

House Standing Committee of Family, Community, Youth and Housing

Inquiry into better support for carers

Submission by SANE Australia, 26 June 2008

SANE Australia is a national charity working for a better life for Australians affected by mental illness. This submission calls for better support for the carers of people affected by mental illness, especially those affected by disabling conditions such as schizophrenia. It contains four main recommendations, supported by an accompanying *SANE Research Bulletin* on this topic, in which these carers report on the difficulties they face and the services which would improve their lives and those for whom they care.

Recommendation 1 **Practical support**

Families of people with a mental illness receive very little practical, day-to-day support for the enormous caring role they carry out. As well as practical, financial and legal support, respite is needed on a weekly, even daily basis, not just a few times a year as a 'break'. Organisations supporting carers need a substantial increase in funding to provide this help more comprehensively and systematically around the country. (A further area of need is specialist support for families when the person with a mental illness goes missing or dies by suicide. Not only is this highly distressing, but research indicates it also places these family members at higher risk of suicide themselves.)

Recommendation 2 **Mental health services**

A major contribution to the well-being of family carers would be to improve clinical services for people with a mental illness, as well as the availability of supported accommodation and other community services. This would ease the caring role of families as well as benefit the person with the illness.

Recommendation 3 **Education and training**

Family interventions based on education and training are among the few treatments – apart from medication – which have proven effectiveness in improving outcomes for people with illnesses such as schizophrenia.

While there are some education programs for carers provided by community organisations, it is disappointing that nowhere in Australia are the proven family interventions provided as part of standard clinical treatment. Commitment and action are urgently needed by government to make this available systemically at a national level.

Recommendation 4 **Education of health professionals**

Many health professionals still exclude family carers from treatment planning, and withhold information, inappropriately citing confidentiality. This is despite changes to legislation and new policies on inclusion of carers. Health professionals need training and supervision to ensure these attitudes to family carers are improved. carers from treatment planning, and withhold information, inappropriately citing confidentiality. This is despite changes to legislation and new policies on inclusion of carers. Health professionals need training and supervision to ensure these attitudes to family carers are improved.

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Family carers and mental illness

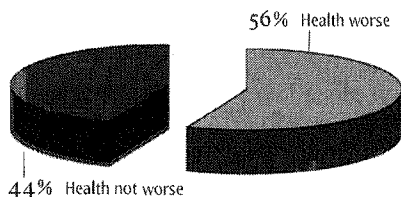
Families play a major role in providing day-to-day care for people with a mental illness, but improved support is urgently needed, especially in education for this role . . .

Families play a major role in providing day-to-day care for people affected by mental illness. A number of government policies and initiatives have been aimed at helping this group over the years, including the recent COAG National Action Plan on Mental Health. Nevertheless, they are still very often unsupported, given no training to help their family member or themselves, and have important information withheld without reason by health professionals.

This SANE Research Bulletin investigates the effects of caring for someone with a mental illness, and what needs to be done to support families in this role.

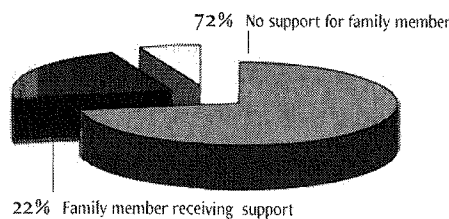
The survey was conducted during March-April 2007, using a convenience sample of 529 family carers who completed a questionnaire via the SANE Helpline or website. Respondents were most commonly parents (30%), adult children (26%), partners (23%) or siblings (10%). The most common diagnosis of the person cared for was schizophrenia (36%), followed by bipolar disorder (23%) and depression (20%). Around one in four (23%) had a diagnosis of a mental illness themselves.

What is the impact of being a family carer?



The majority of family carers (56%) reported that their physical and mental health had suffered as a result of their caring role. Many expressed frustration and anger that mental health professionals did not consult them about taking on this role, did not give any training or support, and disregarded and excluded them from treatment planning.

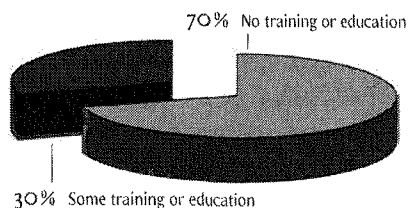
What difficulties are faced by family carers?



Families face an enormous, unfair burden of care, with almost three-quarters of family members with a mental illness (72%) not receiving any rehabilitation or community support. Fifty per cent had trouble finding suitable accommodation for their relative with a mental illness. Around half also experienced verbal aggression from their relative, and 25% had experienced physical aggression.

The majority (55%) expressed deep frustration at the lack of support and information from mental health professionals, especially where 'confidentiality' was inappropriately cited as a reason for excluding them.

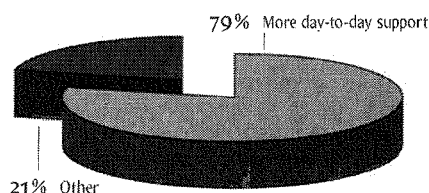
What support had family carers accessed?



The majority (70%) had never received any form of training or education to carry out their role. Over half (54%) had not accessed carer support services of any kind. Around one-third (32%) had used the Internet to find information, and 5% had used a telephone helpline.

Family carers and mental illness

What help do family carers need?



Family carers expressed an urgent need for practical, day-to-day support to ease their role. They asked to be heard, respected and included in treatment planning by mental health professionals, as families often provide the majority of day-to-day care. This is particularly important in relation to discharge planning and ongoing support, and for the one-in-four carers who experience mental illness themselves – whether pre-existing or developing later.

Improved public understanding of mental illness is needed, in order to reduce the isolation and stigma of being a family affected by mental illness. Many family carers also noted that one of the best ways to help them would be to simply improve the mental health care provided to their relative.

In summary

- 1 Families report a range of health, financial and other problems associated with caring for a person with a mental illness.
- 2 Despite a plethora of government carer policies, families remain unsupported and isolated, with very little help for their relative with a mental illness or for themselves. Mental health professionals expect families to provide day-to-day care, but do not give the support or information they need to carry out this role.
- 3 The majority of families struggle alone without help from any carer support organisation. An even greater proportion – almost three-quarters – have never received any education or training on how to care for someone affected by mental illness.
- 4 Families urgently need practical, day-to-day support to ease their role; education and training to make caring work better for their relative and themselves, and respect and inclusion in the treatment team from mental health professionals.

Recommendations

1 PRACTICAL SUPPORT

Families of people with a mental illness receive very little practical, day-to-day support for the enormous caring role they carry out. As well as practical, financial and legal support, respite is needed on a weekly, even daily basis, not just a few times a year as a 'break'. Organisations supporting carers need a substantial increase in funding to provide this help more comprehensively and systematically around the country.

2 MENTAL HEALTH SERVICES

A major contribution to the well-being of family carers would be to improve clinical services for people with a mental illness, as well as the availability of supported accommodation and other community services. This would ease the caring role of families as well as benefit the person with the illness.

3 EDUCATION AND TRAINING

*Family interventions based on education and training are among the few treatments – apart from medication – which have proven effectiveness in improving outcomes for people with illnesses such as schizophrenia.**

While there are some education programs for carers provided by community organisations, it is disappointing that nowhere in Australia are the proven family interventions provided as part of standard clinical treatment. Commitment and action are urgently needed by government to make this available systemically at a national level.

4 EDUCATION OF HEALTH PROFESSIONALS

Many health professionals still exclude family carers from treatment planning, and withhold information, inappropriately citing confidentiality. This is despite changes to legislation and new policies on inclusion of carers. Health professionals need training and supervision to ensure these attitudes to family carers are improved.

* Mihalopoulos et al, 2004. Assessing cost-effectiveness in mental health: family interventions for schizophrenia and related conditions. *Australian and New Zealand Journal of Psychiatry* 38 (7), 511–519

SANE Australia

A national charity working for a better life for people affected by mental illness – through campaigning, education and research.

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