

Doc 28/7/08

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.

I am submitting to the Inquiry because...

I am the mother of a 15 year old son with cerebral palsy who has severe and multiple disabilities. He is unable to walk, talk, sit independently, feed himself or toilet himself and he requires assistance with every aspect of his life. He also has fragile health and complex medical needs. He lives at home with us and we have cared for him since his birth.

Our life has been exceptionally stressful since his birth. For the first 10 years the supports offered to us were very piecemeal. We cobbled together supports from a range of different programs – getting a few hours respite from here, a few hours personal care from there, some assistance with purchasing equipment from the Aids and Equipment Program with top up funding from our own pocket. It was clear that the service system was a shemuzzle and I spent a huge amount of time contacting different service providers to see what they could offer. Often these phone calls just resulted in us joining their waiting list. Things have improved for us since our son was offered a support package in 2004 at the age of 11. However I can't emphasize how much we struggled during those first 11 years and how tired we were all the time.

More information is attached on a separate sheet

1. The role and contribution of carers in society

As a carer, I feel that my role is....undervalued!!

Family carers are essential to the well being of our community. The government would clearly not be able to care for all the people with disabilities in Australia. Carers look after their family member out of love, commitment and a sense of family responsibility but the job is demanding, difficult, exhausting, and at times is 24 hours per day, 7 days per week.

Most people have no idea about the demands that are placed on carers with minimal support provided. Because the care is provided in the privacy of the family home few people would be aware of the work that is done and the sacrifices that carers make. Few see the lights on at 2 or 3am when we get up to turn our son in bed to prevent pressure sores or suction him to remove the phlegm because he has another chest infection. Few understand how exhausting it really is for carers to have broken sleep night after night after night. Most new parents understand the fatigue that comes from getting up to a baby overnight but that experience is generally time limited. We however have been getting up most nights for 15 years. Unless you have experienced that level of sleep disruption it is hard to understand how chronically tired I always feel and the impact this has on the rest of my life.

I'm aware that those in the Army Reserve receive some payments which are tax free as well as recognition for the support role they provide to the country. Well, I feel that carers should be equally recognized and supported for the contribution that we make to society. I think we should receive financial support via tax deductions to acknowledge the 24 hour a day job we

do. I also think better support needs to be provided to assist families to care for their relative. Local councils provide a maximum of 3 or 4 hours per week assistance through the HACC program. These few hours go nowhere towards adequately assisting with feeding, showering, dressing, toileting etc.

More information is attached on a separate sheet

2. The barriers to social and economic participation for carers

As a carer, I face the following problems ...

I work part time and have done so since my son was one year old. It has been a constant struggle for me to meet my work commitments. I work 19 hours per week as this is all I can manage but because I'm only able to work part time this has severely limited my career prospects. It is very hard to apply for more senior positions when one is only able to work part time. Therefore my career stalled 15 years ago which has had a negative impact on our families finances. I am 48 years old and it is only in the last 2 years that I have started contributing to Superannuation. Needless to say that come retirement my superannuation level will be greatly below what one needs to live on.

One of my biggest difficulties with work was only having 5 days carers leave per year (It has only been over the past 12 months that this has been increased to 10 days). Every year I would use my quota of carers leave in the first few months and would then have to take unpaid leave when my son was ill or in hospital. Another difficulty (which I know all parents of school aged children face) is that our children have 12 weeks school holidays per year and I receive 4 weeks annual leave. My employer does not offer 48/52. I have asked them whether they would agree to provide it to me and they've said no because it might set a precedent which other staff with school aged children might also want. I feel however that my circumstances are different due to the difficulty I have finding suitable care for my son with a disability during the school holidays. I think employers should be obliged to provide 48/52 for those carers who request it.

Now that my son is 15 years old he is no longer able to attend after school care. These programs are offered for primary school children. I now use 7.5 hours each week of precious respite to have a worker look after our son at home after school on the days that I work. This therefore means that we don't have those hours available to use at other times (evenings, weekends) to enable my husband and I to go out together. I am using my respite hours to enable me to work which isn't really what they are intended for.

After school hours care and holiday programs for teenagers with a disability is a real problem that needs to be urgently addressed if parents are to be able to work outside the home.

More information is attached on a separate sheet

3. The practical measures required to better support carers

As a carer, I need help with ...

Our family needs more out of home respite. Due to the physical demands of providing physical care for our son day and night we only get a complete break when our son stays in a respite house. This is extremely important for our family as this is when we get to sleep through the night undisturbed. It also gives us the opportunity to do activities that are impossible/ too difficult to do with our son in his wheelchair as he is limited in the amount of

time he can sit in his chair without a position change. We need a hoist to transfer him from his chair and when we are out it is extremely difficult to find a place with a hoist to enable us to do so. When he is in respite we can spend uninterrupted time with our other child, which is important to his well being and development.

The longest period of respite we can get in one block is about 8 nights. After 15 years we would like to be able to go away on a holiday for longer than 8 nights. For example, we would like to go to WA, the Kimberly, central Australia and Kakadu and to do so we would like to take 2 or 3 weeks. This is the kind of trip that other families can do easily but for us it is impossible. After providing 15 years of care I think we should be due for long service leave. I think that after 10 years carers should be able to get a decent block of respite to enable us to take such a holiday. Before our son was born we traveled overseas a lot and enjoyed doing so immensely. Travel was one of our great pleasures in life and it has been very sad for us to give this away but we have been forced to do so due to the severity of our son's disability. We have had to make do with an annual holiday of one week's duration which is barely long enough to fully recharge ones batteries. Neither my husband nor I have traveled overseas since our son was born.

Carers would also benefit from concessions with electricity, gas, telephone and car registration. We are not eligible for any of these concessions because it is our son and not ourselves who has the disability. The bills are in our name and the Health Care Card is in his name so we are not eligible despite us using more electricity and gas for heating due to his disability and fragile health. We also have higher phone bills due to our son having a disability. We make numerous calls to service providers and usually have to ring case managers and workers on their mobiles. This results in greatly increased phone bills.

More information is attached on a separate sheet

4. Strategies to assist carers to access opportunities and choices

I think the Government can better help carers by ...

Increase the funding to States for the provision of disability support services. Long term accommodation for people with disabilities is essential. Our son is currently 15 years old. We will hopefully be able to care for him at home for another 5 – 8 years but by then we will be too old and tired to look after him at home. His care needs are so high that we will not be able to look after him indefinitely. I want to know that a place will be available for him in an accommodation service. We, of course will still visit him and have him to stay for the occasional weekend or holiday however it is clear to me that we won't be able to look after him forever. It is really important for us to know that such accommodation will be available when we need it.

We receive the Carers Allowance but I think this could be increased to better cover the additional expenses that families face and in recognition of the income that they forgo because they can't work full time.

For carers who are unable to work (or who work less than 15 hours per week) I think the government should make superannuation contributions into a fund for them in the same way that an employer would. Hopefully this would reduce the poverty they are likely to experience at retirement age.

If the federal government introduced a national Disability Insurance scheme this would assist with the provision of disability supports to those in need. It seems at the moment that there is inadequate funding to meet everyone's needs.

More information is attached on a separate sheet

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

Anne-Maree

Date

5.07.08