

Submission No. 1108

(Inq into better support for carers)

INQUIRY INTO BETTER SUPPORT FOR CARERS

SUBMISSION TO

The House of Representatives Standing Committee on Family, Community, Housing and Youth

The Secretary of the Committee

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Terms of Reference dated 14th MAy 2008

Submission by

The Horsham Family Advisory Committee (Victoria)

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Organisational profile

The Horsham Family Advisory Committee is made up of family members, friends and carers of people who are or have received a service from Psychiatric Services.

The committee is one of three (3) autonomous committees that provide advice to the Ballarat Health Services Psychiatric Service throughout the Grampians Health Region in relation to the functioning of the Psychiatric Services, regarding inpatient, program and community service provision.

The committee is organized to input into policy, influencing service delivery and service development and is a point of reference for Ballarat Health Services Psychiatric Services.

The committee has been established for over twelve months. The members of the committee have a well developed detailed and sophisticated understanding of mental health family/carers' issues and needs.

The committee has a richness of evidence on the issues that really affect families/carers who care for a person with a mental illness from a rural and remote Victorian perspective

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NOTE: We would be available and interested in attending the public hearing due to take place in Melbourne.

BACK GROUND OF MENTAL HEALTH FAMILY/CARERS IN RURAL WESTERN VICTORIA

In 2007 The Ballarat Health Service – Psychiatric Service, carer consultant with the guidance of the Horsham Family Advisory Committee produced a survey targeting all families and carers that care for a person with a mental illness that were receiving a service of the Horsham Psychiatric Services; Adult Services.

140 surveys sent out. There was a 36% return rate.

Based on those responses; The 2007 FAMILY/CARER SURVEY provides a picture of what it is to be a mental health family/carer, for a person who receives a service from the speciality mental health service (Horsham Psychiatric Service) in rural western Victoria. *(Please note that this is a snap shot of some 40 questions asked in the survey)*

The survey found that the 'typical' family/carer in this region;

- Is female
- Between forty and sixty years of age. 77.8%
- 72.2% of families/carers are living with the person they care for.
- Predominantly caring for their partner 63.9% or Adult child 30.6%
- 55.6% of family carers had not been in contact with the mental health care service for more than three months.
- 63.9% of family carers had not had an explanation provide to them with information about the assessment process.
- 66.7% of family carers had not had an explanation provide to them with information about the treatment planning and review process

Two of the key findings from this data are

- That 61.1% said that they did not or are not receiving assistance in the use of specific techniques or tools to help them and the person they care about cope with the effects of the illness? (i.e. problem solving, illness education, effective communication.....)
- And that 52.8% of families/Carers have not been informed of available services and supports for carers? (i.e. Carer support groups, Carer support persons, respite options, Carer Support Brokerage Funds or others....)

Despite current Federal and Victorian policy and strategy indicating that Families/Carers be given comprehensive information, education, training, and support to help families/carers understand, and advocate for the person with the mental illness.

RESPONSE TO MATTERS IN THE TERMS OF REFERENCE

1. THE ROLE AND CONTRIBUTION OF CARERS IN SOCIETY AND HOW THIS SHOULD BE RECOGNISED;

Response

CARING FOR A PERSON WITH A METAL ILLNESS

While sharing many familiar issues with other groups of carers, there are a number of characteristics which make the needs of mental health families/carers distinctive.

- The fluctuating nature of mental illness
- The impact of the widespread stigma surrounding mental illness in the community that marginalizes and isolates families and carers
- The lack of basic understanding of the impact and the complexity of caring issues families/carers among health professionals, (G.P.s, psychiatrists; pupils and private; nursing staff, allied health, etc.)
- The one hundred year legacy of historical '*health professional*' '*family blaming*' for the illness has left its mark in the way people and health professionals currently view families of people with a mental illness; causing the illness, or the relapse; (*models of madness; psychological, social and biological approaches to schizophrenia, J. Read, LR. Mosher, RP. Bentall; Routledge 2004*) which is exceptionally prevalent in rural and remote communities today.

Mental Health Family Carers not only support the person they care about, they are propping up a mental health system that is failing its patients and communities by not delivering the evidence based treatments known to work to patients, their families and the communities.

THE IMPACT CARING FOR A PERSON WITH A METAL ILLNESS HAS ON FAMILY/CARERS

While it is acknowledged that caring for someone you love and care about can have positive effects for both parties and draw them and the family together, when the person you care about and care for is acutely unwell or chronically unwell in combination with a lack of effect treatments for the person and families not being included in treatments and a lack of social supports, the impact of caring can have some very negative consequences;

- Negative impact that Caring can have on a carer's own health.
- Increased out-of-pocket expenses that have dramatic negative consequences because of accessing service provision for the person who is unwell; from GP access to specialist access
- Fear about the unknown progression of the illness
- Anxiety of the unknown nature of the illness
- Distress watching the person you love succumb to the destruction of the illness
- Apprehension of the unexpected volatility of the illness
- Worry and distress over the damage that that the illness can cause to relationships

The tragedy of the inadequate and ineffective mental health services equates to needless custodial inpatient care and the lack of effective community treatment follow-up care can fate many patients and their families to lives of predictable deterioration and dysfunction. Successive federal and state Governments failure to adequately address mental health service provision accountability issues greatly impacts on the family carer and thus Families and carers are increasingly burdened with responsibilities.

Enough evidence exists from around the world that services delivering mental health care are not using the knowledge or evidence they have to maximize patient and family outcomes by delivering the programs that combine good pharmacological and psychosocial treatments for persons with mental illness and their family.

Therefore we feel that the role and contribution of carers should be recognized by the Governments by;

- Ensuring that services delivering mental health care are delivering those evidence based treatments that are known to work to all patients and their families.
- Ensuring that the fluctuating nature of mental illness is no longer a barrier and does not inhibit family carer's access to government benefits that other carers of physical illnesses can access.

2. THE BARRIERS TO SOCIAL AND ECONOMIC PARTICIPATION FOR CARERS, WITH A PARTICULAR FOCUS ON HELPING CARERS TO FIND AND/OR RETAIN EMPLOYMENT;

Response

Rural communities have been likened to "fishbowls." The comings and goings at services delivering mental health care are observed, and people (the community) listen carefully to comments of staff members. Thus the chances of confidentiality breaches with significant consequences for personal, family, and professional relationships are intensified.

This situation has numerous ramifications; fear of confidentiality breaches prevent patients and families from seeking or complying with necessary mental health care due to the consequences of stigma and social exclusion.

An important factor influencing and compounding the confidentiality dilemma is the impact created by poor mental illness awareness within our small communities.

The impact created by poor mental illness awareness within our communities.

- *Kids of parents with mental illness are not invited to the local children's parties,*
- *When you walk down the street, people who used to stop and have a 'chat' now cross the street to avoid you*
- *You are not asked to local events anymore,*

Discrimination from the community is another complication to overcome in addition to caring responsibilities and inhibits social participation and leaves you socially isolated.

Family and carers in rural and remote areas of western Victoria and the Mallee face additional challenges to those in metropolitan areas when faced with accessing or maintaining employment and social activities. There are numerous barriers to overcome.

In rural and remote locations there are limited or no local availability of mental health specifically skilled service providers (G.P.s, private psychiatrists, and psychologists) and the services that are available for mental health treatment are grossly inadequate in their early detection and treatment of mental illness.

There is a lack of access to carer support groups and a lack of appropriate or accessible mental health respite services. The ones that do exist are too limited in their assistance. Family carers living in rural or remote areas are covered by the same respite programs available to those in the urban areas and as a result, rural and remote areas that are serviced from the urban areas services, in our view are clearly lacking to meet the need.

Mental health family and carers need to travel large distances to access specialised services in regional centres or cities and therefore face increased financial costs for travel. As well there is a lack of accessible public transport options in rural areas which adds to the family burden when an individual with becomes so unwell that they cease driving.

Patients are forced to leave their communities and families for several weeks if they need inpatient admission or years if they require residential rehabilitation care facilities.

There are no residential rehabilitation care facilities for persons who are very impaired by their illness outside the large regional cities. The closest one (1), (up to 300klm away) a 19 bed facility is located so far from visiting family and friends that visiting is problematic, engaging in treatment as a family is near impossible and entails a high cost in time and money for the family who wishes to visit the patient. As well the person in the facility is isolated from family and friends.

The hospital unit that specializes in serious mental illness can be a 2 hour to 5 hour drive away. It's difficult to maintain work and social activities in a time of acute illness and the costs of caring for someone in hospital that is so far away from home is high. (petrol costs, accommodation costs, time off work, child care,.....)

There are limited to no, after school or before school programs or child care facilities in our rural area.

The support and assistance families/carers need to retain or stay in the workforce

Our view is that rural and remote mental health patients and families/carers are receiving inadequate service support and there are not enough critical services for patients and their families. As well there is no attempt by government to address the issue of distance so that families do not have to travel so much for services.

However despite this, there are families that maintain paid or voluntary work.

What makes it possible to mix work with the caring role

- Being able to reduce working hours due to your caring responsibilities
- Having an understanding work place
- Knowing the person you care about is safe and receiving adequate treatment.
- Having flexibility in the workplace
- Having an understanding of the illness and being involved in the mental health treatments so you know what's going on and what to do
- Having a clear understanding of the mental health system and knowing how and where to access services that are required
- Having the person you care about being more independent

- Not being preoccupied by the illness or worried about the future of the person
- Being able to access services early in the illness episode,
- Being able to access after hours respite care

3. THE PRACTICAL MEASURES REQUIRED TO BETTER SUPPORT CARERS, INCLUDING KEY PRIORITIES FOR ACTION

RESPONSE

It is still too common for mental health family's and carers to find themselves excluded from the treatment process for the person they are in a caring role for or to find themselves described as meddlesome or "difficult" when they raise questions about the services on offer or, more frequently, the absence of these services.

- *Ensure that services delivering mental health care are delivering those evidence based treatments that are known to work to all patients and their families, which includes having families as part of the process.*

The fluctuating nature of mental illness inhibits the access to government benefits that other carers of physical illnesses can access;

- *Address the inequities of the accessibilities for the carers payment for mental health carers*

The impact of the widespread stigma surrounding mental illness in the community marginalises and isolates families and carers.

- *Address the need for a public education programme concentrating on the education needs of rural and remote communities regarding what mental illness is and isn't, to reduce the impact of stigma and discrimination.*

There is a lack of basic understanding of the impact and the complexity of caring issues families/carers among health professionals, mental health professionals, work places, and government departments.

- *Address the education needs of health professionals, mental health professionals, work places, and government departments regarding the above statement.*

Evidence-based treatments are interventions for which there is consistent scientific evidence showing that they improve patient and family outcomes, these are not routinely being used and therefore patients and families are needlessly suffering.

Prevention, early intervention, acute care, effective community care, after hours crisis services and respite care are unreservedly inadequate (often non-existent)

- *Address the inadequacy of the mental health workforce and workforce practice in regards to the above.*

Families and Carers have not been able to access adequate respite services in rural and remote areas as they don't exist in most rural and remote areas.

- *Increase accessibility to respite services in rural and remote areas.*

Governments, policy-makers and planners seem to be unaware of the impact of changes in social and economic policies to families and carers who are caring for some one with a mental illness. *e.g. urbanization, has had negative implications for mental health patients and their families/carers.* Health services in Victoria are provided to the community on the basis of the Population Health Funding

model; which, even when 'waited' for rural and remote areas is inadequate and inequitable and leaves many rural and remote families facing massive costs that urban people never experience.

- *Implement mechanisms for monitoring the effects on of economic and social policies for rural and remote communities.*

Accessing Data on Mental Illness outcomes is appalling, (non existent) for the community thus hampering families/carers who wish to compare services and access services who are achieving positive results for their patients.

- *Improve data collection, outcome measures and quality control for monitoring and evaluating services delivering mental health care and respite agencies.*
- *Publicly disseminate reports on outcome measures and services delivering mental health care, comparing outcomes. As they currently do in the United Kingdom.*

4. 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.

Response

You can have all the strategies in the world but if you put no action on them; we have nothing!

The Senate Standing Committee on Community Affairs, Mental health services in Australia, Interim report released in June 2008 made comment on the current state of the Council of Australian Governments' (COAG) *National Action Plan on Mental Health 2006-2011*.

The committee's inquiry also followed the inquiry of the Senate Select Committee on Mental Health, which reported to the Senate in March and April 2006. That committee was established to comprehensively examine mental health in Australia.

The select committee, in its two reports, made 91 recommendations for action.

To date, neither the previous nor current Australian Government has formally responded to the select committee's report and recommendations.

Of the states and territories, only the ACT Government set out a response detailing its position on the select committee's recommendations.

Disturbingly, the 2006 select committee commented that the experiences people related 'were depressingly similar' to those presented in a report ten years earlier, the Burdekin Report (*Report of the National Inquiry into the Human Rights of People with Mental Illness, AGPS, Canberra, 1993*)

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 will not work if Governments do not respond according to the evidence presented in inquiries. Governments who fund services delivering mental health care and respite providers, using tax payers money should hold those providers more accountable – If there is no implementation of current Government policy, recommendations, and strategies (as the last 20 years of evidence confirms) and not getting improved outcomes for patients and their families, why are we continually funding them?