25 July 2010

The Productivity Commission
Inquiry into Disability Care and Support
GPO Box 1428
CANBERRA CITY ACT 2601

Dear Sirs/Madams,

Please accept my submission for the Productivity Commission inquiry into disability care and support.

Introduction

My husband and I are both university qualified Queenslanders. We have been together for 14 years and married for nine of those years.

Six years ago, my husband and I were blessed with our third son Marshall. He was born early at 27 weeks due to maternal APH. He did well at the beginning requiring only assisted breathing through CPAP. His 10 week stay in hospital was like a roller coaster journey but at the end, we took home a happy, healthy baby.

Many tens of thousand of dollars were spent in ensuring that my son survived his early birth. At 27 weeks, he was well above the cut-off period of 24 weeks gestation. Prematurity is a known cause of disability. With increased survival rates, also come increasing incidences of disability. As Australians, have we turned in to a society that believes that children born this early should not be revived?

If the answer to this question is no as it should be, then why is it that we are unwilling to spend the money to ensure that these children who grow up and grow old, live fulfilled and meaningful lives.

At eight months of age, Marshall’s development wasn’t progressing as per the “norm”. His paediatrician diagnosed him with mild cerebral palsy and we were referred to a service provider. However, it was necessary to wait for the next term before we could commence with services.

That was five years ago.

My now six year old son has a severe disability. His mild cerebral palsy was upgraded to “moderate” at 2 years old and then on to “severe” at 4 years old, as his body grew and his abilities didn’t. My son cannot weightbear or stand, he cannot sit unaided, he cannot crawl (though he can roll over sometimes). He speaks though not clearly. He cannot write and requires a computer to do his schoolwork. He is incontinent and has chronic constipation. He has seizures. He uses a powerchair for mobility and is fully dependant on my husband and myself for everything else.

My husband and I have four children in total. We run our own business which like everyone else, has been having it’s own financial difficulties due to the economic downturn. Before my husband and I had Marshall, we had paid off most of our home loan and were living comfortably. Since Marshall, we have struggled to pay all of the necessary therapy and equipment that he has required. At one point, we had to sell our house in order to free up equity. We own very little of our house in comparison to the bank and survive financially week to week.

This submission would read like a novel if I were to address every aspect of our lives when it comes to disability. There are specifics in the key questions that I am just simply not qualified to answer, as I am only a parent. For the purposes of the productivity commission, I have chosen to address two interrelating aspects with specific reference to examples of the failing system and to provide my suggestions as solutions. These solutions aren't all encompassing however would address the most relevant issue to our family – how we fund Marshall's needs.

Equipment & service providers

We have a powerchair that is funded through MASS that we have had for two years. It has had major recurring problems over that last two years. MASS expects the chair itself to last five years before they will fund a new chair. It won't last that long and is falling apart already. Our only option is to raise the funds for a new one. At least this way, we can chose a chair that it suitable and sturdy for a growing child's needs. One that isn't dangerous (we had to take the footplate off his existing one after it almost amputated one of my son's toe-pads). One that is put together correctly (his current chair has one of it's seat belt sewn on backwards affecting the way it secures his hips). We cannot openly seek the assistance of charities for funding due to the nature of the business we operate.

He has a manual chair supplied as a backup chair through MASS. A back up chair is necessary as there are times where the powerchair is either getting repaired or the place where we are going is not a suitable to take a powerchair (the ground is too uneven; too crowded; no suitable parking etc). Back up chairs are supplied as returned wheelchairs to the service. You get what they have. The one we were given was too big. It doesn't have any thoracic or postural supports. A recent quote to add the necessary supports to the back up chair was in excess of $2,300.00 with no funding assistance provided.

When my son was a toddler, we paid $2,500 to get him a supportive chair so that he could play at a desk at kindy and home. We paid this money in full to the equipment supplier and then waited six months for the chair to be delivered. The equipment supplier didn't see any problem with taking this time period to deliver the chair, particularly given they had our money during all this time. We had been promised that it would only take half the time it took. Another broken promise with no way of redress.

We have bought other equipment that falls apart easily or that is delivered together with biscuit crumbs on what is supposed to be new equipment. As there is little competition for equipment suppliers, as a customer you are treated with disdain.

My son has since outgrown this chair however we cannot afford to replace it. Instead we make do with a babies highchair that we bought for $160.00. We have a bumbo as a showerchair that is necessary to replace every six months or so.

We cannot afford to buy my son a showerchair and we have been waiting for over six months for the service provider to assist. We are also waiting for assistance with a sleep system and electric hoist. Nothing happens quickly in the disability related world.

We have applied for one off equipment funding as well as a family package time after time with DSQ. We have been knocked back on each occasion. Please bear in mind that we are not asking for a child who has a mild condition. His condition is severe. It affects every part of his and our lives.

We recently received a phone call from DSQ wishing to update their records as to our past request for equipment funding. Their records showed that we had requested a showerchair and standing frame. I explained to the person on the phone that we no longer required the standing frame as during the time that we had waited for funding, he had lost the ability to stand. When I asked if I could change that request to adaptations for his manual wheelchair, I was told that we would have to put in an updated application form. I’ve put in three of those since our initial request without any positive response.

My son's body is frail. Without correct support, he is at risk of pressure sores and curvature of his spine. He doesn't have four years to wait for the correct equipment. By the time the equipment is obtained (if ever), the damage is done.

During the five years that we have been with the service provider, we have received little by way of support or services. In the first couple of years, it was decided that there was too much demand from clients for therapy such as speech therapy, occupational therapy and physiotherapy, so the service provider limited the allowable therapy for each child using the service to five sessions per year. No distinction was made between mild or severe forms of the disability. That wasn't five sessions per speciality either, that was five sessions in total per year. Early intervention for my son was non-existent.

We used the service provider to obtain respite through agencies last year after my son had major hip surgery. He was in a spica (hip to toe cast) for six weeks and unable to attend school. As I needed to work to keep our business running, respite was organised. The process to get respite was a nightmare. It seemed that it would have been easier to get respite if I didn't work and only needed the time to myself. In the end, we received funding for 16 hours per week. This time was broken into four hours per day for four days per week, for five weeks. Barely enough time to enable me to maintain my work and balance the books.

At a review, it was decided that my then five year old son was too heavy for a single carer to lift. At fourteen kilograms, a two person lift was required to move him. Therefore, I was then required to organise a second person to be at home with the respite carer while I worked. I was lucky enough to be able to cover this with my mother, mother in law and our own paid carer filling in the shifts.

We were twice left in the lurch by carers who didn't turn up at short or no notice (one carer just didn't show up and didn't ring). One of the replacement carers asked if she could have the following day off. Another carer decided that her shift was so that she could watch television or read a book. It was clear that very few paid carers took the position seriously and in the end, we came to the conclusion that we may well have not bothered.

I realise that my husband and I are more fortunate than others. We are able to work by hiring a carer to undertake the duties of before and after school care for our son as he isn't able to attend "normal" day care services. For our hard work, we continue to struggle financially and we worry about our future, particularly as we never seem to be able to put away money into our superannuation. I try to not think about the future. The present keeps me busy enough as it is. I know that it is unlikely that my son will live independently. I am hopeful that his brothers will assist us as Marshall ages. I am hopeful that one day we will get assistance to give Marshall a life outside of the home. I am confident that he will be able to work in some capacity in the future.

Some of the equipment costs associated with having a child with a severe physical disability –

- adaptive chair (>$7,000);
- adaptive table ($2,000 - $3,000);
- mobility devices(>$8,000 per device);
- toileting/showering chair ($3,000 - $5,000);
- electric hoist (>$3,000);
- sleep system (>$3,000);
- vehicle hoist ($10,000+);
- standing frame (>$3,000);
- computer joystick ($500+);
- communication devices ($15,000+);
- and accessible software

Please keep in mind that a child grows, so this equipment needs to be replaced every three or so years. Whilst we have bought and used second hand equipment in the past, this isn't always possible as it is necessary to find another child who has the same disability as your child, who was the same size when the equipment was set up.

My Suggestions

1. Tax off-set

Presently, we can claim 20 cents in the dollar spent for any disability equipment/therapy that we spend during the financial year, in excess of $1,500.00. There are excluded items such as ramps, which just seems quite weird. Have you ever tried to access a building with a powerchair without a ramp? Whilst the money obtained through the tax system assists, it comes nowhere close to the full amount that is spent.

For families such as mine, a full tax off-set for the amount spent on equipment and therapy would make the difference between having to beg to a charity/government departments for funding and actually having the equipment. It would ease pressure on disability services for therapy, cut waiting periods and mean that equipment suppliers would operate as a competitive business (one that provide service and value to their customers).

My husband and I could afford to spend money on equipment and therapy if we knew that it would be returned to us at tax time.

2. Carers allowance

Carers allowance is presently funded at one rate regardless of the level of disability. I would like to see this as a multi-tiered funding, with more severe disabilities receiving a higher amount. Presently, the $106.00 per fortnight almost covers a physiotherapy session ($110.00 per session). My son has physiotherapy every Friday. So the payment almost covers every second session. Nothing else. Doesn't cover his medications. Doesn't cover travel to and from hospital (an hour each way). Doesn't cover the expense of his carer for before and after school care. Doesn't cover the cost of adaptive equipment, which in itself comes to many tens of thousands of dollars. Doesn't cover the cost of nappies (though we do get an allowance for that so some of this cost is covered). Doesn't cover the cost of medical visits and specialist care.

Unfortunately, not all disabilities cost the same amount.

3. NDIS and Individualised funding

Much has been said in the submissions about the NDIS. Whilst I don't disagree with such a scheme, I do believe that it should only be implemented to those not covered by compensation payouts. I strongly believe that a person's ability to litigate for damages should remain in place and that the state shouldn't automatically become responsible for persons who receive payouts. This could be achieved by a provision setting exclusion periods similar to that applied by medicare and centrelink in relation to compensation payouts.

Any funding model implemented should be by way of individualised funding. It should be portable between the states and also service providers, enabling the user to chose between providers and options based on life stage requirements. At the moment, our focus for our child is around physiotherapy and equipment and school. As our son gets older, it will become more about school support and activities in the community. In the past it has been about early intervention therapies.

Conclusion

My husband and I are exhausted from the last six years. It continuously feels like you are head-butting the wall when dealing with different government departments, service providers and equipment suppliers. We live on little sleep and even less time to ourselves as the roles of a carer are consuming.

I love my son dearly. He is a beautiful, funny and well-adapted boy. It is through my husband's and my hard work that he is going to grow into a contributing member of our society. Not through any assistance that we have received to date. I will never see my son as a burden as I am thankful every day for him. He is neither a burden to my family, nor is he to the Australian people. He is in an investment and like other people with disabilities, a very worthwhile investment at that.

What is clear is that the present system is failing those who require the most assistance. I thank the productivity commission for considering all these issues and look forward to reading your findings.

Yours faithfully,

Jacqueline Dalling (LLB)