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Submission No. 444
(Inq into better support for carers)

Committee Secretary

Standing Committee on Family, Community, housing and Youth

PO Box 6021

House of Representatives

Parliament house

CANBERRA ACT 2600

Australia

June 22nd 2008

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.

Background

As a carer of a son aged 39 who has a chronic mental illness, Chronic Paranoid Schizophrenia, I have spent most his life trying to seek out solutions to his problems, having to find the solutions to each stage of care myself, being frustrated at every turn by the myriad of pathways that are presented to you or you stumble upon which end up as wrong turns and dead ends and in the end building a team of interested people and professionals who will deal with his case, by myself, as his personal organiser. Incidentally this same scenario is occurring again, right at this present moment with my mother-in-law, aged 91, who has been assessed under the ACAT system, suffers from Alzheimer's Disease, has an assessment of low care, and this is not suitable for her present state and she has been excluded from a low care hostel. Our family are desperately searching for care for her.

As a carer I feel that my role is.....

To know what is happening with his health as I am the one expected to fix the problems when the treatment takes the wrong turn. I would like to be part of a team that treats my son without continually being the leader of the team that tries to put it altogether in his best interests so that communication flows all ways. Recently I had to find out which doctors fed back to each other as I felt my son was being overprescribed for and we were suffering again the fallout! I would like to think that when I need time out that the whole treatment plan does not fall through as I am turning 65 this year and I have been in the caring role for twenty years. I would like to be respected and listened to where ever I seek help as I am an expert in my son's behaviour and the insidious development of his illness and all its problems I see it daily and deal with it!

I face the following problems with my son.....

When my son was growing up I was able as a school teacher to attend to his learning problems and he was able to complete his education, gain 2 University degrees and work as a Geophysicist. I was

able to accompany him to his medical appointments, he suffered with Epilepsy and a bout of meningitis and I had a handle on his health problems. I have had to work hard for the last twenty years to be included in appointments and know the true picture as his carer and have suffered the fallout from lack of information in the form of mis-handled medication regimes, misrepresentation of his true state of mind and the consequent effect on all family members. To a degree I have a continuing problem in this area as new problems occur with his physical health with pain management, sleep therapy, a family history of heart disease, dental work even though in WA we have the Carers Recognition Act and Charter. This legal requirement has not been well publicised to health care workers and Professionals and we as Carers spend our time demanding our rights as best we can.

I face the continual problem of dealing with Government Agencies as my son's Power of Attorney. I have to report regularly to Centrelink about a problem that will never go away. He is recovering and in sheltered workshop employment but one is continually having to justify his position with rent, his meagre pay of \$9.00 an hour and his circumstances. This makes me feel like a criminal and makes him feel even worse!

I cannot access the Carers Allowance, even though I am his personal organiser, as most questions on the SA 381 Form do not address mental health issues. My resources are continually being depleted because of this.

I am constantly worried about his accommodation arrangements for the future. Real estate has become unreachable for some sections of the community and a safe, affordable, long term situation for him is getting further away. Currently he is accommodated near us but this is not permanent. His name is on the list for Wesleyan Housing but the list is long.

I need help with.....

A programme that is monitored to ensure that his recovery continues, both for his mental health and his physical health. I currently am his personal trainer. Quite a joke!! A 65 year old training a 39 year old! Recovery in WA is poorly treated and restricted to one philosophy.

As he is chronically ill with a major mental illness I need a team with a team leader that is not me! I am older and he will live longer than me. I need a long term plan for his care. Schizophrenia cannot be cured – it must be managed.

Dealing with a more sympathetic bureaucracy who has some insight into mental illness. I actually did experience one Centrelink worker who was in tears as he had to deal with my son's phobias when he was at his worst. I don't think there is enough training in this area. A similar problem occurs with the police whom we also have had the misfortune to encounter due to my son's behaviour. Misinformed or ill-informed people can make the situation much worse.

I think that the Government can better help Carers by.....

Listening to them and consulting them on policy.

Promoting current Legislation and ensuring it has a National orientation and consistency.

Making the pathway that they have to travel, next to their family member, more defined, consistent and accessible.

Developing a team approach to care that is holistic and in the context of recovery in the community. At the first port of call you are directed to the next so that you don't come away confused and uncertain of the next step. This currently only occurs if you as the carer are forward enough in your thinking to remember in your distressed state what to ask!

Making payments to the Carer that reflect their input and the cost of caring to them that is truly reflective of the work that they do in the mental health arena.

Making Respite a more workable option for both the Carer and consumer.

Making the working situation for carers more flexible and the workplace more empathetic with policies that will ensure the carer has rights.

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 the life of Carers in Australia.

Yours sincerely

Helen

Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community , Housing and Youth