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(Inq into better support for carers)

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Megan & Robert

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
PO Box 6021
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

My name is Megan and my husband Rob and our first child Ben (10) welcomed our second child, Lachlan, into the family on 5th May 2003. Lachlan's disabilities began from birth with him suffering from severe Epileptic seizures. He has not progressed well since then and has been diagnosed with Global Developmental Delay, Cortical Vision Impairment, Intractable Epilepsy and is now fed solely via a Gastrostomy button in his stomach. Lachlan is totally dependant on us for all aspects of his daily life and he is now in a wheelchair as he cannot support himself at all, either sitting or standing. He cannot speak and does little to communicate with us or his therapists. He cannot hold or grasp anything which I'm sure is not helped by his vision impairment.

I feel that both mine and Rob's roles as carers for Lachlan are significantly underestimated. For the past 5 plus years, we have struggled financially due to the fact that I could not return to my then current employment due to Lachlan's high medical needs. We only have ever qualified for a Carer's Allowance as Rob's income is considered too high (his yearly wage is approximately \$75,000). We have a mortgage to pay each week, which has always been almost half of Rob's weekly wage in addition to this we have all the usual costs involved with paying off our own home. Rob has been employed by the same company for just over 30 years and I was employed full time from the time I left school (I have a trade in hairdressing) until our first son Ben was born in November 1997. I then continued to work part-time until Lachlan was born in May 2003. Neither I nor Rob has ever been unemployed since leaving high school. We have always been responsible with our finances; having never missed repayments on our loans, always paid our household accounts on time and have contributed towards health insurance continually for 30 years. Rob has always personally contributed towards superannuation and until I had Lachlan I too on occasions, made my own contributions. While I am not employed due to being Lachlan's carer, I am unable to collect superannuation along with Life & Death and Disability insurance, which is customary when you have employment. I now pay for a Life & Death and Disability insurance policy through my existing AMP Superannuation policy. This is not an ideal situation to be in as it is gradually reducing my super but we felt that we had no choice as Rob would be left in a bad financial situation should anything happen to me.

As Lachlan's disabilities became more challenging, we realized we would need to purchase lots of additional equipment to support him. We were lucky enough to have a fund raiser held for Lachie last year and the proceeds of this went towards several purchases, which included a van, floor matting, a bathroom stretcher, special low floor chair, a car seat, switch adapters and adaptable educational toys and many more incidentals. We have recently contributed \$4000.00 towards our home being modified to accommodate Lachlan and we are currently waiting on council approval to erect a carport out of the front of our home so that we can bring Lachlan in and out of the van in any type of weather, this will cost us \$5,500.00. We still need to modify our vehicle so that we can transport Lachlan in the rear whilst in his wheelchair. This is vital and needs to be done sooner rather than later as he is becoming far too big to be in a car seat. The reason why we haven't done this yet is due to the cost, which is approximately \$23,000.00. We will need to raise the majority of this money to have this done. We also need to purchase special formula for Lachlan and this costs around \$150.00 per month. The above mentioned goods have been paid for through our own means – be it from money raised or money we have had to find ourselves.

There are several other issues we face with caring for Lachlan. As a family unit it is difficult to take holidays together as the planning that goes into this is significant and the cost involved usually too high. Our eldest son Ben definitely misses out on lots of normal things that other children his age do, however he is an extremely well balanced child for his age considering the issues that are going on daily in our house. As far as socializing, we mostly do this at home as once again it is very difficult to take Lachlan places where he will be comfortable and safe. We have also found that we have lost contact with a number of friends over the years as we can never just drop everything and pop over to people's homes or go off to the local club for dinner as it just takes too much organization. We are certainly no longer spontaneous.

I would love to be able to return to some form of work – for financial reasons as well as personal reasons however having been out of the workforce for almost 6 years, I would more than likely need retraining in most areas of my previous employment. This is just too costly for us and I do not qualify for any job assistance to help me do this, therefore at this stage this is not an option. I also face the problem of the type of employment I would be able to accept as Lachlan also suffers from Chronic Lung Disease which means he has many chest infections and inevitably ends up in hospital for treatment. I do not know if too many employers would be able to support this, understandably.

We feel that we have both either made or are making significant contributions towards society. We know that it is unreasonable to expect to be given everything on a platter, however we feel that we are constantly fighting an uphill battle for things that really should be more readily available to help children like Lachlan. For instance we are currently on a waiting list with PADP for a portable ceiling hoist for Lachlan so that we can maneuver him around the house better without lifting him so much, and we have no idea when the funding will become available for this. We have also recently been rejected to receive funding from PADP for a CPAP Machine for Lachlan's Obstructive Sleep Apnoea as this was asset tested and Rob's wage was again "too high". One thing is certain and that is that you don't go through life putting money away just in case you will have a child one day who has a major disability.

As far as our futures go, we do have many worries and uncertainties. We have worried with each stage of Lachlan's life so far but we have somehow muddled through. There is definitely too much pressure on sourcing solutions to problems that arise with caring for Lachlan. I would love to see

someone produce some sort of guide to help families through the maze and steer people like us in the right direction in the first place. I cannot begin to tell you how many phone calls I might make to access either a service or equipment. I have found that I have become a lot more assertive as this is the only way to be heard. In the beginning we were both rather uncomfortable when it came to accepting help and we still come across some ignorant people who do not think we need help or special assistance, however we realize that without assistance it will be Lachlan who suffers ultimately.

We would also like to see the Government somehow determine the needs of children like Lachlan on an individual basis instead of just a monetary threshold. While it appears on paper that Robert earns a good salary (keeping in mind that all thresholds are based on gross wage and not the "realistic" net wage) we have very little left over at the end of the week after mortgage, bills, food, petrol etc. The costs involved in raising a child with a disability are enormous and ongoing and this is something that really should be addressed individually, each step of the way.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for carers in Australia.

Yours sincerely

Megan, Rob, Ben and Lachlan