Submission No. 600
(Inq into better support for carers)
A.o.c. 8/7/08

1st July 2008

Committee Secretary
Standing Committee on Family, 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.

I am the mother of 4 sons, the third of whom, Jackson [redacted], has a profound intellectual disability and autism partly due to Phelan McDermid Syndrome (a deletion on the 22nd chromosome) and partly due to some extra 1st chromosome material.

Jackson is 22 years old and requires a high level of support – he needs full support in every area of his life except for mobility: he is able to walk.

My husband is also diagnosed with bi-polar disorder which adds another dimension but is not what I am addressing here.

Role and Contribution

Yes I am a Carer and yes I contribute because of the caring I do. However, I can contribute much more by being able to work in my areas of expertise which, strangely enough, is now as a leader and trainer for families of PWD and a presenter and trainer for many other people in disability-specific professional positions. People who have to leave the workforce because they *must,* deprive the Australian community and economy of an enormous range of skills. We are all the poorer for it – and I do not mean economically.

Barriers

As his mother and primary Carer my experience has been that we, as a family, have been disabled by Jackson's disability. I am still socially disabled but my other three sons have all managed to create their own non-disabled lives which is, of course, fabulous – they have moved to Sydney and Melbourne.

I have been unable to work full-time for 16 years and when Jackson finished high school I had to stop work altogether due to the severe lack of support for families like mine. That meant that I lost my right to work and therefore became isolated at home. I lost my income and, to some extent, my mental well-being. I work part-time now but only because my job allows me to work from home whenever and however I want as long as the job is done.

The single most important point that I would like to make is that being a Carer shouldn't be so hard. I do not mean hard in the sense of the caring I do as a mother of a son with a profound intellectual disability, but impossibly hard in trying to access funding, accommodation, services, community support and a real life of inclusion and quality for my son. Hence, impossibly hard for me to have a life that is not entirely defined by my being the mother of a son with a disability. And, naturally, I do not fully participate in social or recreational life.

Choices about caring

Carers on the whole do not have a choice about transitioning into and out of their caring role.

It is common for parents of people with a disability to continue fulltime care when they, the parents, are in their 70s and 80 and their adult children are in their 40s and 50s. As they contemplate their death, they worry about what will happen to their adult son or daughter – who will care for them, where will they live, who will ensure that their life is a good one and not one that merely satisfies their most basic human needs such as food, clothing, shelter and safety. These will keep people alive but they will not give people *a life*. As it stands, however, parents cannot even be sure that their adult son or daughter will have a home to move into, let alone the other things that ensure a life of quality.

I, like everyone I know, worry about the future of my son.

Practical Measures

There are no easy answers to any life that is defined by caring for a person with a disability. But the following would help:

1. The community in general is not ready to fully include people with, in particular, intellectual disabilities. Segregation of people with disabilities (PWD) in all areas of life should cease. There is much talk of inclusion but the policy and practices of the past decades have been of segregation and congregation and those policies and practices have been highly successful. PWD cannot magically be included in our communities when they have not been included from birth.

    a. Parents of PWD often continue to choose segregated options because they do not think there is any other way. You cannot choose what you do not know. And parents have learnt the lesson that their disabled son or daughter is not welcome in the community and so choose what they perceive to be the safer, more protected, more limited option of segregation.

> *"What we learn, we can unlearn and that includes fear and distrust. Prejudice, bias and racism are all learned responses and we can unlearn them."*
>
> (*A Truly Civil Society* 1995 Boyer Lectures by Eva Cox)

    b. The policy and practices of the past have been based on the philosophy that PWD are better off with their 'own kind', which has always meant with their 'own *disabled* kind'. But my argument is that their 'own kind' is primarily 'human kind' with the focus on *human* and not *disabled.* But the community, as well as parents, have learnt that 'disabled' comes before any other label and so people are seen in terms of their disability and not in terms on their humanness.

2. Parents, like myself, who devise innovative accommodation options should be fully supported by Federal and State Governments. I have support now (I think) but it has taken me 3½ years of relentless work and gentle but persistent lobbying to get that support. Many Carers do not have the language, strength, tenacity and verbal and written skills that are necessary to make things happen and so they give up. They should NEVER get to the point of giving up because people who have the power to make the decisions that influence their life do not listen – or if they listen, they then disregard what they have heard because professionals often think that they know best.

3. People with a disability should not be considered as an isolated individual. They should be considered as a member of a family – no-one exists in isolation and whatever happens in the life of a PWD affects their family. The family must be seen as a unit.

4. The natural authority of families should be recognised in all areas of service provision, policy making, procedure development and decisions that concern the person they care for. Families know their person best and have much knowledge, experience and expertise regarding their care and life needs. Too often families are disregarded when decisions are made. Families report that dealing with services and bureaucracies is the most stressful part of caring. This has been and is my experience.

5. All motorists/motorcyclists pay a levy with their registration that is used for people who are physically damaged or brain damaged because of a motor vehicle accident. This would free up some dollars for people who are born with a disability or acquire one through illness or other accidents.

6. For PWD, government is the provider of last resort. However when families fall to pieces, there is nowhere for PWD to live. In the ACT PWD often live in respite for months or even years while some accommodation is found or created for them. Somehow, there needs to be a strategy which is implemented *as a matter of urgency* to organise and provide some accommodation options for families who have a PWD. Even if families survive intact, disabled children will most likely outlive their parents, and so this is not something that will ever go away. It has to be addressed.

A final word from Andrew O'Hagan, Sydney Writer's Festival, May 31, 2007

"This is a great country and your greatness may always lie in a notion of your inclusiveness. But it is your job to make that more than just a notion: inclusiveness is a virtue to be fought for and won, and Australian has the heart."

Let's hope that he is right.

Thank-you for reading my submission.

Sincerely

Sally