

June 3 2008

CARERS INQUIRY SUBMISSION

NEW CARER

SUMMARY

The role of carer isn't a career choice. It is a hideous, permanent role forced upon mothers when their children are diagnosed with autism. There are 125,000 mothers in Australia just like me which I am sure make up the single largest subcategory of carers. The hardest thing about being a carer is government agencies seem to think we are toothless morons who cannot choose appropriate therapies because our children have disabilities. Most of us are intelligent, normal, hard working people with an ability to read the mountains of information out there as how to best help our children. What we don't have is the funding and resources to act on that information. And we don't have a future.

1. Recognising the role of carers

On top of my fulltime job I engage in specific therapy (ABA therapy) with my son for a further 20 hours per week and spend approximately 10 hours per week preparing his therapy. (That is a total working week of 75 hours.) I know what works for my son. He has made great progress. Yet none of his therapy – which costs about \$700 per week – is covered by Medicare. The \$50 carers allowance barely scratches the surface. When you contact politicians you get shunted off to secretaries and the like who have no idea what is best for each individual child. I recently wrote to Kevin Rudd regarding early intervention funding and got a response from some secretary in the suicide prevention unit! My son is autistic, not at risk of suicide just yet. It is a complete insult for intelligent people to be palmed off like this.

Recognise the role of carers by giving them proper, genuine **funding** now for effective, intensive early intervention to **reduce the demands of caring** in the long term.

2. Social and economic barriers

Working mothers of autistic children don't have time for friends or socialising – and you don't take autistic children anywhere unless you absolutely have to because they make such a fuss and it is such an embarrassment. This term of reference is an irrelevant extravagance which shows how little government understands about carers and indeed about autism. The last time I took my boy to a café the menus were thrown at us. Yet I had been to the same café with my older (normal) child many times. We are just not wanted. And the last thing I want is to hang out with a bunch of autistic families. I want my son and my life to be as normal as possible.

Exclusions from normal playgroups and childcare make it difficult for the children to learn socialisation. Funding six autistic childcare centres as the government has promised to do isn't exactly going to cover all those children, is it? And how does being in with a bunch of severely autistic children help my less-affected child?

Paying for therapy is a massive drain economically. It robs you of your savings, your super, your mortgage redraw, and any opportunity the family might have had for a decent life after 20 years of hard, honest fulltime work. Because my son's therapy isn't funded, we will end up pensioners rather than self-funded retirees – if we live that long - the government pays for this at some point. It sickens me that there is no government funded intervention for autistic children, other than maybe two hours a week of irrelevant, completely underfunded DAHDC therapy if you are lucky enough to get spot. Nine months down the track we are still waiting for that.

Yet everything for deaf children is completely government funded. Why one rule for one disability and one rule for another?

3. Key priorities for action

++Fully fund intensive early intervention for 20 hours per week for all autistic/ASD children, thereby **reducing the pressure on carers to be carers**, mothers, therapists and breadwinners all at the same time.

++Government departments to treat carers as intelligent, informed human beings. Sending us to Centrelink to claim carer's allowance was the most terrifying experience of my life with all the drug addicts and alcoholics pushing and shoving and screaming. No carer should ever have to do that walk of shame. I haven't done anything wrong and shouldn't be treated like a moron. Treat me like a normal, working human being, please.

4. Transition into and out of caring

If only there was such a choice. I didn't choose to go in; God will decide when I get out. Again, an irrelevant term of reference which shows no understanding of the hell in which we live and the fact it is forever.