

Rec. 17/7/08

Submission No. 879
(Inq into better support for carers)

From: Sally |
Sent: Friday, 4 July 2008 4:14 PM
To: Committee, FCHY (REPS)
Subject: Submission for Parliamentary Inquiry into Better Support for Carers

Friday 4 July 2008

Sally

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
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.

In 2005 my family was involved in a vehicle accident. My then 5 year old son, now 10, suffered a severe traumatic head injury. Five years later he is still learning to walk, talk, eat and socialize.

I am fully aware of how easy it is to not have a child with support needs as I have experienced both sides. I have been extremely shocked at the inadequate amount of assistance available to those who are caring for children/people with support needs.

I currently am not able to take a paid job. We have my son with significant support needs and a 4 and 2 year old. My older son's schedule each week ie physio, occupational and speech therapy, constant gym work to maintain strength, continual consultations with specialists and the list goes on would not allow me to stay in the workforce. What I would need is a support worker to take my son to school and pick up from school ensuring that he made it to each of his sessions. This would amount to 20 hours per week of care. My son would not be able to attend before or after school care because of his support needs. What happens when my son leaves school is of grave concerns for me as he is very social and has an active brain.

My husband has had to reduce his hours of working by one day per week to ensure our son, can attend his one physio session (more is needed but....).

Caring for somebody with support needs takes time, a lot of time. It is like having in our case a toddler around the house. My son needs to walk to ensure he receives as much weight bearing as possible to ensure his bone density increases and to try and keep his muscles. Walking him is a daily

7/07/2008

requirement with almost his entire weight on us, his carers, he must walk around the house which means we literally have to hold his hands and walk with him or grab his walker for him to walk himself. Then he still receives a feed through his gastroonomy button, needs assistance with dressing, putting on his special boots, preparation of his medication to be given through his button, continual exercise and massage to maintain his muscle tone, constant assistance with his school work ie I have to type out his assignments.

The government needs to recognise that each person with special needs is different and has different needs. What is needed by every parent/person caring for that person with special needs is RESPITE. Time to be with their partner and their other children or just time to do their own thing.

It is very extremely difficult to obtain support workers. Government needs to recognise the importance of the support workers role and reward accordingly.

The government also needs to recognise that the more money put into the rehabilitation of those with special needs will make it cheaper in the long run as some of them can become more independent.

Most organisations run for those with special needs are run by the parents of those with special needs. We are surrounded by everything to do with special needs. Previously I was heavily involved in my school P&C, tennis club etc but now I have no time for this as I am continually administering and supporting my son. Again what my husband and I need is respite.

Due to the accident my son's basic needs are currently being covered by third party insurance. We have not yet reached settlement. Until that time we have no way of knowing how much financial provision we will have to make for our son. My fear of what would happen to my son when I die is paramount. I have attended a 6 day government funded course to try and build a plan to ensure my son's welfare and quality of life is sustainable as he gets older. The course I attended was run by Pave the Way based in Brisbane.

ACTIONS the current Labour Parliament could enact are:

- The government can assist carers by making Pave the Way courses available whilst maintaining the quality.
- Consistent & More Carers made available – eg for long distance travel ie shopping, going out we use a wheelchair. So I am limited to when I can go out especially when I needed to use a pram for my younger children. So again I needed assistance just to do the shopping.
- Wheelchairs – the government can assist those in supporting those in wheelchairs by putting into law that every doorway in Australia be made wide enough to fit an adult wheelchair and the biggest adult walker both domestically and commercially. By putting into law that the entrance to every commercial building should be wheelchair accessible.
- By legislating that 10% of all 1 and 2 bedroom holiday accommodation should have an entrance that is wheelchair accessible and have a wheelchair friendly bathroom.

As a family of fully abled people, since our accident, the knowledge we have gained about the Disabled sector, has been an extreme shock. This issue, has complete bearing over our lives and the lives of extended family/friends – they are now fully aware of the inadequancies of the Carer system in place at Local, State & Federal levels.

Our family has been severely impacted these past five years & our personal, economic & social resources have been seriously depleted. We have not asked much of the public system to date but without improved Carers support & resources, the next few years could see the physical demands of caring for our son, begin to impact heavily. Increased support now for Carers, will begin to pay off

immediately to all of us, the circle of family/friends locally.

Please acknowledge receipt of this email.

Thanking you
Sally