

A.O.E. 2/7/08

Submission No. 431
(Inq into better support for carers)

Date: Thu Jun 26, 2008 11:35 am

Subject: Inquiry into better support for Carers

To Whom It May Concern

I am a 35 yo mother of three autistic children, with a husband on a disability pension. Our daughter (Asperger Syndrome) is 10 in September and our twin sons (Autism Spectrum Disorder) will be 4 in July. All three children were diagnosed in July 2007. At the time, the boys were non verbal and our daughter was dealing with many difficulties at school.

The news that all our children were dealing with this devastating condition was extremely difficult. I was faced with having to make the difficult decision to leave work on carer's leave to take care of all their needs. I applied for Carer's Payment in August, which was rejected. I knew that my twins needed urgent intervention to have any hope at a normal life and this pressure was too much to cope with. I ended up having to leave work due to having a breakdown and ended up spending 9 days in Adelaide Clinic in October 2007. This situation placed a huge strain on my husband and his health worsened at that time. I was then put on a sickness allowance.

The medical costs in our household have been astronomical. The boys require OT, ABA, Speech therapy and need to attend child care for the development of social skills. Our daughter requires OT, social skills therapy and regularly sees a psychologist because she talks about wanting to kill herself and requires constant tutoring because she can't do her homework without someone sitting with her the whole time. The children are also seeing a biomedical doctor and the cost of this medication is more than we can afford. Without melatonin (not subsidised!) my children do not sleep!!! This means WE DON'T SLEEP! There is only one out of the four medications that they receive from this doctor, which is subsidised. We keep this up because the results have been amazing. I am asking that special medications get special consideration for subsidies, as they are critical for their development.

In addition, I now need to see a psychiatrist on a regular basis as she is the only person who is able to keep an eye on how I cope with the whole situation. My husband and I also need to have marriage counselling because we are growing apart due to the responsibility and pressure of the situation. Separation has been a consideration when times get really tough and the children obviously suffer!

My main request for consideration is the following:

- That biomedical treatment is considered as invaluable treatment of autism and is made affordable;
- That therapy/medical appointments are bulk billed (this would give parents choice when it comes to who provides therapy, etc - free services give you NO choice). It has been fantastic that there are now mental health care plans where we can claim Medicare rebates for psychology and therapy, etc. I am

extremely grateful that this was in place at the time the children were diagnosed;

- That travelling costs are acknowledged. We go through more petrol now than we ever have and the costs are huge!;
- That parents health is taken into account and that maybe free therapy/counselling is provided. As parents - we are no good to the children if our health is suffering or if the family is separated due to a marriage breakup;
- That parents receive counselling immediately after diagnosis would have made such a difference to us;
- That better education services are provided for our children. My children don't qualify for a special school, and don't 'fit' into a mainstream school. This makes us feel like social outcasts and makes their lives much more difficult than is necessary. A better education system for children with special needs would greatly increase their chances of becoming contributing members of society and to pay taxes;
- Student teachers should have a mandatory subject on children with special needs as in general, they don't seem to know a great deal about what to do and the issues you have to deal with. It impacts greatly on the strain placed on parents and the mental health of our children;
- That being a carer can be a very lonely and isolating occupation where all your hopes and dreams for the future go out the window;
- You can't provide your child with everything they need when on the pension. You can't work because they need every minute you can give them. What a predicament!!!
- That having a child with a diagnosis of autism should automatically qualify you for carer's payment.
- That as a carer of autistic children, you are their parent, therapist, psychologist, health care coordinator, taxi, dietician, play coordinator, tutor, etc, etc..... More than one child with a disability requires you to be a super hero.

After 10 months, I am still fighting for the approval of Carer's Payment. The time I have spent dealing with Centrelink regarding this matter would have been much more useful spent giving my children home therapy. My health wouldn't have suffered as it has because having the Carer's Payment rejected was devastating for me. I felt that my own community didn't care about my children or our family. I felt extremely let down and failed by a system that I have paid a great amount of taxes into over the years.

I am extremely grateful you are undertaking this inquiry and hope that my feedback will assist you to provide better services for people like me. Please do not hesitate to contact me for further information should it be required as I am only too happy to assist.

I look forward to learning of the outcome of this inquiry.

Yours sincerely

Allison