Submission 26th June, 2008

Submission No. 484
(Inq into better support for carers)
A.O.C. 7/6/08

From: carers of an 8 year old autistic girl – my husband and I share this duty and have both changed to part-time work to make sure that one of us is always available. She has a negotiated attendance at public primary school for 8 hours a week after the first attempt at mainstream (only place available to her, no specialist class or school offered) fell apart entirely.

- the role and contribution of carers in society and how this should be recognised;

The number of carers is currently unknown in the community. This should be the immediately ascertained. Plenty of people are completely unaware of carer payment and allowance (and why are they called 2 such confusing things – I had no idea for 6 years that the 2 existed or what they did). So the overall contribution role has yet to be established and can certainly not be taken from the Centrelink payment system.

It is clear that the contribution is enormous and comes at a huge price. That price is financial, physical and mental. We know that the incidence of depression and other medical conditions is higher than for the the normal community and we have have never made any attempt to address this to our shame. We know that the vast majority of parents of disabled children end up divorced. We know that these people work 24 hours a day and that many of those they care for do not ever sleep though the night so on top of all the rest the carer is chronically fatigued and sleep deprived.

How to recognize this; by financial, physical and emotional support. The only one they even try to go for in our case is the financial and ninetysomething dollars a fortnight is not exactly supportive.

We have taken an income drop in the order of $150,000 a year to care for our child. We would have been starting to seriously look at our retirement plans if we were not in this situation but no such luck now. We have funded our own early intervention form aged 2-6 and worked in the program ourselves for 40 hours a week for 4 years. We have paid for speech therapy, psychology and occupational therapy for years for our daughter.

- the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment

Carers are fully employed and doing ten ton of overtime already – they just aren't paid for it. Not only that, I have to shop, clean, cook go to my own appointments and attempt to keep fit all in the 8 hours a week my child is at school or pre/post my own work when my husband is the primary carer. I homeschool her for the rest of her education and all her core education is taught by me. School do not even produce an outline of what her class is doing so that I can make sure we keep up (too much trouble for them). How about a proper education system – in our state every special small class is vastly oversubscribed and the rest just mingle back into unsupported or only just supported mainstream. Why no autism satellite classes in SA like they have in NSW? The final educational straw for me was when I told her first school that things were about to fall apart (she was only part time anyway, aged 6) and the district director told me I was an overanxious mother. Two weeks later they were begging me to come and retrieve her from the table she was hiding under howling and I then had her at home full time for the next year before any other placement and support was organized.

Social participation requires respite and that respite has to be high quality and qualified. Nothing exists unless you pay for someone and train them yourself. I wouldn't put my autistic child in the one respite home there is in this city – she would loathe to be in that sort of mayhem and it would make her highly anxious. So I train up and pay for someone to come in occasionally so that we can go out together as husband and wife. But frankly, I'd rather go to sleep than go out. I have no interest in socializing – I am too tired.

Working in the community and caring. Well, the only way we do it is by having one of us caring and one working and changing that around over the week. We are fortunate to be in demand as tertiary educated professionals who have no trouble finding part time work. A single carer can only work if there is adequate respite on offer and as this is as rare as hen's teeth you rarely meet one who does anything outside their home.

I have friends who care for autistic children who receive weekly demands that they be picked up from school to give the school respite!!!! No job is going to stand for that and although the tough might tell the school where to go it is rare that anyone refuses to comply as their child will clearly be very stressed by this point and actually would benefit from being taken out.

- the practical measures required to better support carers, including key priorities for action

IT IS NOT ENOUGH to throw out money. You can't actually go out and easily buy the respite we need. I need someone my child likes, someone who understands her autism and her giftedness to come in and take over from me on a regular basis. I need a proper educational placement for her that she goes to like every other child. I would like not to be her primary educator. I need to be able to do the things that we know help the chronically depressed like regular exercise and meditation but that I never have time to do. I need to know that there is a plan for her future if she is not going to be able to work and care for herself.

Why is there nothing advertised by govt for carers? Even the things that do exist are not advertised on TV or in magazines.

No mother of an autistic child should have to sit in Centrelink with a melting down autistic child trying to get paperwork lodged. Why can they not do appointments like the rest of us provide our clients with?

- 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 is no choice at all for many, many carers unless you are desperate enough to throw your dependent on the steps of social services and run off to another country under an assumed name or stick a pillow over their head and hope that the jury accepts that you were out of your mind. I always thught that these people were truly wicked until I found out what it is like to be at the end of your tether. Now I know that they are not wicked at all - just overwhelmed and so, so depressed that you can see no future. I had never reached this level of despair before but now I have true insight and it makes me a much more sympathetic person and doctor. This is your responsibility until the day you die and heaven knows what will happen then. This is a huge burden to bear and the main reason that so many carers are on antidepressants - they sort of numb the worry for you and let you detach a little from it.

There is no access for the majority to supported accommodation and care so I suppose this area should be a priority. I have no idea if my child will ever acquire independence or employment. I know that no one apart from us has any interest in helping her to achieve this. I know that any transitions will be paid for and arranged by us in the current system. How lucky we still earn money. There should be case workers for these children whose job it is to arrange self help skill classes and transition living arrangements but we don't possess anything like this and I can not see it happening in my lifetime.