Worried, Tired & Alone -
A Report of Mental Health Carers' Issues in WA

Briefing Paper

INTRODUCTION

This research into the issues affecting carers of people with mental illness in Western Australia was commissioned by Carers WA in July 2003 as part of their ongoing commitment to identify carer needs and to advocate on their behalf. The research was undertaken in partnership with the Mental Health Carers Issues Network which works collaboratively to identify, promote and address mental health carers' issues in WA.

The aim of this research was to identify the current needs of carers and the issues impacting on their lives. The research also aimed to establish if there were any new issues emerging that have not previously been identified.

The research was conducted by Mr Brendan McKeague, an independent consultant.

METHODOLOGY

Invitations to participate in the research were distributed to carers through the Mental Health Carers Issues Network and four mental health services during August and September 2003. Carers were invited to complete a written questionnaire or to participate in a telephone interview or to attend a focus group.

A total of 144 carers participated in the research.

- 127 completed written surveys
- 10 participated in a telephone interview and
- 7 carers from culturally and linguistically diverse backgrounds participated in a focus group.

RESEARCH FINDINGS

Carers were asked to respond to a series of questions identifying their needs and issues. A summary of the questions, carer responses and some quotes appear below.

Written Surveys

1. What Is The Most Difficult Part Of Your Role As Carer?

Emotional strain was identified by 52% of carers as being the most difficult part of their role as a carer. This resulted from feelings of uncertainty and fear about the future; the unpredictability and uncertainty of the consumers' behaviour; abusive, angry and intolerant behaviours; feelings of helplessness; the carer's own deteriorating personal health; the difficulty of letting go of the responsibility; and sense of isolation and loneliness.

> *"He is constantly demanding and because he is so strong willed he won't give up. I need to try to be a step ahead of him at all times which takes up all my energy.*

Carers Association of Western Australia ABN 38 219 836 631 255 Walcott Street, North Perth WA 6006
Telephone: (08) 9444 5922 Facsimile: (08) 9444 8966 Freecall: 1800 242 636
Website: www.carerswa.asn.au Email: carers@carerswa.asn.au

> *Because mental illness is something you can't see and he looks so good and normal it makes it hard to accept."*

A further 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.

Other responses to the difficulties in caring were physical strain (12%); loss of personal freedom (9%); family attitudes and behaviors (4%); finding help and support and financial difficulties (4%); and community attitudes/other (4%).

2. What is the best part of being a carer?

For many carers the best part of being a carer related to personal growth and the opportunities provided to develop stronger family relationships. **Providing care within the family** was identified by 29% of carers who reported that caring for their family member with mental illness had enhanced the bonding within their family and maintained and strengthened family relationships.

> *"Providing love and support....valuing and honouring your loved one in a way no-one else can."*

Many carers identified **personal and family growth** (26%) as the best part of being a carer. They had developed personal skills in self-knowledge and empowerment; understanding others; role-modeling; helping others; and received affirmation; and love. Seeing improvements in behaviours, achievements and family connections (17%); caring in the community (7%); and gaining new knowledge and skills (2%); were all positive aspects of being a carer.

Of significant note is that 19% of carers reported that there was nothing good about their role or experience as a carer.

3. What would make your role as a carer easier?

Support from mental health service providers was identified by 25% of carers. This included an increase in the level of mental health services available; visits from nurses and other staff at home; better access to information; more support from carer support groups and organisations; and more support services and activities for their family members/friends with mental illness.

The second most frequent response to what would make the carer role easier was better and more respectful **relationships with mental health service providers** (18%). Carers wanted a better relationship including more communication, understanding and consistency from staff. Carers want to be listened to and given more information about the availability of assistance and support.

> *"When consumer is in hospital, better communication between all parties, staff, psychiatrists, social worker, case worker or community nurse and us and more integration with Drug and Alcohol services/psychologists for on-going maintenance of care and treatment."*

Other responses to what would make carers' lives easier were domestic and financial help (14%); an improved relationship with the person they care for and their family (11%); more respite (9%); better relationship with the community (7%); greater independent accommodation (6%); more research into treatment of mental illness (1%); and a better relationship with other government departments including Centrelink (1%). Some carers could not think of anything to make their role easier or were satisfied with their current situation (8%).

4. What impact has being a carer had on your life?

The majority of carers (88%) reported a negative impact that being a carer has had on their life. **Loss of personal, physical and emotional freedom, and restricted social and work opportunities** was identified by 30% of carers.

> *"What life! My life belongs to him!"*

Impact on family dynamics was the second most frequent response to how caring had impacted their life (25%). There were effects on children and siblings, disturbing family emotions, difficult relationships with partners, and marriage breakdown.

Other negative impacts included personal illness, tiredness and sadness (22%); additional home management and financial responsibilities (7%); and social isolation (4%). A minority of carers (12%) wrote of the positive aspects of the personal learning and growth they had experienced from caring for someone with mental illness.

5. What three things would you change about mental health services?

This question received the greatest response. The most important change that carers want from mental health services is **respect for and involvement of carers** (21%). They want more recognition of and respect for carer knowledge and their role; to be heard and be believed; psychiatrists to take more notice of their knowledge and experiences; to be involved in their family member's/friend's treatment program; a team approach to treatment; a holistic treatment program; greater respect for people with mental illness; and greater monitoring of people with mental illness.

> *"Official recognition by Mental Health Service providers of support that is given by carers and the carers' need for support ie. Information on who they can contact for information, counselling, education. Caring can be a lifetime commitment."*

Carers also want **more care for carers** (14%). This includes increased practical and domestic services; access to comprehensive information when they need it; increased information and education; increased carer support; and more respite.

Providing more direct support for people with mental illness was requested by 13% of carers. They want more independent living, training and employment programs; quicker access to services; more home visits; provision to be made for when they can no longer care; greater activities for the person they care for; and attention to address the poorer physical health of people with mental illness.

A range of changes relating to **hospitals, doctors and research** were nominated by carers (12%). Carers want to see more immediate access to hospital and professional help when needed; better communication among mental health service and hospital staff; more specialist hospital facilities; more appropriate facilities and better services at Graylands; more clinics; better discharge planning and rehabilitation services; better education of GPs; and increased research into mental illness and medications.

Other changes that carers would like to see include increased availability and standard of accommodation for people with mental illness (8%); increased public awareness and community support (8%); increased and improved training of mental health service staff (5%); increased funding for mental health services (5%); increased services in country areas (5%); increased financial support for carers (3%); and a clarification of confidentiality issues (3%). Some carers suggested no changes as they were currently satisfied or were unsure (2%), and 1% affirmed existing services.

Telephone Interviews

Forty percent (40%) of the telephone interviews were with carers from rural and remote areas of WA. The findings from the telephone surveys are consistent with the written surveys with the following addition.

To the question "What three things would you like to change about mental health services?" carers emphasized that there needs to be greater resources for mental health services especially in rural areas. This included more hospital staff and facilities; additional community nursing; and access to private health care.

> *"In the rural area, the counselor only comes around once per fortnight. So even if the consumer recognises and accepts the need for help, there's not very much available."*

Focus Group

The focus group was held with carers from culturally and linguistically diverse backgrounds. Again the findings from the focus group were consistent with the written surveys with the following addition.

To the question "What three things would you change about mental health services?" carers would like to receive more respect for their different cultural backgrounds and that mental health service staff understood their particular cultural and family background better so that carers' own situations would be respected.

> *"My mother will only speak to anyone if I'm there with her – she needs more specialist support from people who understand her cultural background."*

PRIORITY AREAS

The final part of the survey asked carers to rate 8 previous identified priority areas to improve services and support for Carers. The priorities in order were:

1. Carers role in treatment
2. Carer information
3. Carer respite
4. Legislation
5. Carer support
6. Confidentiality
7. Internal culture
8. Carer participation

Publication Details
Author: Brendan McKeague
ISBN: 0-9751663-0-1
Date: November 2003
Enquiries and requests for copies of the full report should be directed to:
Sue Taylor, Carers WA 255 Walcott Street North Perth WA 6006 Tel: (08) 9444 5922
Fax: (08) 9444 8966 Email: info@carerswa.asn.au Website: www.carerswa.asn.au