it all comes down to the dollar.

The Wider Community. We're not talking about being overweight!! Strategies to assist carers to access the same range of opportunities and choices as the wider community including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring and effectively plan for the future.....

* There's a lot in that one!

I cannot go as far as "the future". I was at a Carer's relaxation meditation group and the leader suggested we imagined travelling up a river with our "cares" and stopping at a jetty and putting them off.... I imagined my son falling off the jetty and drowning. I am not a true pessimist, more of a realist. I'm happy just dealing with today, as it is. I should rephrase that. I cope better dealing with today and not worrying about the future because it becomes too bleak.

I don't get "the transition into and out of the caring", I have had no choice about getting into it and the only way out is a death in the family and I don't want to go there either!

Again, to get to the same range of opportunities and choices as everyone else, we have so many more issues to deal with, with a lot less, or no support the only way to achieve this would be through the power of the dollar.

I am a single parent (stress was a big factor in our marriage breakdown) and struggle with day to day living with an autistic child let alone the pressures from society to be normal as well as the financial burden of a special needs child, with a sibling with issues. It's a sad sign of our times but yes it comes down to the dollar. You ask me what I need, unless you want to come to my home and clean up the poo, wipe away my tears, deal with my daughter, cope with my work and kids when it all falls apart, yes it's the dollar!