Rec 17/7/08

Submission No. 883
(Inq into better support for carers)

To: The Secretary of the House Standing Committee on Family,
Community,
Housing and Youth

Inquiry into Better Support for Carers

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.

Background
My husband and I are carers for our son. He is 7 years old with a profound disability and complex medical issues. Although our family adore him and he brings us a lot of joy, at times it can be incredibly difficult, and physically and emotionally exhausting. My father also requires full time care (from his wife), so I see the role as carer from more than one perspective.
It is important for the Australian community to value the role carers play in our society, and value the lives of the people being cared for.
I am concerned that there has not been adequate consultation in this process. For example, how many carers would send a submission where English is their second language? How many older carers would have easy access (and time and availability) to the relative ease of the internet? I think that considering the difficult situation many carers are in, not enough effort has been made to encourage feedback and ideas by all those that are labeled 'carers'.

I have responded to the terms of reference relevant to this submission as follows:

1. The role and contribution of carers in society

As a carer I feel that my role is sometimes overwhelming, and often isolating. The majority of respite facilities are not of a standard where many people can feel that the person they care for is being adequately supervised, respected and stimulated. These people who are sick, frail or have a disability are (or should be) equally valued members of our society and require their own choices and opportunities that are of a standard that any other person would expect and demand. If this were to be in place, the burden of carers would be greatly reduced. There is often immense guilt when admitting that you need a break, which is accentuated when leaving the person in a sub standard facility that they may not enjoy.

The role of carers is greatly undervalued, as is the contribution they offer to our society. For some reason, carers are not given much recognition, even though they often sacrifice their lifestyle and life choices to be in the caring role. The government relies on the love and obligation carers feel, because the economic cost to the community would be staggering if all carers were to just stop. Carers need to be respected, not pitied, and they should have choices, not limitations. Even the word carer gives an impression that caring is the sole role we play. Carers not only care, they play, talk, stimulate, read, clean, clothe, supervise, shower, toilet, lift, transport, chaperone, feed, prepare, medicate, manage, educate, organize, love, advocate and worry about the person they care for.

2. The barriers to social and economic participation for carers

As a carer I am restricted in everyday opportunities for my family and myself. For example, our local primary school where my daughter attends (and is not wheelchair friendly) encourages ride to school day. Logistically impossible for us, so our daughter misses out. Also, before and after school activities, again a logistical nightmare because it is just too hard to take my very heavy son out again after school. Going out for dinner, the movies, the park, visiting friends: all very difficult to organize and participate in on an adhoc basis.

Employment. It is very difficult to have employment and be reliable when you are caring for someone who has complex issues. Often, you need to rely on other people or paid carers who also have lives and get sick etc. Organizing a paid carer at the last minute is not an option. Family and friends often don't feel that they are able to manage the person with complex needs. The after school opportunities are difficult to establish and the increased sick leave required can make employment not viable. An example of this is where I worked part time for an organization. My son was very unwell and in hospital for an extended period, including time in the Intensive Care Unit. He had multiple complications, of which I would relay to my employer, and was only able to work about half my regular hours. This was probably the most challenging and emotional period of our lives. Although my work was of an agreed good standard, my employer thought I was abusing a substance because my pupils were often dilated (possibly also because the variety and severity of my son's complications may have seemed implausible). As funny and ridiculous as it was, it was actually very hurtful and disappointing that there was just no empathy or comprehension of my family's predicament, or any support offered. I resigned soon after.

Exhaustion and poor health. I don't remember when my husband or I have been able to sleep through the night. This on a long term basis is detrimental to our health. It would be similar to getting up to a newborn baby, except it has been seven years, and he is very heavy and not as easy to manage. We have no energy to exercise regularly, and those opportunities we do have, then place additional pressure on the parent left at home alone. Personal care requirements are also exhausting. This is heavy work every day, multiple times. Our son has ten different medications daily, or twice and even four times daily. These medications need to be made up and administered every day, wherever we go. He is fed four times a day via his PEG, a tube in his stomach. Again, this needs to be set up, administered, supervised, four times a day, one hour at a time, every day, wherever we go.

Financial stability. There are many increased associated costs when you are a carer. This, along with limited employment opportunities brings to a halt any financial plan. Also, study opportunities are limited for financial and logistical reasons. The financial contribution from the government for a carer is not anywhere near the minimum wage, again reiterating how undervalued carers are perceived.

Travel. Almost impossible. Even to spend a weekend away requires so much prior organizing and preparation that, assuming our son doesn't get sick at the last moment, is almost too hard and physically limiting to even bother. And overseas travel is out, never will be a viable option.

Respite flexibility (lack of). Our son receives care from multiple service providers, who are funded from a variety of sources. The limitation of each provider is frustrating and not productive or helpful. For example, one provider does not allow PEG feeding (feeding through a tube into the stomach), has strict restrictions on hours worked, and does not allow you to work on a 'respite' shift. Another stipulates the carer must do a shift at least every fortnight, will not let you bank any hours and reassesses your situation every three months. The facility based respite must be booked three months in advance, with some bookings not guaranteed as definite.

3. The practical measures required to better support carers

Flexibility. Carers need more flexibility and choice, particularly when it comes to respite. There needs to be more better quality in home, and facility based respite options. Families have different needs, people have different care needs and this should be taken into consideration on an individual basis. People should be given more control and flexibility over their funding options. The people being cared for should also have choice and flexibility in their care options. Far too much of the valuable resources and money are wasted in the bureaucracy of these systems.

Less Paperwork. Nobody chooses to be a carer, nobody chooses to need to be cared for. The amount of bureaucratic paperwork is overwhelming and unnecessary. The opportunity to rort the system for Carer's money and services would have to be negligible, so the need to assess and reassess situations is insulting. The regulations around many of the services and the funding attached is designed to prevent litigation in almost every circumstance, no matter how unlikely and frivolous, and to the detriment of the vast majority of its users. Service providers and government need to communicate and work together to streamline paperwork and services they offer. Permanent disabilities are exactly that, permanent.

Financial security. Carers and their families need more employment opportunities and more financial support if employment is not a viable option. Study opportunities should be encouraged, and financial support for this should be available.

Future planning. Support the 2020 submission for the National Disability Insurance Scheme It could be funded as a special supplement to the Medicare levy, third party car insurance and/or workplace insurance. Every carer worries for the future of their child/partner, whether the care will be adequate, whether they will be given choices and opportunities. This scheme is economically viable and a sound solution for the future.

Aids and Equipment. People with disabilities are left waiting for extended periods to receive vital aids and equipment that allow them and their carers to participate in every day life. There needs to be an immediate injection of funds and a review of the amount funded. To wait 12 months or more for $3500 for a wheelchair that costs thousands more is fundamentally wrong.

Carers health. The emotional and physical health of carers has been recently acknowledged to be poor, and by the very nature of the role of carer, really needs to be better than average. There is emphasis on carers' needs when apportioning funding, and carers often feel that they need to be not coping before any extra support is offered. Families often have to play the 'poor me' story (like now) which is not positive, and not productive. Carers should be allowed to cope, enjoy their lives, and still ask for what support they require without guilt and repercussions.

Ongoing communication and feedback. Engage and ask what people need, what they are happy and not happy with. Find alternate ways to receive this information. Encourage further consultation and work towards continuous improvement for government and service providers.

4. Strategies to assist carers to access opportunities and choices

Making essential aids and equipment available in a timely manner.

Encouraging employment and study opportunities to carers.

Streamlining and improving quality to service providers and their services

Investigate and implement the NDIS.

Offering true flexibility to families.

Understanding and valuing carers, and the people being cared for.