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The Secretary
House Standing Committee on Family, Community, Housing and Youth
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Submission from a Carer – Queensland

Background

I am a mother/carer of a physically disabled 20-year-old son. I am the sibling of a physically disabled 50 yr old man, recently deceased. My brother was severely affected by Cerebral Palsy and lived most of his life in the city. My son is affected by Duchenne muscular dystrophy and has lived most of his life in rural townships and cities. I am married but my husband works away from our home travelling for almost half each year, and has done for over 15 years. I have two older sons unaffected by Duchenne, (which I am told was a spontaneous mutation in my youngest son) -one who has not lived at home for 6 years since he was 18 and one who moved out last week aged 22.

I am a Teacher-Librarian and worked full-time up until my son was about 14, cutting back to a 4-day week at that point as his condition deteriorated. For the past couple of years, I work a 3-day week. I am the founding secretary/current president of a national voluntary non-profit, which aims to support families and professionals further our knowledge of Duchenne to add quality and quantity of life, since Duchenne is life-limiting. I spend most of my days off performing these voluntary duties like the web page and grant submissions and of course I have been networking internationally since the mid 90's and belong to an international community affected by Duchenne.

My disabled son is already an old man in terms of his disease. I choose to assist him by assisting all persons affected by Duchenne, or otherwise nothing will ever change. This life and death "battle" has consumed me as a carer and I have had far less time and energy to advocate for my son on a personal level than I would have liked and part of me failed to comprehend why this is necessary in the first place. Organizing some regular respite, appointments or equipment repairs isn't as difficult as helping to find a treatment for Duchenne, but sometimes it seems that way. What advocacy I have attempted has shown me that I am not very good at advocating for my son or his peer group but I don't think I am alone in this.

My son is not disabled and I am not his carer in isolation. We are linked together because my maternal role has been extended into his lifetime beyond childhood due to his disability. His adversity and mine are linked, his access and mine are linked, his successes and failures are linked to mine, his circumstances are linked to mine, and our ability to participate in society is linked. Our contentment is shared. Even our need to be independent of each other regularly, is linked. I fail to see how carers and the person(s) they care for can be considered in isolation and so my submission must also be his submission because of our shared circumstances and satisfaction as Australian citizens. *I cannot be satisfied as a person who cares, until society values the person I care for, by deeds and not just in words.*

The Role and Contribution of Carers in Society and how this should be recognized.

This is inextricably linked to the role and contribution of the disabled in society. By recognizing that both are important and implementing a fair, nationwide, accountable service or network of services and facilities (not a lip service policy) to support disabled persons and their families, carers will feel valued and their contribution recognized. It would be easier to say we need a better carer's payment but that does not make one feel more valued long term because it doesn't address the other problems/working conditions. Like most pay rises gained in the workplace, it shuts the employee up making them feel temporarily more satisfied, but the problems that keep the worker or carer functioning well throughout their carer and thus content, will re-emerge if the working conditions are not improved. I believe that the contribution of carers will be well recognized if their "conditions of employment" are improved universally. There is already disability elitism based upon age, geographical location, advocacy ability, type of disorder etc One way to address this would be to specialize and separate the services offered to separate disabilities as with our clinical services – then someone who understands would be responsive to our needs as a family because you can't separate the

person out of his family or the carer out of their family, unless they are living independently. In the process would flow more equitable assessment of needs and more efficient satisfaction of those needs.

The Barriers to social and economic participation for carers, with a particular focus on helping carers to find/retain employment.

Whilst it is accepted that physically caring can be a full time job, it isn't recognized that advocating and being responsive to the bureaucracy is very time consuming too. Even my son seems to get regular paperwork to do with his entitlements in which he needs to affirm that he hasn't suddenly been cured, when his diagnosis is progressively and universally degenerative.

I have only one suggestion and it fits the current communication/technology revolution. I have several skills as a teacher-librarian for instance. I can catalogue resources, or use my skills as a cybrarian, I can teach online and review literature (and have done so to earn money and resources for my school but not for myself), I can ghost write, populate websites, and various other jobs. I can also complete creative projects if I had time or the information about sourcing funding for this. Perhaps we could be assisted to start an online business, which would be a creative outlet for some. I imagine that any carers could find online work comparable to their own employment experiences. I have many passions including my son's disease and so I have experience and success in grant writing, reporting, event management etc. I yearn to work from home and at least be available to support the person I care for full-time instead of working out of the home, rushing home in 30 mins to make sure he has lunch and to check on him. Meanwhile because his tertiary course takes up so little contact time, he is left alone for as much as 3 whole days a week. We cope by hanging up a camel pak for fluids and I come home for lunch. But despite expressing interest in several projects, and having extensive online experience as a volunteer, I have not been able to find paid online employment. The same would hold true for my son and his future career opportunities as he becomes even less independent. Even if a business is an online business, or a large govt dept's core business, the irony is they still want you to sit in a central building in the capital city to do it! Online learning is without geographical boundaries yet in my department at least, there is no such thing as paid online teaching, management or resource development unless you sit in a central office in a capital city. Can the government develop an online employment agency for carers? If we had flexible hours, we could do our work at night if we had doctor's appointments through the day or used up a portion of the day being responsive carers?

Practical measures to support carers.

Respite – Since moving to a larger city some five years ago, we have an allocation of flexi-respite for about 5 hours weekly (1.5 hours X 3) from a service provider for my son's personal care. This is wonderful and outside of public holidays or long service leave, the gentleman who cares for my son is very reliable and personable. If my son chooses to have a shower rather than hydrotherapy, he always makes time for a game of cards or chess before he leaves. We have another current allocation of 6 hours from another flexi service (for many years it was 4 hours but the actual commitment was either 0 or 2 hours – never 4) and recently this has actually amounted to 3 hours in one block on a Thursday – never the full 6 hours he is allocated. I fund this flexi service with my carer's payment but would appreciate it if someone could tell me why we can never really receive the full allocation of hours, despite frequent requests for them to support my son in his university course or assist him with recreation needs. See my education sub-heading. The excuse is always that there is nobody to work. Do these providers proactively advertise? If so, why is this a perpetual problem? When we lived in a smaller city out west, it was worse and zero hours a week for many months would be our actual support. Who does/did receive my son's annual allocation of hours with these services? Someone must have. Why does a service approve a certain number of hours in the first place if they have no intention of fulfilling the commitment year in year out? Another family who won the DSQ lottery for a support package and receives approx. \$20,000 per year in recurrent funding (there are probably about 10 in hundreds of applications per year who win this lottery in our district) has no complaints with this particular service provider but is that because they do have a big account with them as the managers of the family's support package?

A few years ago, this particular service held a meeting to ask clients for new ideas, but the only outcome we were lead to was to accept a smaller allocation of flexi hours in order to shorten the waiting list for others. I suggested an idea for a service that I had heard about in Brisbane from a mother of a young man with the same disorder - something that worked well there to give mothers of severely disabled children who had to be turned sometimes 4 –6 times in the night, some respite. I was suggesting a fortnightly night shift for a couple of carers who moved from house to house turning the boys so the mothers could sleep through. I asked if I could find a handful of mothers with similar needs so that we could sleep through the night without getting up

to turn our children once a month, but the response was to say that it would be an expansion into a whole new service requiring a coordinator, a desk and a computer and they had no intention of extending their service— all this infrastructure to have an extra shift a month for two workers, who worked at night instead of in the daytime? Service providers need to be more responsive to the needs of clients and have the ability to think outside the square.

In the city my brother could access approaching 30 hours a week from a combination of service providers. His personal care needs were greater and his age and my mother's age made him a high priority I understand that, (although another sibling was both paid and unpaid carer for some years) but why are there such huge differences? Surely persons with a severe physical impairment should not be at totally opposite ends of the scale in terms of needs? Surely the respite services offered in the city should also be offered in the country? One service provider who have been historically unreliable with flexi respite, have another strength – they have a good respite house for emergencies or longer term respite up to three weeks a year. We use this if I have to travel to work meetings or for family funerals etc.

My son has been on a waiting list with another service provider for five years for some regular aide to attend a recreational activity. Lately my son was told it is finally his turn and we have had two orientation meetings with a desk jockey but after some weeks there is still no sign of the person that would accompany my son, because they have to advertise for the position. I am not being fair, but one wonders if this will happen this year, based on the lengthy term on the waiting list. It was frustrating when we came to town that we had to have endless duplicitous interviews with various service providers to find out whether you fell within their scope or not. It seemed ridiculous to repeat this process over and over.

It is interesting that all employees in health/respite have a no lifting policy and at times when no equipment is suitable or available, carers or hospital staff are unable to help us. Yet we perform these lifts all the time in our own homes amongst family members. If there are two people or more using the right technique, we should be able to get assistance from carers and health workers to perform a manual lift without equipment. Also there is a rule that two people are meant to work a hoist, yet we use the hoist alone all the time – that's what the hoist was made for, so that one person could lift another unassisted.

Living Independently - In England there are wonderful hospices/independent living centres for rehabilitation or respite for males with Duchenne. If only in Qld, Montrose Access could have the funding to create one or more of these centres – they certainly have a beautiful estate to situate it in Corinda but they should also be situated in other districts too. I know of 2 Qld brothers affected by Duchenne who were offered the opportunity to live independently very recently at the end stage of our disease – renting the house back from DSQ and having 24hr carers supplied to the housemates by a DSQ funded service provider. I only recently found out that DSQ had an independent living waiting list, which we are told is more like a fantasy than something that can ever actually occur... One carer of a "pioneer" (an old/ young man with DMD) only just found out that there was an incontinence aides subsidy scheme! So there really is not a complete guidebook we can access to know about all the assistance available to us. If one asks for some kind of logical explanation about the huge differences in care able to be accessed, the enigmatic response is "That comes out of other funding".

It seems the currency is information and those who have it, plus a great deal of "fight" can use the system far more effectively than the rest. I know my son would like to live in a palliative care facility for portions of the year so he can experience the sense of being an adult, so funding whole of life rehabilitation/palliative care centres for disabled youths and women as in England, would enhance their quality of life immensely.

Equipment – MASS is an OK scheme and we contribute towards equipment such as wheelchairs. They don't have cough assists or ventilators on their supply list, and that is shortsighted, as we want our boys to breathe well in the daytime as well as at night. We want our boys to avoid and recover from pneumonia too and require less hospitalizations so cough assists should be subsidized under MASS and the comparable agencies in all states. In some states these schemes provide the full cost of wheelchairs for instance, but in Qld sometimes it involves a subsidy/top-up contribution. If this scheme were universal across the nation perhaps it would enable the medical aids subsidy schemes to add more life-saving equipment to their approval lists. So one problem is that there we need more equipment covered by MASS and equivalent provision interstate.

There is a problem with the subcontractors...the people who supply the cushion covers, wheelchairs, parts etc and the people who repair them. They do not deserve MASS business if they are not accountable from the perspective of the end users. Does MASS ever ask end users if they are satisfied with long waiting

periods, botched up orders, ineffective repairers? I am fortunate that my husband has mechanical and welding ability because often these have been the saving of my sons "legs" and mobility when a repairer cannot do the job.

What company would take \$7,000 from a paying customer loses the electronic payment for a couple of months, then spend a couple of months supplying it so that it arrives before Christmas. The problem was that it was not fitted out for my son, but someone else, so for over 4 months it sat in my lounge room waiting for the right supports, tyres and upholstery to arrive. As his old wheelchair began to fail, my husband spent a weekend putting the old fittings and upholstery from his old chair onto the new base so my son could have a reliable wheelchair. We are still waiting for some missing parts that are new 3 months later. My son's contribution was over \$2,000 and he is a pensioner – the taxpayer probably paid over \$5,000, yet this inefficiency would not be tolerated in the commercial sector. A PPA member in WA tells me they pay no top-up contribution on wheelchairs at all, but that is not my preferred option. I believe that if you don't contribute, you don't fully appreciate something. However, such inefficiency beggars belief, when you are contributing a significant amount towards a mobility aid. My son hasn't always received new wheelchairs either – his first electric wheelchair was second-hand and he received another near-new chair for which he didn't have to pay the top-up. But twice he has been supplied brand new chairs and this last time is by far the worst service of all of them.

One member of our association told me that there is a delay in NSW in ordering his sons' wheelchair because the government is broke - yet this is not reflected in the knee jerk announcements of spending on high profile disorders, we see announced on the news recently?

Something DSO seems to do well is disburse left over funding at the end of the financial year, if one includes a standing request for non-recurrent funding in the support application package that remains active. One year we received partial assistance to make our bathroom accessible and another year we received full assistance to buy a poly pool wheelchair as the donated one at the local pool had been unsafe for some years.

Transport – I have read an Australian wiki recently about this issue and astounded by the carer's 6 figure estimates for wheelchair accessible vehicles when we have probably owned 3 vans to date and none of them cost over \$20,000 second-hand and already fitted with hoists or ramp. I don't believe that the community or the govt should supply families affected by a physical disability with a vehicle. People have different tastes and some are a lot more expensive than others. Why should the taxpayer pay for expensive tastes? With Duchenne, there is quite a bit of warning before a child needs a wheelchair prior to adolescence, so families should plan ahead and look for bargains. Vans can be used with ramps or hoists. Our last 2nd hand van hoist cost only \$1200, so perhaps modifications to vehicles and homes could be subsidized equitably?

I was speaking to a WA parent the other day about taxi vouchers. The passenger pays 50% in Qld but only 75% in WA? Why isn't there a universal rate? Taxi drivers have a national association don't they?

Buses are an environmentally effective, cheap alternative too – except roundabouts. In the USA, the buses have chair restraints so that the person can feel safe, why can't we bring these to Australia?

Access – There are still many venues, public places, business premises that do not welcome disabled persons. My son cannot independently access shops in a nearby shopping centre because whilst there is a ramp to the sidewalk, there is a large step into the shops. He enjoys playing video games and watching occasional DVDs but he cannot access the shop. Someone needs to go with him and hold up DVDs he might like for him to choose through the window. There are laws about the provision of access to buildings but nothing can be done about this situation as with many others for one reason or another. If there are laws but not consequences, then these are token laws. If there is going to be no compliance to make people live the laws, then they may as well not exist. It is depressing to be thought of as second class citizens supposedly defended by laws which nobody cares to enforce. We are saying in our society that we do not care to have disabled people for customers, nor members of their family who are part and parcel. My son is disadvantaged not being able to access a local barber or Pizza store too, let alone many other public and commercial premises further afield. If businesses/owners knew there would be a fine as a consequence for instance, they would provide access – perhaps this revenue could be used to subsidize access projects. Why doesn't the government offer a rebate so that businesses are encouraged to provide access the way they offer rebates on energy saving measures or water conservation?

Education – Contrary to other young men with Duchenne interstate who attend classes at a tertiary institution, my son receives no physical support. He attends alone, waiting outside of doors until a kind soul walks by, toilets and feeds himself (usually ineffectively), struggles to use the library preferring to source information online because of the weight of the books. He is not given any concessions in the length of assignments or exams despite his weakness, unlike his counterparts interstate. Yet there is a disability officer who belongs to a national body stationed at his institution. An automatic door and a rain awning have been built since Doug commenced his studies, but as far as having personal assistance by another young person, to all aspects of campus life, he seems to be disadvantaged. Lecturers have no concept of what his life is like and his very great adversity. He is too proud and he will not allow me to interfere. He works very hard to scrape through but could do much better with some physical support. If children in Victoria and Western Australia and no doubt other centres in Qld can have support in their education, why can't my son? Recently, on one day per week, for 3 hours we have received a carer to do personal care and go to the library with him. This brings my son's total flexi-respite hours up to 7.5 hours a week. See Respite heading and you will see that this 3 hours is supposed to be 6, but that is in "words" only in our experience. There is an afterschool support package that must be applied for before a child leaves year 12. But what happens if you degenerate after that as in the case of my son. 6 months after leaving school, he could no longer effectively toilet himself or access his own house alone. Is there a solution in the bureaucracy? I don't know. Perhaps there is but we don't have access to the information or feel part of the elite group who do. We assume that these privileges are as we have heard about, the reward for "making enough noise" for threatening to suicide or demonstrate desperation and frustration in some way we don't.

Contrary to popular belief my son didn't receive any one on one teacher aide time in either primary or secondary school, though he was rated at the highest levels of physical disability, level 5 & 6. He did access support when he needed to at the special needs dept but this was up to him to initiate and he was not in the habit of it. At this point in his education, he felt he could cope by opting out and not demanding daily assistance he was entitled to. It is unfair that now that he does require assistance, he has no access to physical assistance of any kind to complete his education.

Clinical Services -We are fortunate to have a clinical service provider in Qld that is a centre of excellence. Our children are very well cared for clinically away from a hospital in a relaxed setting (if they live in SE Qld) and there is even an outreach team that visits other parts of the state although we do not have a chance to see the doctors and specialists – only therapists. They even provide some kind of post school options for older boys but only those who live in Brisbane. On the whole their clinical services do cut out at 18 years but therapists who see the gap and the need, will often provide consultations with the "pioneers" to assuage their anxieties because who knows more about Duchenne in this state? No one. I'm sure with more funding that this centre could become a whole of life service and even have a facility for respite for older boys who want to live independently for a few weeks and give their parents a break. As it is they are critically short of any physios because they cannot afford to pay the wages offered by the health dept. This affects our outreach services too. Here is an example of a service provider, recognized around the world as a centre for excellence for Duchenne, with a unique deep knowledge of our needs – and they do not have the funding, which I know they would use well to assist us. I believe that if specialized organizations with the deep understanding of the disorder were to broker funding for a family – then it might be done efficiently and with skill and respect for the natural progression of the disorder and the needs of the family. I believe that mostly everything and anything to do with Montrose is comparatively "easy" and without a battle because of this deep understanding and appreciation for my son's adversity and for my adversity. Locally, Blue Care are "easy" too....why can't this consideration be true of other aspects and service providers?

Public/Government Consideration of Duchenne

The parent project movement began internationally in the early 90's and I have been involved since the mid 90's even though our Australian organization is only 5 years old. Duchenne is both the most common and severe of all forms of muscular dystrophy. It is a separate disease to any other form – so only by focusing on Duchenne will any progress be made for 1 in every 3,000 males. This disease remains, by comparison to many other disorders, critically under funded although in recent times, this is changing due to the genetic revolution (largely funded by parent project directly or by imitation) and improved care (international gold standards advocated once again by Parent Projects)...We have experienced limited success in changing these attitudes in Australia however since Duchenne has a low profile publically and thus a low priority in terms of research and treatment considerations. Nobody famous has died of Duchenne or, as our current state and federal politicians have shown us recently, we may have had proportionate funding to care and treat Duchenne. I believe that boys with Duchenne, who have historically succumbed in adolescence, lacked the

maturity and energy to advocate on their own behalf and this is part of the reason for the neglect of the treatment and research into the dystrophinopathies in Australia.

Last year one of our dads was told by a researcher for a high profile disorder that they didn't have enough projects to spend their money on. Yet historically our researchers couldn't scratch their uncertain livelihoods year in/year out without overseas funding and our researchers are good, designing and creating knowledge that is so important for the global quest to find a treatment for Duchenne. Lifestyle diseases are prioritised in Australia – some of which involve a character weakness of some kind - all have hope, treatments and a survival rate at least. Not so Duchenne and it is very disheartening to me to see our government lets so many young men slip away quietly with only their families to care...we are a health and medical underclass and our intelligent dedicated professional stakeholders should not be anxious about pursuing their research. There is a critical shortage of physiotherapists who are skilled in Duchenne – and it is so very different to the usual rehabilitation/therapy of "use it or loose it"...what lies beneath my child's skin is horrific – not nice red muscle/tissue– fat has grown where the muscle has died. People look at a chubby child or adolescent in an electric wheelchair and they do not comprehend his adversity and assume that the person is too lazy to push a manual chair or that sitting requires no effort when every little movement requires so much effort in the absence of most of one's muscles. He cannot lift a glass to his lips; move his arms in bed or from his lap when he is sitting. He is barely able to work his joy stick on his chair, yet I go to work to help support the family and he is given a total of 7.5 hours (in a good week and only since moving to a larger town) mostly for personal care, and so otherwise no one to assist him to get to and from university, or access the library and facilities, or while he is sitting alone at home three days a week.

I live every day disgusted and disappointed in the land of my birth – fighting for medical rights available to men with Duchenne in Spain, Turkey and the Czech Republic, let alone in the richer countries like USA and most of Europe. It is no wonder that indigenous people strongly identify with my son. Our PM should say sorry for this blatant marginalisation of boys who lived and died in Australia now and in the past too– with our national health authority not the slightest bit interested in even recording their statistics, the fact that they lived at all with Duchenne via a central registry. The crime here is that this national registry would make our children visible to international researchers conducting multicentre treatment trials – treatments which could give them a little more strength and quality of life, which even have the potential to cure them. The life and death of my easygoing son, is not worthy of acknowledgment – someone whom 1,000 of his peers made high school captain! As a carer, I have to live with this neglect and contempt for a silent/low profile killer of young men, every day. I am so very tired of fighting for some help on all levels. I only know Duchenne – but I imagine that all carers quite wrongly have to fight similar battles. We should have a system like in Denmark where all cases are treated equally according to a protocol for similar disabilities and the same level of medical care, respite, hospice and recreational care is given regardless of where a person lives or what information they can source. I believe basic equipment and treatment should be freely available to all – families who felt they could afford it themselves could refuse it – let's have an opt out system of looking after our disabled people. If the govt wants an organ donor opt out system where each of us automatically give for the good of all, then it should work both ways, so that we can opt out if we don't need assistance to modify our cars and homes or respite care. We certainly need assistance to employ trusted people to help us care for our children, or how would we know their intentions and their credentials, regardless of who pays?

Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

Even if carers and the people they care for were properly assisted and universally assisted without feeling failures because their advocacy skills are lacking, or they are punished because of where they chose to live, or their need to earn some money, their choices can never be on a par with those who are not carers. I don't believe there were any services 30 years ago as my brother didn't have access to any or we were not aware of them so I realize that in many ways this submission is a long ungrateful diatribe. But I hope I have pointed out some successful and helpful supports we have received from certain services and agencies. I really want to ask why with such good intentions and so much money invested already, why our support services can't be at least effective?

The powers that be still won't get it – they'll probably suggest that we all attend some advocacy courses and learn these skills and I've heard that one before – but why should we spend our lives advocating competitively, our lives are hard enough as it is? From my limited experience with two disabilities, why can't

our needs be met by a state service provider with a deep holistic understanding of our disease, rather than the plethora of different community services with different quality controls. If our excellent clinical service provider could be given the mandate via financial assistance to extend their responsibility for all regions and for all aspects of our child's care, I know he would be better off. But their services technically end at 18yrs and their geographic scope beyond short outreach visits is limited.

Tokenism isn't going to work either...like an increased carers payment, because that isn't going to change the farce of being allotted hours but never employing anyone to work them all...I work part-time so I can afford to pay my contribution to my son's flexi respite hours if I knew how to make our service provider meet the allocation effortlessly. I'd like to see conditions improved, not to be exactly in the same position as those who are non-carers or able bodied, but at least in a position where we can expect better value for money for us and the government. I'm sick of hearing that those who make the most noise or who are on welfare are supported better. I shouldn't have to give up my job and home and become disadvantaged so my son can be more advantaged than the son of someone who not only cares but works as well! Go figure! Besides, I believe that being insular and consumed by yourself is a sure recipe for unhappiness whereas working to help others is a source of happiness.

Perhaps we need an ombudsman to lobby for us and investigate inefficiency, because we have too little time with our children to be fighting for the support that comes so easily to a few. I maintain that this ombudsman could be one and the same as our clinical services provider who has a deep understanding of the needs of our separate restrictions and circumstances caused by the course of the disability.

If you need me to explain any of my personal experiences or opinions further, I'd be happy to.



Deborah