



**Carers  
WA**

## Submission to Senate Select Committee Inquiry on Mental Health

**Organisation:** Mental Health Carers Issues Network  
Carers WA

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### **Introduction**

We welcome this important and necessary Inquiry into mental health care in Australia. This submission has been written by Carers WA and represents the views and concerns of mental health carers in Western Australia. These views have been obtained through a range of consultation activities including regular carers issues forums, the Mental Health Carers Issues Network, carer representatives on mental health service committees and “Worried, Tired & Alone” research. A copy of the research briefing paper is included with this submission.

#### Carers WA

Carers WA is a not for profit organisation and registered charity, dedicated to improving the lives of the 200,000 West Australian family carers, who overwhelmingly provide the majority of care in our community. As the peak body recognised by both State and Federal governments, Carers WA is the voice of family carers, representing their interests in WA.

In addition to representing Carers generally Carers WA is funded by the Division of Mental Health, Department of Health WA as the peak body representing the interests of carers of people with mental illness in WA. Carers WA performs this role in partnership with the Mental Health Carers Issues Network.

#### Mental Health Carers Issues Network

The Network is a collective of non-government organisations and carer representatives and works collaboratively to identify, promote and address mental health carer issues in WA. It is auspiced by Carers WA and was originally established in 1997 as the Carers Issues Committee, a standing committee of the WA Association for Mental Health (WAAMH).

Members of the Network include:

- Carers WA
- WA Association for Mental Health (WAAMH)
- ARAFMI (WA) Mental Health Carers and Friends Association
- Mental Illness Fellowship WA (formerly Schizophrenia Fellowship of WA)
- Mental Health Access Service
- Ishar Multicultural Centre for Women's Health
- Interagency Collaboration of Parents Who Have a Mental Illness (ICOPMI)
- Pathways Bunbury
- Carer representatives
- Learn About Mental Problems (LAMP) Busselton
- Learning and Attentional Disorders Society WA (LADS)

Members of the Network may also make their own submissions.

### **The Role and Contribution of Carers to Mental Health Care in Australia**

Carers are family members and friends who provide care and support to children or adults who have a disability, mental illness, chronic condition or who are frail aged. Carers can be parents, partners, brothers, sisters, friends or children of any age. Carers provide both emotional and practical support in helping their family member/friend cope with their illness.

Carers have an integral role in the care and support of their family member/friend with a mental illness. Carers consistently report that mental health services are inadequate and their family members can't get access to services when needed. On these occasions the responsibility for care and management is transferred onto the family carer who tries their best to manage and provide the care and support that is not available through mental health and community services. Without this sustained contribution from carers, the mental health system which is already under extreme pressure would be placed in greater jeopardy.

There needs to be a greater acknowledgement of the huge contribution that carers make in meeting the inadequacies of the mental health system.

"Carers are experiencing undue responsibilities and pressures in their caring roles due to significant gaps or inadequate practice in formal consumer mental health service delivery" (Mental Health Council of Australia & Carers Association of Australia, 2000, p. 4).

Carers fill the gaps in the system, providing the care and support for their family members and friends with mental illness who are unable to access the services they need. Without carers, the system would collapse.

The Carers of People with Mental Illness Project identified the enormous contribution of carers who on average contribute 104 hours per week caring for a person with a mental illness. Consequently it is "primarily carers who are sustaining the fabric and operational effectiveness of mental health service systems across Australia." (Mental Health Council of Australia and Carers Association of Australia, 2000, p.4).

## **Carers' Views and Concerns Regarding Mental Health Care in WA**

### Carers are unable to get treatment and support for their family member's mental illness

Carers consistently report that mental health services are inadequate and their family members can't access services when needed. Often people with mental illness do not receive treatment unless they are in crisis. On these occasions the responsibility for care and management falls onto family carers who try their best to manage their care and support at home. Where community services are inadequate, families pick up the pieces.

Carers report that current funding and provision of mental health care in WA is clearly inadequate to meet the level of need. This is demonstrated by:

- People presenting at hospital emergency departments requiring treatment for mental illness waiting in corridors as beds are not available in psychiatric hospitals;
- People unable to access community mental health services unless they are in crisis and are a threat to themselves or others.

### **Valda's Experience**

Valda migrated to Australia five years ago with her four sons. Her oldest son, John has schizophrenia and her youngest son has a history of self harming behaviour which has been attributed to the impact of John's illness on the family. About a year after Valda arrived in Australia and John was diagnosed with schizophrenia, Valda and her husband separated. John was recently admitted to hospital after taking a drug overdose. He was due to be discharged from hospital but had nowhere to live as his mother could no longer deal with his violent outbursts. His behaviour was also affecting her other sons. Valda has tried to find supported accommodation for her son but all the services have waiting lists. She also wanted to find employment for John but the employment support agencies also had long waiting lists. Valda managed to find private accommodation for John but she doesn't believe it will be suitable in the long term.

Access to mental health services in rural areas is becoming more difficult as services are closing. Last year, the mental health clinic was suddenly closed in Bunbury, a regional centre for the South West of WA with a population of approx 30,000. There was a complete lack of consultation with carers, consumers and health professionals regarding the closure. There is also no living skills, acute therapy and rehabilitation services. With the closure of these services, people with mental illness are forced to travel to Perth for treatment and care which has an emotional and financial impact on their families. Family contact is vital not only for the consumer's rehabilitation but for carers who struggle with the emotional pressure of caring for their loved ones who are unwell. Carers who travel to Perth to maintain contact with their unwell family member incur financial costs from travel expenses, accommodation and lost income.

## Carers are excluded from being involved in the care and treatment of their family member

A major barrier to high quality mental health care is the reluctance of mental health professionals to involve carers in their family member's treatment and care. In the Worried, Tired and Alone research conducted by Carers WA and the Mental Health Carers Issues Network, carers identified the carer role in treatment as the number one priority to improve services and support for carers and their family members with mental illness (McKeague, 2003). Carers continue to report that they feel there is minimal recognition of them by mental health services and minimal efforts to consider their views and/or involve them. The valuable role that carers have in the care and treatment of their family member is not recognised by mental health professionals and therefore they are excluded from assessment, treatment, and care planning. Whilst Carers respect the need for confidentiality the lack of possible involvement of carers is a significant barrier to carers in providing care and support for their family members with mental illness.

In many instances the reasons for this exclusion are identified as confidentiality issues. Confidentiality can be the reason given for not sharing information, for not involving the carer and for not consulting with the carer. On the other hand carers have complained of confidentiality being a one way street where what they have said is not respected and is shared with the patient. The balance to date has been the primacy of the confidentiality of the consumer. This needs to be reviewed and a more clearly defined confidentiality policy needs to be developed that recognises the rights of both consumers and carers.

### **Brenda's Experience**

Brenda's frustrating experience is representative of many carers. Her son was being discharged from hospital with a strict regime of medications to take. Upon leaving the hospital, the psychiatrist said to her "Now make sure he takes his medication, or he may have to be readmitted to hospital. She replied, I'll try my best, what medications is he taking and when does he have to take them?" The psychiatrist replied, "I can't tell you that, it would be a breach of confidentiality". How on earth is she supposed to supervise his medications if she doesn't know what he's taking and when he should be taking it?

Carers also have their own needs which are completely overlooked as their role is not even acknowledged. Carers want mental health services to adopt a Family Inclusive Approach to mental health care which acknowledges and assesses both the needs of people with mental illness and their carers.

## Lack of recognition of the carer role by mental health services and health professionals

The carer role in the care and support of people with mental illness is largely unrecognised by mental health services and health professionals. In the Worried, Tired & Alone research (McKeague, 2003) 15% of carers identified mental health services attitudes and lack of support as the most difficult part of their role as a carer. Carers expressed frustration and dissatisfaction with the attitude and lack of respect some mental health service staff displayed toward their knowledge and experiences. They were not allowed to be involved in the diagnosis and treatment of the consumer, were not kept informed and not provided with support. Carers want to be heard, be involved, be informed and be supported by mental health services staff.

## Paul's Experience

Paul is the primary carer for his daughter Linda who is in her early twenties. She was born with a genetic disorder and has obsessive compulsive disorder and depression. For years as parents Paul and his wife struggled to provide additional support for their child throughout her school years. After leaving school Linda got her first job but due to her illness was becoming extremely angry and frustrated and found it difficult to cope in the workplace. It was at this point that Paul and his wife realised they needed professional treatment and support for their daughter.

This was where Paul's frustrating journey began trying to obtain the treatment and care his daughter needed. He experienced continued barriers by mental health services and health professionals who didn't acknowledge his caring role or involve him in Linda's treatment and care. This was despite Linda providing consent for Paul to be involved at every stage of their struggle to get the help she needed. In one incident, the lack of involvement of Paul and his wife had serious consequences when Linda was admitted to the mental health service who then released her into community accommodation despite her condition. Neither Paul nor his wife were informed of her release until she left the next day. Paul and his wife spent an anxious day not knowing where their daughter was, if she was safe, and whether she would come home soon. Fortunately, the next day she hitchhiked home and was unharmed.

The mental health workforce including medical practitioners, psychiatrists, mental health nurses, occupational therapists, psychologists and social workers should undertake carers issues training to enhance their knowledge and understanding of carer needs and the role they have in the care and support of people with mental illness.

### Carers experience an increased risk of developing mental health problems

In the National Survey of Carer Health & Well-being 2000 'Warning Caring is a Health Hazard', two thirds of all Carers reported that providing care had directly affected their overall mental and emotional well-being. Carers identified being sad or depressed (28%); worried / anxious (27%); other feelings included being easily upset, frustrated / bored, mentally exhausted or stressed (12%). (Briggs & Fisher, 2000, p. 25).

Recent research conducted by Carers WA supports the survey's findings regarding the poor mental health of carers. 'Emotional strain' was identified by 52% of carers as the most difficult part of their role as a carer. (McKeague, 2003).

*"I have blamed myself for years over my partner's condition. I have lived in depression. I have lived in fear and isolation. I have not looked after myself properly, at the moment. I journey with my husband who is much better and journey with my 3 adult children who have their moments of depression too."*

Mother caring for her husband with schizophrenia

The poor mental health of many carers results from their caring situation and the impact it has on their lives. The provision of emotional and practical support for carers assists them to cope and in turn reduces their stress, depression and anxiety. Unfortunately the lack of information regarding carer support services can hinder their access to these services and getting the support they need. The GP Awareness of Carer Needs and Issues research

(Bulsara, 2003) reported that doctors are more likely to respond to dealing with carer depression by prescribing medication which while it treats the carer's depression, doesn't resolve the cause of their depression which is due to their caring role. Doctors recognised the financial barrier to carers in accessing private counselling but were unaware of carer support services including counselling that was free to carers.

### Carers are not involved in the Reform of Mental Health Services

"Whilst the principles of consumer and carer participation in the development, implementation and evaluation of the mental health system appear to be enshrined in National Mental Health Policy and Plans, there appears to be a lack of genuine consumer and carer involvement in mental health care or reform at the jurisdictional, regional and local levels." (Groom, Hickie, & Davenport, 2003, p. 16).

Consumer and carer input is essential if improvements in services are to be achieved. Carers have unique expertise in the mental health system and through their role know what improvements need to be made. There needs to be a real commitment to the value of consumer and carer participation by State and Federal governments, mental health services and mental health professionals. The commitment needs to be demonstrated through the provision of realistic funding to support participation programs and activities. Mental health services should be required to include consumer and carer participation as performance measures.

Carer representatives on mental health services' committees report that their representation is tokenistic and their views are not given equal consideration with other members of the committees. Mental Health Services require training and support to assist them in implementing genuine carer participation and consultation practices.

#### **Linda's Experience**

Linda cares for her daughter with depression and is the carer representative on a committee set up by the mental health service to establish a new early intervention program for children. She has felt quite isolated on the committee and feels that her views are not respected and her contribution not acknowledged. This is confirmed when she receives the minutes and her suggestions are not included. She feels part of the problem is that the other committee members are unsure of her role and feel threatened by her presence. Meetings are changed and she is not consulted but just informed of the changed times.

### Carers and people with mental illness living in rural and remote areas experience additional barriers to accessing mental health services.

Carers living in rural and remote areas experience additional challenges. These include difficulty accessing limited health and community services, social isolation, and the lack of continuity of care for their family member due to the difficulty in attracting and retaining health professionals. People in rural and remote areas are also reluctant to disclose a mental

illness and seek help and support due to the stigma of mental illness, which can be compounded in small rural communities.

### **Tracey's Experience**

Tracey lives in a town with a population of approx 3000 in a remote part of WA. She cares for her son with schizophrenia and is very isolated. She experiences the effects of stigma in a small town where everybody knows other people's business. Only a few people know about her son's illness. The greatest help for Tracey would be getting her son actively involved in daily activities but there is a continual staff turnover in the living skills service. Just as her son develops a relationship with a support worker they leave and her son withdraws from any further help.

### Lack of Carer Respite

Respite for carers, time away from the caring role, is essential to maintaining the care relationship and improving the quality of life of carers and their family members with mental illness. Without it there is the danger of relationship stress and breakdown and social isolation. Carers continually report their need for respite and their difficulty in accessing it. A specific respite program for carers of people with mental illness is required in WA as they aren't a recognised target group for other Commonwealth and State funded programs.

### Lack of Treatment Services for Non-Psychotic Illnesses

Carers are concerned about the additional difficulty in accessing treatment and support services for people with neuroses such as obsessive compulsive disorder, anxiety disorders and depression. The impact of these illnesses on people and their families can be just as debilitating as psychotic disorders such as schizophrenia and bi-polar disorder. It appears that the majority of mental health services are focussed on treatment of people with psychotic disorders however people with neuroses also need treatment and care.

In WA there is a lack of specialised treatment and support services for people with eating disorders and a lack of support services for their families. As there is no specialised public treatment service for adults with eating disorders, people either pay for private treatment or do not receive treatment at all due to the cost barrier.

### **Jenny's Experience**

Jenny is 20 years old and has had anorexia for 5 years. She received treatment through a specialised treatment service at a children's hospital but when she turned 18 she was sent to an adult mental health service. Her treatment by the mental health service and the transition from the children's hospital were poor. Jenny has had periods of receiving no treatment at all but has now accessed a private service, which is a huge financial burden to her.

### Carers Need More Information

The ability of carers to care and support their family members with mental illness is hampered by a lack of information. Carers are not provided with the information they need to care including:

- Their rights and the rights of those for whom they care;
- Their family member's mental illness, signs and symptoms;
- How to live and cope with the illness; and
- Carer support services.

Carers should be provided with this information by GPs, mental health services and health professionals.

### Carers Suffer the Stigma of Mental Illness

There is a huge stigma associated with mental illness. This often discourages carers from seeking help for their family member's mental illness and support services for themselves. There needs to be more community education programs to reduce the stigma of mental illness.

### **Attachment**

Briefing Paper - "Worried, Tired & Alone – A Report of Mental Health Carers' Issues in WA.

### **References**

- Briggs, H., & Fisher, D. (2000). *Warning Caring is a Health Hazard - Results of the 1999 National Survey of Carer Health & Well-being*. Canberra: Carers Association of Australia.
- Bulsara, C. (2003). *GP Awareness of Carer needs and Issues*. Perth: University of Western Australia.
- Groom, G. Hickie, I. & Davenport, T. (2003). *"Out of Hospital, Out of Mind!" A report detailing mental health services in Australia in 2002 and community priorities for national mental health policy for 2003-2008*. Canberra: Mental Health Council of Australia
- McKeague, B. (2003). *Worried, Tired & Alone - A Report of Mental Health Carers' Issues in WA*. Perth : Carers WA
- Mental Health Council of Australia & Carers Association of Australia. (2000). *Carers of people with mental illness project – Final report*. Canberra: Commonwealth Department of Health & Aged Care

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