DISABILITY CARE & SUPPORT

Productivity Commission Inquiry

SUBMISSION

By Dianne Murphy

Although I have appeared in front of the Productivity Commission's Perth hearing on July 22nd 2010 as a member of the Developmental Disability Council, I've also felt it necessary to present a written submission from a Carers perspective to share some of the issues currently faced by my family and how my family's lives could be enhanced by implementing a system such as a *National Disability Insurance Scheme.*

Firstly, I would like to highlight that many Carers took part in the Better Support for Carers Inquiry, back in 2008/09 and I suggest that submissions previously made are taken into consideration for this "Disability Care & Support" Inquiry. The submissions and full report "*Who Cares ... Report on the Inquiry into Better Support for Carers* is available through the House of Representatives, Standing Committee on Family, Community, Housing and Youth on the fahcsia.gov.au website.

Many Carers don't have the time to sit down to compile a submission and the reality of a Carers role is, they don't usually have the time to do much else but care for their loved one with a medical condition or disability. I can only highlight my own situation and find myself sitting at my computer the day before the submission is due trying to compile 13 years of grief, trauma and the stress of caring for 3 children with special needs and the journey my husband and I have been on, whilst my husband and a paid carer look after my 3 beautiful children.

It's not easy having to share your family story each and every time you try to make a difference to your children's life, but I find myself having to publicise my private life once again, with the hope that substantial changes are made in the future which will enable my children and my husband and I to lead a decent and fulfilling life.

My husband, Shaun and I, married 17 years ago. We're both from hard working families & both Shaun and I also worked extremely hard to save for a deposit & purchase a home together after we married. We went on to parent 3 beautiful children & this is where our journey differs to most as all 3 of our children have special needs.

Although our eldest son Ryan was born with a congenital disorder called Bladder Exstrophy (Bladder outside of his body) we were told by medical people he would have a few reconstructive surgeries and live a fulfilling life. We even got the all clear to have more children through a Geneticist and were advised there was no genetical factor in Ryan's disorder. This was 13 years ago. We continued to raise our beautiful son and also worked hard to own our own home, pay our taxes and enjoy life as much as we could, and welcomed another child into the world, our son Kieran in 1999. A year later (2000), our beautiful daughter Erin was born and two years later our lives were turned upside down again when both our younger children were diagnosed as being Autistic and intellectually delayed.

Unfortunately the earlier advice from the medical people were misleading and to date our son Ryan has endured 38 surgeries, most major reconstructive surgeries and some minor, and in excess of over 300 trips to hospital. Ryan requires daily medications, catheterises every couple of hours and is connected to a drainage bag nightly to avoid blockages and additional kidney damage. He now lives with chronic kidney disease as a result of having ongoing infections.

When Ryan undergoes surgery, he could be in Hospital for up to 4 weeks with an additional recovery period of 2 months at home. It is up to my husband or me to care for him for that 2 month period at home.

To highlight how difficult our family life can be, I should also share additional information about my parents. My Dad, a very patriotic Australian worked for 50 years and suffered a stroke just prior to his retirement. Both Mum and Dad worked hard all their lives to ensure my brother had a good start to life by attending a good school, being active and enjoying activities within our local community. There were no travel the world rewards for all those years of working and Mum then became Dad's full time carer. I don't have a large family and Mum and Dad were living in Sydney. My parents relocated to Perth to be closer to me so that I could provide support for my Mum, who really wasn't coping to well with the physical and mental demands a Carer has. My Dad never came to terms with becoming disabled and felt ripped off that he didn't get to enjoy his retirement with his wife. He felt ashamed that Mum had to provide most of his care and it wasn't easy for him or I to watch my Mum's health also deteriorate. Not only was there a lack of support for my Dad, but there was a lack of support for her as a Carer. My husband and I became her main support & we were already trying to cope with our children. All our lives deteriorated. There's a lot more to the story which emotionally I can't compile, but sadly my Mum passed away 5 years ago.

A year before Mum's passing, I had a breakdown. I was struggling to take my two youngest children to appointments as well as accompanying my eldest boy to hospital. After experiencing complications after 9 hour surgery Ryan became carbohydrate intolerant so not only were we seeing the surgeon regularly, we were also seeing a dietician, gastroenterologist, having regular urine tests, blood tests, x-rays and having special formulas being made up at the hospital because he couldn't tolerate any food at all. Of course, we also needed to drive down to the Hospital to pick up the formulae and our appointments were never coordinated on the same day, so it became a life of driving back and forth. On alternate days, we had therapies for Kieran and Erin and of course the service provider didn't offer flexibility for families like mine and once again it was a case of driving close to the City for therapies, and might I add, it was a struggle for me to even get my kids ready to put in the car. After we arrived at the venue, I would struggle for half an hour to get my kids inside the gate because one would try to run one way and the other child would attempt to go the other way. I then had to find the money to pay for the parking and this is all before the therapy begins. After all of this, I would then need to attend to my parents needs .... so it was no surprise that I had a breakdown. I would drive tired most days because I didn't get any sleep, all of this whilst my husband worked 6 days a week to keep us financially afloat.

After my breakdown, my husband gave up work. There was **no** alternative for us.

I attended a session once where the facilitators representing a therapy organisation advised us parents to ask our cousins, aunties, uncles, parents and friends for help. What friends ? What family ? I remember thinking is this a joke .... Is this meant to be the solution for all of us, because if it is we're stuffed ! Our friends had left us behind once we had a child who was different. I actually think they were frightened in case we might ask them for help. Therefore, we became an isolated family.

I mentioned in my speech to the Commissioners that my husband and my journey together have been difficult and we've fought every single step of the way. When I look at my beautiful children, my innocent children, I try to gain strength to advocate on their behalf. We approached Centrelink when Shaun gave up work to secure a Carer Payment for him. Everyone had advised us he'd most certainly be entitled to support. To be totally honest here, I can still remember trying to find the time to even call Centrelink. If you can try to picture this scenario. One child is banging their head against the wall whilst the other is screaming and biting you whilst you're on hold waiting for your call to be taken. It would often take me 3 or 4 goes to try to talk to someone. Then you had to find the time to complete the paperwork, pages and pages of reports. I am going back many years now, but this was the system. I would be sitting at our dining room table at 1am in the morning trying to complete paperwork, to try to secure some financial assistance for my family. We went through two appeals to receive the Carer Payment when Shaun gave up work. A panel of "know it alls" assessed our situation and determined our children as not being profoundly disabled enough. I ended up going back to full time paid employment to support our family whilst I handed over everything else to my husband and when I finally found some time to once again sit up after midnight; I completed the form to take Centrelink to the Social Securities Tribunal. Of course we won our case, but it was another emotionally draining process.

Over the years, we've also sought support from agencies. One agency in particular decided to send out a Volunteer who came with a story book and her intention was to sit my kids down to read a story. We realised very quickly the hour's respite we were hoping to get, was lost as not only would our youngest children not cope with a stranger in the house, but they'd tear up the book and scream in fear. What a let down that was for us, especially after finding the time to meet with the Coordinator of the program weeks before and having to complete a series of documents before anyone would be considered to come to our house.

Another Agency worker (this time a paid worker) turned up one day, advising us that she was so experienced, she use to manage an Aged Care Facility. She couldn't manage with one child, let alone three and after her shift; she was never to be seen by the Murphy's again. No phone call, no good bye, no nothing. We weren't worthy of such a phone call, yet we're expected to be grateful with being allocated some support by letting a stranger come into our home to provide "care" for our children.

Caring for our children and my parents has affected my husband and my health. We don't have the time to exercise and "find 30 a day for ourselves". We've had to really think outside of the square such as, we have a hairdresser come to our home, because our children can't always cope with the lights at the shopping centre or the crowds or someone not familiar aiming scissors near their faces. We've been having family hair cuts at home for nearly 5 years now because we need that flexibility in our lives to get by. Not only is it more convenient for us, but it's much cheaper too, and we get the haircuts done at a convenient time for us.

Id like to highlight another example, Carers get sick too and because we no longer have the capacity to earn a lot of money, we can't afford private health insurance. I underwent a hernia operation years ago, I was sent home from hospital less than 24 hours after surgery. We informed hospital staff that I couldn't be cared for by my husband because of our children's needs and they couldn't care less. Having that bed available was more important than me and my husband. We just weren't a priority to anyone and were once again left to fend for ourselves. As a consequence to that, my husband was so stretched to the limit, we had to borrow some money from our mortgage and fly my elderly mother in law over to help us. Even after an extended period, having to one again provide hands on help with the kids meant that not long afterwards, I had another tear from having to lunge at one of my kids and I now have another hernia.

Carers are very under valued in this country. We're also discriminated against. I'd like to highlight an example when my eldest boy was unwell and our other son Kieran had an accident at school. He required medical attention and one of our paid Carers weren't available to assist. I quickly left work and managed to get in to see our family Doctor. We then proceeded to Hospital with a letter. Not only did I have a little boy screaming and not understanding what was happening, but I had to try to find parking at a very busy Hospital. When I eventually found parking and my son was still screaming because blood was oozing from his toes, I then tried to find some money to purchase a parking ticket. The nearest machine was out of order and I proceeded to carry my son to Emergency. Hours later after receiving treatment, we were sent home, I received a parking infringement for not purchasing a ticket. Weeks later, I challenged this infringement with my local council and was "let off only this once". Where's the equality here. Most people I know who live a relatively normal life not having to provide care for someone hardly ever go to hospital but what about the families like mine who has a loved one who practically lives in Hospital. I only wished we'd kept a record of how much we've actually spent on parking over the years, with my Dad, my Mum when she was unwell and the 13 years we've now been going back and forth to PMH and the 300 + times we've been there with our son Ryan. Why aren't Carers allocated a special parking pass … where do you expect us to keep finding the money from ????? Something has to give here. I already pay my taxes to the Government, my rates to my local council. I do the right thing, but who does the right thing for me and my family ???

I haven't really touched on the therapy my kids need. Early intervention ceased for them at 6 years of age. I know a lot of money has been allocated to Early Intervention services but it's really too late for me. Why didn't this happen when my kids were younger. Oh that's right, I was one of the parents that had to find the time to advocate for change and when the change happens, I don't reap the rewards for it.

I should also share another story from the parent forum held by the Therapy provider. It was a struggle for both Shaun and I to be there, but our kids come first and we both shuffled things around so we could both attend. We had booked into several sessions we thought would assist us to gain the knowledge to help our children, keeping in mind that Shaun and I still needed to provide the Therapy. One of the sessions was about fussy eaters and we were struggling to get our daughter to eat any food. I was advised that the session was cancelled because not enough people had booked into the session. Once again I thought, is this a joke ? and I advised them that I was here and my husband was here and surely that was enough reason to still hold the session. No, we were told - it wasn't. I then spoke to someone more senior and had to become quite irate to even find out how many people were actually booked in. There were actually 7 parents booked into that session, but this figure wasn't good enough for them because they had decided if they didn't have 10, they wouldn't hold the session. We were creating a scene and were virtually told to calm down otherwise we'd have to leave, so we ended up having to attend another session about toileting. The room was full of therapists and a couple of parents and I wondered why the "therapists" weren't providing therapy for our children rather than sitting on their bottoms listening to information they should already know. Is this where all of the funding is going ??? Yes, a lot of it is. Let me also say, they provide fantastic statistics and reports & constantly pat themselves on the back because of the great work they do. They even showcase their great work in a Newsletter now and I wonder how much one on one therapy could be given to our children for the cost of the Newsletter ??

Over the years, both my husband and I have attended numerous sessions about our children's conditions. We're always wanting to gain the knowledge and skills to support our kids. As mentioned in my speech to the Commissioners, there was another occasion when I looked around the room and wondered if the other attendees had gone through what I had to even get there that day. Had they had to accumulate extra hours of work first so they could have the time off to attend ? Did they have to use up sick leave days or annual leave days like I do, when my eldest son is hospitalised. Have they had to skimp and save so that they could even pay for the session ? No they haven't. There circumstances are totally different to me. In most cases, they work for an organisation or an agency that receives funding to support people with disabilities and part of their funded professional development is to attend such sessions to gain knowledge, just like me. Not only are they paid to attend, they often drive their in a work car, or in the cases where they do drive their personal vehicles, they can then claim a travel allowance. I don't get paid to attend. I don't have a work car and nor can I claim any travel. I'm just a carer & Mum to some kids with disabilities ! Where's the equality here for Carers ??

When my husband takes over the full nursing care of our son, and I'm talking about lifting, medicating, catheterising, measuring urine and keeping a record of how much has been drained, changing soiled bedding because the drugs affect his stomach and bowel, he's not paid the same as a Registered Nurse who deals with this in the hospital, nor does he undergo any paid professional development days nor offered in-service training linked to a hospital for education or occupational safety and health purposes. He's just a carer and undervalued in this country. Where is the equality here ??

I really don't know how many examples I should provide but this just isn't my life, its thousands of other Australian family's lives. I don't know how we do it each day; there are some days I'm surprised I even wake up. Stress overwhelms us most days and that's before I even come to work. We're a husband and wife who just love our kids and we try to do our best for them every single day. Somehow, we've gained inner strength over the years and we're trying to make a difference for our kid's future.

Although we've managed to secure funding from the Disability Services Commission so that we can organise and pay for our own Carers, our children still require therapy's and support to participate and live in the community and will do for life.

My husband has now been a full time Carer for 6 years and hasn't been able to return to the workforce. The years of physical support for not only my children but also my Dad, have impacted on his own health and the reality is our youngest two children will need support for life & its highly likely our eldest son will require some sort of support as well. I should also mention, when I refer to "life" I mean till the day they die, and not comparing to the sentencing of some murderers in Australia who are sentenced to life equating to a 12 – 15 year period. Come to think of it, Carers would be looked after quite well if we were in prison. 3 meals, our own room, time to exercise, medical and dental care and even time to rehabilitate sounds like a reward & a luxury to me and other Carers ! How depressing is that … a prisoner, a rapist and even a murderer is more valued and cared for than a person with a disability or a Carer and its probably best at this point that I get back on track with this Inquiry.

Carers come from all different walks of life. Although I'm currently working as a Business Support Officer with a Government Department, I've previously worked as an Accounts Manager and whilst in paid employment my husband worked in the hydraulics industry. Our caring roles mean that we were no longer able to sustain or work in well paid jobs.

We're not really in a position to provide detailed answers to questions about eligibility, & policy implementation. There are consultants, senior project people already working in these areas who can answer these questions from an analytical point of view. But I will say this, Carers should have more power and there should be a push towards more individualised funding so that Carers and people with disabilities can purchases the services they need. There are many people trialling this option and I know of an organisation called "In Control" who has been supporting families in the UK to manage their own funding which in turn has not only saved money in the long run, but has guaranteed better provision of service due to the person being able to purchase flexible services such as therapy and carers and being in full control of what's provided.

I hope that the power to make decisions on what services are needed and provided is taken away from the actual service provider. This system fails as no one receives a quality service. Service provision becomes crisis driven because of miss managed funds and let's face it; a lot of the funds are absorbed administratively before families even receive a dollar. I believe we should remove the middle man.

Having a National Disability Insurance Scheme is our last hope. We need more flexibility in service provision and for services not to be crisis driven as they are now. I know there would be an influx of help for my family if I was to dump my children with the authorities and say that we just can't care for them anymore. I've actually heard of a family that did it, and because their child was looked after by a particular agency that offers a good respite program, this then affected other families such as mine in getting their allocation (which is a two night period every 6 weeks), and of course a chain reaction of events occurred due to one child being left to the authorities to look after.

We are a rich and resourceful country and the disabled and their Carers should most certainly be able to have flexible services offered in the future with such a scheme.

Let’s finally do something about it. This is the second inquiry I’ve participated in and I don’t know if I’ll even be around for a third, and even if I am, how much more talking and report writing are we going to do.

I don’t know how we’ve done it, I don’t know how we even get out of bed some days, but we do for the love of our kids. Somehow, we gain inner strength to carry on each day. What can I say, we love our children unconditionally.

I didn’t expect my life to be over when I decided to have a child and there are days where I feel I’ve stopped living as “me” since I turned 33. I’m now 46 and I want to live a good life with my husband and children and we need help to do this. A National Disability Insurance Scheme would be advantageous for families like mine. We would be in a position to receive the funding required to support not only our children but my father too. We could purchases the services required and manage to get the flexibility needed too and would most certainly ensure we get value for the money spent.

Dianne Murphy