

23<sup>rd</sup> June 2008

Clerk Assistant (Committees)  
Inquiry into Better Care for Our Carers  
House of Representatives Standing Committee on Family  
Community, Housing and Youth  
Parliament House  
CANBERRA ACT 2600

**TO WHOM IT MAY CONCERN**

My name is [REDACTED] and along with my husband [REDACTED] feel it is time to write to you regarding the role as Carer for our son Christopher.

We have been asked to help you understand why the current system of support does not work. We can only comment to you based on our role as Carer's to a wonderful 10 year old boy.

We feel the main issue comes down to the fact that we are just simply not compensated enough for our role...Frankly...we need a lot more funding!!!

For your information, Christopher is Intellectually Disabled, has mild Dystonic Cerebral Palsy, executive Verbal and Developmental Dyspraxia, ADHD and all the associated disorders that come with these four main diagnoses. The symptoms of all of these disabilities we will not go into...but you can imagine that it isn't easy.

[REDACTED] can work up to and over 60 hours a week. I, up until recently, worked two jobs to keep up not only with the rising cost of living but more importantly so we can keep up with the amount of therapy Chris requires. Normal Australian families are complaining...imagine what the families with a disabled family member/s are going through? (Do we eat or fund therapy????)

We feel one of the key areas that needs to be revised is Carer Allowance and Carer Payment. It needs to be made more assessable. It needs to take into account the role of the carer not only caring for the individual, but the actual **COST** of caring. Add to this that there is not any consideration for carer's who have issues with illness etc themselves nor any support! I myself have SLE (Lupus) and have had for over 25 years. Sometimes it does get "Very Hard" having to take care of Chris when I can hardly take care of myself! There doesn't seem to be any allowances for extraordinary circumstances...nor assistance for carer's with illnesses. We don't know why but it is a BIG issue...

The one allowance we were able to secure for Christopher is the Carer's Allowance. This allowance is approx \$100 a fortnight. With the current cost of petrol, the Carer Allowance of about \$55 a week only just covers petrol required to take our son to the many therapists, psychologists, doctors, paediatricians etc he needs to see.

Then there is the paperwork. Has anyone looked at the process of applying for Carer's Allowance or Payment? The paperwork alone and the requirements that go along with applying for these payments are so involved, that quite frankly, you just give up even trying to apply and really who has the time to get it all done? Then you question why you need to confirm that your child has a disability to Centrelink when he already is acknowledged as Disabled and registered with Disability Services? Why double up...don't we have enough to do? We would challenge anyone to spend a week with us in a caring role and see if they have time to apply for services (filling in page after page of forms) let alone run around getting doctor's reports and then sitting at Centrelink for hours on end waiting to be seen. Honestly, panic set's in when we are sent forms for renewal of Carer's allowance. It just takes forever and costs even more when a doctor needs to be involved in the process.

Then there is the services provided at school. Therapy Focus, Rocky Bay for example. The best these wonderful services can do is offer advice. They are simply not funded adequately to be able to provide much needed therapy for example one on one Speech, Occupational Therapy or Physio (The Basic therapies). We can tell you frankly that trying to offer advice to teachers who are trying to teach approx 30 students on how to help your child with his pencil grip just doesn't work. This is the best that can be offered as there just isn't enough MONEY going into these important Service Providers.

Long ago we were introduced to the fact that any help Chris needed in the way of therapy would need to be funded by ourselves...and we have tried to do our best. We have been able to somehow pay for Chris to see a private Speech Therapist and an Occupational Therapist, funding it with private health care and our own funds (including extracting money from our Superannuation Funds). To give you an overall picture, Speech and O/T each cost \$80 for a 45 minute session. Chris currently has fortnightly Speech and sees the O/T for two terms per year. What he requires is weekly sessions of both. We simply cannot afford it. Factor in psychologist bills, doctors bills and paediatrician bills, just to name a few....and you should get the picture as to how much it costs. Where is the Help? Again, we repeat, the lesson was learnt long ago that there really isn't any help...we would need to do this ourselves...or he misses out.

To take care of Christopher's personal needs is not easy. To then have to carry the guilt that you could be helping him so much more but cannot afford to, to us, is unbearable. We are grateful and consider ourselves fortunate though, that we can at least afford some therapy. My heart goes out to Carers who are unable to work, who are single parents, who are caring for more that one. How do they survive, let alone be able to fund therapy?

My advice to the committee is to try and see the **BIGGER PICTURE. HELP US TO HELP YOU.** The disabled child will grow to become the disabled adult. With assistance now the financial implications to our country would lessen as to would the support needed in later years (if there will be any support). Obviously it makes sense to assist now with gains later. We can't see why no one will accept this as fact.

As a family we absolutely adore Christopher and are fully committed to his needs. We would love to be able to see Chris mature into an adult who has reached his full potential and not an adult who requires ongoing care simply because he did not receive the required therapy and support as a child. I am sure that every parent of a child with a disability would love this. It is achievable however, we need so much more help and support than currently received.