

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
PO Box 6021
Parliament House
CANBERRA ACT 2600

Submission No. 799
(Inq into better support for carers)
AOC 16/7/08

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 submitting to the Inquiry because I am a carer for a family member with mental illness, and I am employed part time as a carer consultant in Mind Australia, which provides services for people recovering from serious mental illness in Victoria and South Australia. Mind is part of the Psychiatric Disability Rehabilitation Support Services sector. As far as I am aware, I am the only paid Carer Consultant employed in the PDRSS in Victoria or South Australia.

In my submission I draw upon both my personal experience as a carer and my growing experience as a carer consultant in a large mental health organization.

1. The role and contribution of carers in society

(the role and contribution of carers in society and how this should be recognised)

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

Terrifying, traumatic, overwhelming, confusing, stressful, isolating, lonely, undervalued, under resourced, not understood, unsupported, unheard, invisible, frustrating, depressing, emotionally draining, physically exhausting.

The contribution I make in society is to provide all that is lacking in the public and private mental health systems as they respond to my family member's mental health needs. Sometimes, this contribution is **everything**.

This role and contribution should be recognized through a **change in culture and practice for our mental health system**.

Research shows that "The participation of families in mental health care is of central importance for its success" (Froggatt et. al; 2007, "Families as Partners in Mental Health Care"). When carers and family members are included as **partners** in the care of people with mental illness, the outcome is often better for the person with mental illness (reduced incidence of relapse, better overall recovery), the family/carer (reduced stress, increased skills and resourcefulness), and the service provider alike (a useful resource with unique experience, increased information, decreased rates of relapse).

My own experience has shown me that when strong and trusting relationships developed between my family member, the mental health professionals involved in her care, and myself, a far better outcome was achieved than any of us could have hoped for in caring for or treating her independently. Sadly though, this has not been the experience of the majority of carers I have come in contact with. Many, particularly those involved with the adult mental health sector, describe being shut out, ignored, disempowered and disrespected by the mental health system within which their loved one is treated.

2. The barriers to social and economic participation for carers

(the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment)

As a carer, I face the following problems ...

The burden of care for many carers is a full time, unpaid role which leaves neither time nor scope to participate either socially or economically in the community.

During the worst of my family member's illness, I was unable to continue with any of my own life whilst caring full time for my family member with severe mental illness. As a result I became disconnected from friends, family, my usual activities and interests. Because of the intense demands of my caring role, I was reduced to surviving on minimal, casual work. It has taken four and a half years to get to the point of being able to re-enter the workforce, and even now I am only able to work part time.

Apart from the isolation and loneliness I was experiencing, like many carers I experienced anxiety and depression, trauma and grief as a direct result of the caring role. Whilst these conditions are considered mental illnesses in their own right, they are a fundamental part of the lived experience for carers. These symptoms become a major barrier to social and economic participation for carers.

The lack of respite options for carers of young people (adolescents) with severe mental illness is a major barrier to social and economic participation. Although I conducted an extensive search for it, I could find no respite whatsoever when I most needed it, and I have since come into contact with many carers who describe respite as difficult to access.

For carers to participate socially in the community, they need adequate and prompt respite options.

For carers to find and/or retain employment, they need adequate workplace flexibility to accommodate the caring role.

3. The practical measures required to better support carers

(the practical measures required to better support carers, including key priorities for action)

Carers need help with the following, but these requirements would be met if the mental health workforce was inclusive of carers, treating them as **partners** in the care of people with mental illness.

Identifying as a carer

By this I mean that many carers perform the role for a long period of time before identifying themselves formally as a carer. Service providers (doctors/clinicians/mental health professionals) could help carers identify themselves as carers by putting them in contact with Carers Victoria, or Carers SA, early in their caring role.

Support

Carers need support for themselves and their families (individual counseling, family therapy, respite) instead of being shut out of the mental health service systems.

Carers need to know about available services for carers and how to access these services. Families and carers should be supported through counseling services, family therapy, respite and other support provided by professionals with knowledge about carer issues and mental illness, who can resource them to continue with their work as carers.

Information about the mental health system

Carers need help with how to access mental health services and how to navigate our complex mental health system (eg: understanding the difference between clinical and non-clinical services, and the types of services offered in each). Even more helpful would be the integration of services, which would simplify access to and navigation of services.

Advocacy skills

Carers constantly need to advocate for themselves and their mentally ill family member, but often don't have the skills, leaving them and their family member vulnerable to the power imbalance between them and the mental health professionals.

Carers need skills and the scope to work with mental health service providers, in a culture where the current focus is on the individual, not the family.

Education about the privacy act, and how this impacts on caring for a person with mental illness. How to negotiate with clinicians around issues concerning confidentiality. It is important for family members to be able to get information about what is happening to their loved ones. This is particularly the case when it is clear that after treatment most mentally ill people will be returned to their families.

Information about mental illness

Specific information about the mental illness of the person who is cared for, and about the impact of the illness on the person and the family (behavioural, guilt, grief and loss). Vulnerabilities, management strategies, do's and don'ts for families.

Treatment options, best treatment approaches (local, national, international).

Community awareness and acceptance of mental illness (stigma, stress, behavior of others towards family & family member).

Information about Medication

The side effects of medication (long term effects and significant short term effects);

What to do if a bad reaction occurs. How to cope with non-compliance;

The appropriateness of medications for children and adolescents;

Medications are not always effective and often require specific instructions to be effective (i.e. to be taken in a particular order, or with food, or before food);

Medications used to treat mental illness are often addictive.

Service providers and other health services

Health services are poorly equipped, or do not collaborate, when a person has multiple mental illnesses (eg: eating disorders and mental illness with the physical implications of these).

Mental health services are underfunded and overworked (case loads too large). There is uneven funding of different parts of the Mental Health service system, creating an impression of a first and second class service system.

Lack of access to public mental health services: long waiting lists or no psych beds when in crisis, leading to inappropriate treatment in hospital emergency departments.

Information and skills for communicating with mentally ill people

Emergency department staff often have harsh or even punitive responses to people with Mental Illness in crisis. The environment within emergency departments often adds to the stress experienced by the mentally ill person, and families are often left without support, explanations and reassurance.

4. Strategies to assist carers to access opportunities and choices

(strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future)

I think the Government can better help carers by ...

Allowing carers to access the same range of opportunities and choices as the wider community. This includes employment, education and health care.

Whilst the government's paper "Caring Together" suggests that Service providers can employ carer consultants to better address the needs of carers, elsewhere it is clear that in general this is being done by using carers brokerage funds, since, to date, mental health services have not been formally funded to employ carer consultants. This practice decreases the amount of direct financial assistance to carers by depleting funds for access by carers in crisis. At the same time, the carers employed as carer consultants are invariably employed on a part time basis at an inadequate salary which does not reflect their education, skills and experience.

Service providers in the mental health system are not adequately prepared, resourced or trained to work with families and carers. Strengthening the mental health workforce by providing education to existing and future service providers and developing policy frameworks focused on including families and carers as vital partners in the care of people with mental illness is the key to service system improvement across the board.

Educational institutions have an important role to play in changing the culture of the mental health system by including family focused training in the curriculum.

Financial assistance

The full time caring role creates a financial burden on carers through the inability to continue with employment. When carers are able to return to work, they are often forced to work casual or part time in less rewarding jobs.

Centrelink requirements are overwhelmingly complex, and not all carers can qualify for centrelink assistance. The government could help by increasing financial assistance to carers including eligibility for assistance.

The carer brokerage fund is a useful initiative to help carers with some of the one-off costs associated with the financial burden of care, however, funds are not widely publicized, are very limited, and can only be accessed through case managers. This system discriminates against carers of mentally ill people serviced by the PDRSS sector which does not have access to brokerage funds.

Carer health and wellbeing

The burden of care leaves little scope for carers to maintain their own health and well being, and as a result carers often neglect their health for prolonged periods.

Whilst some initiatives (better access to psychologists, carer counseling service) have been introduced and are working well, access to services is limited and response time can be lengthy. The cost of private dental care is prohibitive for many carers, and access to public dental services is very limited.

Not all carers qualify for Centrelink benefits and health care cards, but all carers should be offered accessible, affordable, timely and appropriate services for general, dental and mental health care.

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 life for carers in Australia.

Yours sincerely

Michela

Print your name

2 July 2008

Date