Submission No. 1003
(Inq into better support for carers)

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The Secretary of the Committee
Inquiry into better support for carers
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Individual Submission

I submit the following to the committee from my perspective as an elder carer with multiple care responsibilities. Although I am currently the Chairperson of the North Coast Mental Health Forum and a Committee Member of Carers NSW (North Coast) this submission is from my individual perspective only and not an official view of either of these organizations.

Personal Situation.
My name is Jeanette I am 70 years of age, a retired secondary English teacher and my current income is the aged pension.

My son Richard, who will turn 50 in 2009, was diagnosed as paranoid schizophrenic in his early 20's, around 1980. At that time he was receiving training in classical guitar at Queensland Conservatorium of music but could not continue his studies.

Currently Richard is in the mental health ward of the Manning Base Hospital, Taree NSW. This is the final stage of a recurrent pattern, which has occurred many times, over many years and I believe this to be similar to that of other people with a mental illness. Basically this pattern is as follows: -

- For varying lengths of time Richard has lived either with me, or near by in various forms of subsidized housing, caravans or flats (or maybe "missing" as detailed below). He is dysfunctional even when "well" and has problems with general living functions such as personal hygiene, diet, housekeeping (when attempting to live independently) and managing his finances on the disability pension. To try to ease his financial problems, since approx 1989, the Protective Office has controlled his finances and disability pension. This has limited success, as I am constantly required to provide additional funds.
- During these periods Richard's medication and general living conditions are reasonably well monitored by health professionals and myself. If he is

attempting to live independently, I have always had to set him up with furniture, linen, clothing etc.

- He does, however, always eventually break down into yet another serious psychotic episode. At these times he runs away and is listed as a missing person with the police either by the mental health professionals or myself. Generally he will have been off his medication for some time, have taken nothing with him and left his accommodation in absolute squalor.
- At this stage he may be living on the street, camping in the bush or in a caravan. He will frequently (two nor three times a week) phone me requesting money be put in his bank account but refusing to say where he is.
- Eventually his behaviour will draw the attention of the police or health professionals will become involved and he will be scheduled into hospital.
- The process will then start again.

Given this very brief outline of more than 25 years of battling with the emotional and financial trauma of caring for a son with a mental illness, I submit the following comments for your consideration. I shall attempt to confine my comments to the terms of reference listed for your inquiry.

1. The role and contribution of carers in society and how this should be recognized.

Carers provide the essential <u>direct</u> contact and support needed by people with disabilities. This is a multi-role function, which in my case includes the following: -

- Providing the daily ongoing physical and emotional support needed for basic living. When my son is living with me this involves factors such as monitoring diet, personal hygiene, taking of medication and physical safety.
- It will often involve providing additional financial assistance on a regular basis, as my son is unable to budget or manage his own finances.
- Provide essential items such as linen, furniture, cooking utensils, etc when my son needs to set up independent living. <u>Note.</u> As these items are usually left behind when he moves on, this is an ongoing requirement.
- Clean the squalor and remove rubbish after accommodation has been abandoned.
- Provide additional clothing when admitted to hospital (usually after having lost or abandoned all possessions while off his medication).
- Liaise with case managers, health officials, police and (in my son's case) with the protective office, regarding ongoing problems, court cases and hospital admissions. <u>Note.</u> The phone bills resulting from situations can be extremely high and are added to by my son's tendency to phone via "reverse charge" when he is unwell.
- The total cost of all these factors has been that, although I live modestly, my $27,000 superannuation is now completely gone and I receive the Age Pension.

I believe these and similar contributions of carers should be recognized in a number of ways: -

- The role of carer needs to be recognized as continuing even when the person with the disability is not living with them. In my case this often involves long distance phone calls to health workers, police, hospitals etc. There is frequently extensive travel to hospitals and costs involved in replacing personal possessions abandoned while my son was off his medication. I am able to prove that I have provided ongoing financial support and support by phone and believe I should receive a Carers Allowance at least and possibly some reimbursement for costs involved.
- Recognition of the role of the carer in monitoring the well being of the disabled person needs to be given more status. For example, when my mentally ill son is "missing" one of the ways to locate him is for the bank to reveal the location of the branch where he is withdrawing his money. At the moment, despite the new mental health act, banks will not do this because of privacy limitations. Recently my son was registered as missing with the police department for 5 months before being located "waterlogged," camping in the scrub and in a state of acute mental disorder. His mental and physical deterioration was acute and could have been avoided if the local mental health team had been able to locate him earlier.
- Carers should be included in all professional discussions regarding the immediate and ongoing treatment and support for the mentally ill. Not only is this team approach very desirable but also the carer provides an ongoing continuous link when mental health staff changes occur.
- A national register of mentally ill patients needs to be created. This register should show medical history, current medication and contact details (including carer details and most recent case manager). Given the common itinerant pattern of many mentally ill people when they become ill, dysfunctional and separated from family and support, this register would form an important link in improving mental health outcomes.
- Carer advocacy is important this should include actions to coordinate the contact between providers such as Centrelink, mental health professionals, case managers, hospitals, accommodation providers, and so on with the carer informed of the approaches taken.
- Attention needs to be given to respite care for carers. This should not only include time away from the mentally ill but also community support groups, outings and respite 'treats.'
- The public image of mental illness and the role of carers needs to be de-mystified. Media focus, which is appropriately developed, would bring the role of carers forward in the public mind. Current media approaches tend to demonize mental illness, this needs to be changed so that the mentally ill and their carers are socially accepted.
- Free, ongoing counseling is needed for parents, families and carers of the mentally ill as many families break up due to the stress of 'caring.'

2. **The barriers to social and economic participation for carers, with particular focus on helping carers find and/or retain employment.**

   This section will be addressed in relation to four criteria: - Time, Finances, Social Stigma, and Employers.

   - **Time.** The carer's role requires a time commitment that is far in excess of that normally encountered in a domestic situation. For example, mentally ill people are notoriously poor at maintaining a clean and tidy environment. Normal household chores such as cleaning, washing, cooking, etc are all left to the carer. This even occurs when my son is living elsewhere. Added to this are duties such as monitoring medication, medical appointments, liaison with mental health professionals and the merry-go-round of events that occur when my son's health breaks down and he is missing.
   - **Finances.** Carers are poor. Most of them are mothers who sacrifice their pensions and allowances to assist the disabled/dysfunctional person. In addition to the constant requests for money for 'smokes' or similar items there are costs for transport, telephone and so on above the normal household expenses. In my case there is also the frequent costs of setting my son up in independent living situations only to have it later abandoned (including the cost of replacing clothing that has also disappeared).
   - **Social stigma.** The social stigma attached to mental illness is a barrier to participation socially and in the workplace. The carer of the mentally ill can become socially isolated and depressed quite easily. The public need to be educated about mental illness. It distresses me for instance that many crime shows on television so often depict the perpetrator of a crime as a paranoid schizophrenic. The majority of these sufferers are passive-gentle people more fearful than aggressive.
   - **Employers.** Employers want people who can be relied upon to attend to their job. Few carers can take on a full time job and still 'care' properly. Part-time work or work-share programs should be encouraged with government assistance to employers for training/retraining. Attention needs to be given to programs that will allow carers to enter the workforce at a level they can manage and still 'care' appropriately outside their working hours.

3. **The practical measures required to better support carers, including key priorities for action.**

   - A superannuation scheme for Carers who have been denied a full super because they were unable to work full time.
   - A more realistic Carer Allowance and Carer Pension to cover all actual out of pocket expenses.
   - A National Register of mentally ill patients who have a pattern of leaving their accommodation and are 'missing.' This would allow carers to reconnect when the person is hospitalized and immediate transfer of essential medication information and medical history.

- Banks should be instructed to inform the carer where a missing patient is drawing out from their account so police can locate them quickly.
- Carers should be included in consultations with mental health professionals who are treating the patient.
- Case managers need to liaise with carers to make sure they are coping adequately and that the client is in appropriate accommodation and care.
- Encourage professional advocacy for carers.
- Encourage carer support groups.
- Invite carers onto professional committees for their perspectives AND pay them.
- If the patient is not living with the carer, a professional team (2 people) should visit the patient daily (say between 5-6 pm) and sight that the patient takes his/her medication.

4. **Strategies to assist carers to access the same range of opportunities and choices as the wider community, including to make choices within their roles, transition into and out of caring, and effectively plan for the future.**

- Being a carer is like living a nightmare in a prison. It is a lifelong commitment to someone you love dearly who is terribly debilitated with mental illness.
- I only know that I need better financial support as an Aged Pensioner.
- Also I need better understanding of the issues when you are caring from a distance and still have to assist and support the patient financially and emotionally via STD calls.
- Regarding transition into and out of caring, I see no chance of getting out of the caring situation. In addition to the situation with my son's mental illness (as briefly outlined above) I have recently found that my husband, who is diabetic, has chronic kidney disease and a future prognosis of dialysis treatment five hours a day, three times a week.

I trust this submission will be of interest to your inquiry.

Yours Sincerely

Jeanette