Submission to the Senate Select Committee on Mental Health

This submission is a personal, but informed view from a carer's perspective, and draws upon actual experience together with knowledge gained as a member of various mental health carer groups in my home State of New South Wales.

I would like to address three of the terms of reference.

TOR (b) – Adequacy of various modes of care

In a nutshell, the care available between acute episodes is considered by myself and by all the carers I know as cruelly inadequate. There are indeed community mental health teams, but these are so severely under-resourced and the case loads so high as to render them frequently ineffective in the face of the demands. In addition, they only operate in office hours. This means that early intervention and relapse mitigation is pretty much just a dream. Out of hours it is necessary for the consumer to be a danger to themselves or others for anything at all to happen, and even then the system does not respond directly, but merely places you in the hands of the long-suffering Police Service.

To their credit in our area the Police do a wonderful job, turning up rapidly and displaying significant people skills in managing the consumer. However, the downside is that in the normal case where the consumer needs taking to hospital for assessment, this occurs in ways that mostly tend to increase their agitation and to make their current condition worse. (Imagine being led by Police through an emergency department in front of waiting patients, some of whom you know.) Plus, if the consumer appears at all dangerous they will be hand-cuffed as the Police carry out their public safety duty. In some cases the consumer may be taken to the Police Station and questioned at length. More agitation. Longer in hospital to recover. Not a great use of stretched resources. And in the meantime, the confused, scared, angry carer is busily turning into a prospective consumer, thus potentially adding more load to the system.

Community-based services including non-acute care are great concepts. We now need sufficient resources to turn the idea into a genuinely workable reality.

Sadly however, even acute care is of limited adequacy. Despite recent efforts, bed numbers remain too low and many carers relate tales of their loved one being carted all over the State in the search for a bed. And to make matters worse, too many carers do not find out this is happening. Too frequently, narrow interpretations of confidentiality rights and a system based on a medical model that does not recognise or value carers (see next section) means that carers are left in the dark, desperate with worry, and ever closer to the day they too will need psychiatric care.

Having found a bed, the consumer, especially if clinically depressed, will be too often be placed in a forbidding environment that is a long way from conducive to good mental health, even for well people. We can and must do better.

TOR (g) – Role of primary carers - training and support for primary carers

The typical role assigned to carers is to be regarded as being completely outside the model of care and to be ignored. This is bizarre given that all States have adopted a de-institutionalised approach, but have minimal community-based resources. Carers and family do 95 plus percent of the caring hours. In the absence of government resources, it is inexplicable that better use is not made of carers. They are a neglected resource.

Various Australian standards, policies and guidelines do in fact recognise a real role for carers, but this seems to be largely ignored in practice, despite system rhetoric to the contrary. Implementation lags significantly. Some services have made a good effort in setting up models of carer participation in systemic service delivery and development of local policy, but genuine carer participation in individual care is essentially non-existent in any formal or institutionalised sense.

This situation persists despite a wealth of evidence that building the capacity of carers through psycho-education and through provision of support for their well-being produces measurable improvements in consumer health. Relapse rates in particular are reduced. Although some clinicians to their eternal credit do include carers in a partnership of care, real collaborative models of care, which would deliver even more beneficial results than simple psycho-education and the like, do not exist and are resisted in some quarters.

Apart from the obvious need for carers to have round-the-clock access to immediate advice and help when things are going astray with their loved one, the primary needs of carers are information on the illness and its treatment, plus help in comprehending and navigating the mental health system. This should be core business for mental health systems and will have positive paybacks way beyond the quite small direct costs.

Workers in the field are also now starting to recognise that carers go through a number of phases in their caring journey and their needs change accordingly. Whilst the initial need is for information, it is not long before the stress of caring begins to tell and a need for short-term emotional support and coping skills arises. This need I believe is best met through non-government organisations, but with government support and in a manner which is tightly linked with the mental health system. Coupled with this are the benefits that can flow from peer support groups, which may provide nothing more than tea and sympathy, but which can also be useful vehicles for delivery of coping skills education. Support for such groups would be highly cost-effective in improving consumer outcomes and thus making scarce public resources stretch further.

One of the greatest advances in the treatment of mental illness available to government would arise from the two-pronged strategy of raising carer capacity, and moving from purely medical approaches to a collaborative model of care. And as an added bonus, a few less carers would graduate into consumers.

TOR (l) – Role of education in both de-stigmatising and in provision of support service information

1. The stigma issue. Stigma continues to reach right through the community and up into government, where it is reflected in budget allocations. Committee members can test this for themselves by taking this simple test. Visit both the psychiatric acute care unit

and the cancer care unit of your local area health service. Compare the adequacy and quality of buildings, staffing, service levels, furniture and fittings, culture and attitude. You will find chalk and cheese. Then compare population cancer rates and population mental health incidence. Completely out of whack with resource allocation isn't it? I am well aware that Australian funding for health generally is quite high by OECD standards and that this makes it easy to offer the excuse that humane levels of mental health funding will cut into other health areas. But nobody said it was easy. Simple human rights nonetheless demands some re-balance of resources.

Education of the community and its public bodies is clearly and desperately needed. Success will not have occurred until the broad community regards equally all illnesses with biological underpinnings such as diabetes and schizophrenia.

2. Support service information. Mental health services, both in the government and in the non-government sectors, comprise some of the country's best kept secrets. New carers especially in the early throes of fear and confusion really struggle to find out what is available and what is appropriate. It took one carer two years to even discover that the mental health service existed.

Apart from the dysfunctional fragmentation in both sectors, experience shows that the limited and sporadic public education currently offered makes little impact. This is primarily because it is indeed limited and sporadic, but also because of an inadequate approach by mental health services wherein such education is often carried out as extra duties by well-meaning health professionals aware of the problem and trying to do their best in the absence of systemic support for psycho-education, when the scale and nature of the education needed is well outside their training and demands professional communication and education specialists, and expertly delivered and well-integrated communication strategies.

This must surely be an outstandingly valuable public investment with the highest dividends for the public purse. Better carers equal better consumers! Cheaply!

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