

Submission No. 1293

(Better support for carers)

AOC 27/11/08

Sean

The Honourable Kevin Rudd MP
Prime Minister
Parliament House
CANBERRA ACT 2600

Re: Letter from The Honourable Jenny Macklin dated the 6th August

Dear Prime Minister,

Sadly I missed the opportunity to hear what was said at the public hearing for better support for carers held on the 26th September 2008. I was unaware the opportunity existed until I decided to respond to Ms Macklin's letter. The hours were unsuitable in any case as I work.

I am writing to you to let you know how disappointed I am at receiving the notification that our carer's payment will not be continued. My wife and I find it hard to accept the Australian Government has abandoned us in our time of need given the long term benefits the country will receive in the form of reduced disability payments to our daughter Caitlin. Accordingly I would like you to read this and pass it on to the inquiry into better support for carers.

My daughter Caitlin suffers from Cerebral Palsy. She acquired this condition when she stopped breathing soon after a Hepatitis B vaccination on day three of her life. In the eight years since we have been on a rollercoaster journey as we seek to minimize the effects of those few short minutes she went without Oxygen. We have had to deal with depression on a daily basis.

Only those in similar circumstances can know:

- What it is like to watch your child miss all their milestones.
- The pain of knowing that they are severely delayed with little hope of them ever catching up to their peers.
- What it is like to field the constant questions of why they are not standing, walking, talking, and doing the things that other children their age do.
- The feeling of isolation that comes because you just don't want to answer fifty questions every time you go out.
- The feeling of helplessness at not being able to progress their development due to a lack of resources in the local area.
- The frustration of finding solutions but not being able to get sufficient contact time to make a difference or worse still not being able to afford them.

In my own case this past year has been a particularly hard, as I battle on at home my daughter is making amazing progress in Hong Kong under the care of Professor Zhou Jiefang. The forced separation of our family has meant I have missed both of my daughters birthdays, Mother's day and Father's day. I receive a daily report over the phone but I am not around to share the responsibility of bringing the children up. Whilst I will be eternally grateful for the support my wife's family have provided; the conditions are extremely cramped and there is very limited contact with other children of the same age, particularly English speaking ones. I have to deal with my wife's exhaustion as she negotiates the incredibly congested Hong Kong public transport system six days a week with two small children in tow. The two hour therapy session each day takes a minimum of five hours to achieve and twice a week she backs up with a double session. This incurs a further minimum of four hours break between each session.

We do this because nowhere in Australia have we seen such progress with a non-progressive disorder such as Cerebral Palsy. My wife deserves a medal for her dedication as she sits for an hour cross-legged until the first part of the session finishes. During that time she holds onto my daughters head with electrical wires intertwined through her fingers and connected to the acupuncture points in my daughters head. This is done so she can control Caitlin's head movements; she goes numb in the legs but will not move lest the needles fall out.

My daughter deserves a medal for tolerating twenty-four acupuncture needles a day with eighteen of the connected to electrical stimulation firing pulses around three times a second. I don't know any eight year olds that can sit still for so long and do so whilst receiving the electrical impulses she does.

Jane and I moved to Canberra on promotion with the government and I left my immediate family in Brisbane. As previously stated my wife's family resides in Hong Kong. We have had no family to rely upon for respite, and no one was able to mind the children until Caitlin was six.

The high cost of therapeutic equipment has also been a barrier to Caitlin's progress. Fortunately for us some of the equipment has been funded through community organisations. The down side of this is; whilst health professionals are recommending expensive equipment to aid mobility or communication the budget often does not stretch that far. The effort involved to apply for funding from community organisations also takes its toll and very often the rejection causes deep depression as you slip into the abyss of poor, poor pitiful me; I am not even able to organize something the doctors have told me my child needs. Your feeling of self worth plummets and you feel like crying because nobody cares about your baby and nobody believes a word you say. Quite often you find yourself justifying every bit of expenditure as you alienate friends with your seemingly endless obsession to better the quality of life of your child. Often we have felt we have had to prove to all and sundry our daughter is not intellectually disabled as she has been unable to answer for herself.

The emotional costs outstrip the financial costs every time but the financial costs are significant. We have kept our head above water by having private medical insurance and using the equity we built up in our home to fund our daughter's treatment. Terry Snow of the Snow foundation has supported our self help group Friends of Brain Injured Children ACT and his philanthropy enabled my daughter to walk.

It costs me between \$250 and \$300 a week for therapy (eight sessions a week). My daughter has been over in Hong Kong since the 3rd April this year and is due to return on the 27th January 2009 in time to start the new school year.

One of the key things we have come to realise is children with brain injuries need frequent intense stimulation over long periods of time. Whether it is swimming or hydrotherapy every night, or acupuncture the key is lots of stimulation every day over years not days, weeks or even months. It also requires a lot of follow up work to continue the gain in movement.

Our experience has already saved the community significant dollars. Now that our daughter can walk she no longer needs a wheelchair approximately \$7000 she is now beginning to talk this has saved us and the community around \$5,000 for the Voice Output Device that was recommended when she was five.

It makes good sense to me to help parents like us parents who put their child's independence ahead of their own needs. We want our daughter to participate fully in the community holding down worthwhile employment gained through mainstream education. In time our daughter will fulfill these aspirations and not be reliant on disability pensions or group housing. I was shocked to find out that a single place in a group house in the ACT costs the government \$75,000 per year and in NSW \$92,000. These figures were taken from the Senate report into unmet needs of the disabled and were based on 2002 costs. You can see my point money spent up front on therapy reduces these figures to \$17,000 per year for those able to look after themselves.

Of course not all parents are willing to dedicate themselves as much as Jane and I and some therapies work for some people and don't for others. The tragedy of it all is if you don't try your child will go down the path that relies more on community / government intervention.

I acknowledge the \$600 bonus and the \$1000 Child Disability Assistance Payment in July mentioned in Ms Macklin's letter as help we may not otherwise received. I would however like to put into context with our on going costs. In Australia \$1600 buys us 11 hours of acupuncture spread over 3 weeks and 13 hours of physiotherapy spread over 13 weeks. As previously stated children with brain injuries need frequent intensive stimulation over long periods of time. It is impossible to get the same level of treatment that we receive in Hong Kong as there are simply not enough booking places available and the expertise is simply not here. It has taken us four years to repair the damage done in just a few short minutes and we are not there yet, but we are a long way towards our goal. If we had taken the advice we would have learned to deal with the fact our daughter was disabled and she would be in a wheelchair using a voice output device to communicate instead of singing and dancing as she now does.

Please forward this submission to the parliamentary inquiry into Better Support for Carers.

3 Oct 2008