

BLACK DOG INSTITUTE

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TOPIC: “ A Non-Government Organisation Turning The Tide on High Prevalence Disorders”

Abstract:

It has been generally accepted that Non-Government Organisations should focus their efforts in the areas of greatest need. Public perception is that the so-called “Serious Mental Illnesses” have needed the assistance of NGO support particularly in the de-institutionalised era because of the severe reduction in government spending in mental health. NSW, for example, spends only one third the dollar per head amount of New Zealand, and is the lowest spending state government in Australia.

What has been overlooked in the analysis of mental health expenditure is that mood disorders with anxiety disorders comprise by far the largest group of mental illnesses in the community. In terms of morbidity and mortality as measured by the World Health Organisation Burden of Disease Report, depression alone will be the second largest burden of disease by the year 2020. In the developed world it is already the greatest burden of disease if mortality is excluded. Deaths from mood disorders far exceeds deaths from any other mental illness, for example of the approximately 2500 deaths by suicide each year at least 60% are estimated to result from depressive disorders. (Some estimates put a higher figure on it.) One study from Western Australia, “Duty to Care”, introduced the concept of “excess deaths” to raise awareness that many of the deaths from mental illness are avoidable. They estimated that about 400 deaths by suicide were unnecessary each year.

The incidence of depression in the community is about 5.8% at any one time, meaning that about 800,000 Australians suffer depression each year. Non Government Organisations that represent these High Prevalence Disorders (HPD) are very limited. The Black Dog Institute is one of the smaller group of NGOs to focus on this group of disorders. This paper reports on the progress of one NGO in this huge but difficult area.

Introduction: Non-Government Organisations have traditionally been initiated by concerned individuals having had experience of a need and attempting to respond privately rather than leaving response to governments alone. Consequently, there has been a mixture of approaches, services, philosophies, resources and outcomes. Perhaps the greatest strength of the NGO sector is the passion and commitment of the staff and that an NGO usually arises in response to a need to fill a gap that otherwise would not be filled. The greatest weakness of the NGO sector is lack of cohesion

between different agencies and the greater or lesser strength of lobby power, financial support and community acceptance.

The Changing Role of the NGO:

In the field of mental health, the NGO sector has become increasingly important in provision of services to patients otherwise not serviced. Perhaps the greatest policy change in mental health services in the last twenty years has been the so-called “De-institutionalisation Movement”. Without getting into the debate regarding the merits or otherwise of this policy, it is evident that one consequence has been an ever growing call on the NGO sector to provide services to the de-institutionalised population. An area of great demand has been in housing and community support particularly in regards to patients suffering Schizophrenia and other Chronic Psychoses. Collectively this group has come to be called “the Seriously Mentally Ill”. The NGO sector has responded to a perceived need by concentrating efforts on providing to these people. Notable examples are the Richmond Fellowship, the Schizophrenia Foundation, Sane Australia, the Mental Health Association and many others. Other NGOs have found themselves reacting to the occurrence of need, rather than planning in advance of the need. A notable example here is the Mathew Talbot Hostel, a religiously sponsored temporary accommodation in Woolloomooloo, Sydney. Burich et al have reported that greater than 30% of the clients of this service are former patients of mental health institutions, a change from the period prior to de-institutionalisation when few were primarily mentally ill and the establishment serviced homeless alcoholics and other homeless individuals. This NGO accepted the change in clientele by changing the service orientation of the hostel. However, this NGO had not made a policy decision to enter the area of mental illness until it found its clientele had developed in this direction. Now trained staff assist with medications and mental health service contacts.

This picture has been replicated in other organisations, and some new ones have commenced in response to the new need no longer serviced by the public sector. In NSW, a specific policy decision was made for the public sector to move out of supported accommodation in favour of NGOs where possible.

Given the previous comments about the relative strengths and weaknesses of the public and NGO sectors this has had problems in the transfer of responsibilities. Some diagnostic groups in some areas have been well catered for, whilst in under-serviced areas the lack of public services has not been replaced. A major concern for the NGO is that their funding has not been supplemented by the amount the public sector has reduced and thus one of the inherent weaknesses of the NGO sector is the lack of comprehensive services to all potential clients. Recent statistics indicate that NSW spends only one third on the state public mental health services per head of population as New Zealand, a comparable community. Australia spends roughly 1% of its health budget on public mental institutions, whereas Canada or the United Kingdom spend greater than 5% of their health budget on these facilities. This money has not gone to the NGO sector who are now largely supplying services deleted from the public sector.

A New Direction?

What is summarised here is not new and has been stated in various ways elsewhere. However what is sometimes overlooked is that the occurrence of great need due to

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change of government policy with de-institutionalisation has distracted the NGO sector from its traditional diversity of interests. In the mental health field, most organisations focus on the “seriously mentally ill”. In my examination of the “Way Ahead, Mental Health Information and Services Directory” which has an authoritative listing of NGO groups, approximately 40 of 1000 organisations are listed as directly servicing mood or anxiety disorders. What goes unrecognised is that the greatest morbidity and mortality, sometimes called “Burden of Disease”, lies with the group identified as “High Prevalence Disorders”. Mood Disorders and Anxiety Disorders are way out in front in burden of disease measurements. (WHO statistics identify Depression as the second greatest burden of disease in the current Australian community and likely to become that in the world by the year 2020).

In prevalence, depression affects 5.8% of the population in Australia. Numerically, this amounts to 800,000 people each year across the country. In mortality there are 2500 deaths by identified suicide each year in Australia.

Estimates of “Serious Mental Illness” suggest a rate of about 1% of the population or numerically about 200,000 individuals each year.

With this prevalence it would be usual to direct 75% of services to the conditions that create 75% of the burden of disease, and 25% of services to the conditions that create 25% of the burden. This does not happen in the public mental health services, partly because there is a parallel health service in the community provided by the General Practitioners subsidised by the Medicare system through the Commonwealth Government. This sector provides more service to the high prevalence disorders than to the “seriously mentally ill”. However, the NGO sector is not replicated elsewhere. If services are not provided by the public sector and not provided by the NGO sector there is no where else to turn for these services.

What are the services that high prevalence disorders require?

Mostly accommodation is not the highest priority. By the nature of these conditions there is not a relatively greater accommodation deficiency than the general community. However, there are specific needs that are neglected presently and could be met within the NGO sector.

1. Consumer and Carer Support.
2. Respite care in chronic conditions.
3. Alternative sources of therapy.
4. Financial support.
5. Family support including supportive care for children.
6. Relapse prevention.
7. Primary and secondary prevention.
8. Education for professionals and the community.
9. De-stigmatisation.
10. Population based identification of risk patterns with appropriate interventions.
11. Employment assistance including job maintenance and workplace assessments.
12. Ongoing research towards improved outcomes.
13. Access to effective and appropriate psychiatric treatment.
14. Adequate information and support in the legal framework, as many instances of legal transgression are related to psychiatric illness.

15. Anti-discrimination action.

This is not a comprehensive list of potential services that could be offered by the NGO sector, but it certainly a pointer towards such services. It is also evident that there is considerable need in these diagnostic groups that goes unmet, at least in part because these diagnostic groups do not declare themselves openly within the community for reasons relating to the relative risk of exposure versus non-disclosure.

Interventions do not have to be on a grand scale to be of benefit. Gaynor Ellis, Co-ordinator, Mental Health Resources Service, Cairns, Queensland, in a recent article (“Prevention, promotion or just survival? A consumer’s perspective” Australasian Psychiatry Vol 11 Supplement 2003) described a small intervention of great merit: “In our quest for finding solutions to some of these huge and difficult issues, we often tend to overlook the small, community responses that can turn people’s lives around. Pat Deegan’s grandmother and the “Barbie-in-the park” do not meet the standards of evidence based research. But we cannot overlook their effectiveness – certainly consumers do not. Bureaucrats should appreciate these approaches – they are low cost, rely on goodwill and are devoid of paperwork. But they are seldom, if ever, acknowledged and governments are reluctant to provide the very small amounts of funding that make the difference as to whether these types of activities happen at all.” A particular strength of the NGO system has been that it is largely consumer responsive. If consumers want a service, the NGO network is more likely to listen and respond. Public facilities because of their funding requirements, are often prescriptive to the consumer rather than responsive to them, and rely on evidence based research. The point that Gaynor Ellis makes is that there may be much that slips under the radar of evidence base that is nevertheless life changing and the NGO sector is well placed to act.

Focus of NGO Activity:

It has been customary for the NGO sector to direct its focus on the areas that have been left unattended by the public health services. In the case of the High Prevalence Disorders there remains plenty of territory to attend. However, there are different issues in different diagnostic groupings and different geographical areas. The Black Dog Institute has directed considerable energy to rural, remote and under-serviced areas. In these sites there are unique challenges. “Staff are usually required to adopt a broad approach to their work and be competent in a range of activities from individual clinical interventions to group-based prevention work and office-based administration” [ref Kowalenko et al AP supp Vol 11 2003]. In addition, many workers in such sites work in isolation. The demands on a fully staffed service in a well-serviced area such as certain parts of the metropolitan area are considerable. The demands in an under-serviced area include most of those and then more. The NGO sector is more accustomed to working in isolation and making inroads into certain areas without having to be comprehensive in all areas. Getting services into under-serviced areas requires these skills. When a base of activity is established, more comprehensive services can be introduced. It would take a greater commitment of resources and money for public services to take up these challenges than is likely to

occur in these times. Hence there is a need for the NGO sector to recognise the challenge and attack it. I do not suggest that resources be taken away from the important activities in which the NGO sector is currently engaged. There is need to expand the activities to encompass the new challenges.

The Black Dog Institute:

The Black Dog Institute is one of the NGOs that is focussed on the high prevalence disorders. It is a specialist Mood Disorder Unit, funded partly by NSW Health and partly by private fund raising. It is housed within the Prince of Wales Hospital and the University of New South Wales.

Two years ago it existed only as the Mood Disorders Unit of the Prince of Wales Psychiatric service. With NSW Health and private support it has grown and developed new and significant activities that compliment government services but do not replace or compete with them.

It has several divisions, **Clinical Services**, (on-site clinics, telepsychiatry clinics and satellite clinics at rural locations), **Education for Professionals** (General Practitioners, Psychologists and Community Mental Health Workers), **Research**, (with NH&MRC Funding), and **Consumer and Community services** so ably represented with us, and here today by Ms Sue Grdovic who is our permanent consumer and community affairs project leader. I thank her for getting me here and advising me on this talk.

There are several innovative initiatives that the Institute has developed. We conduct Telepsychiatry Services across the state. This allows some redistribution of psychiatric resources from higher concentration areas to lower concentration areas, and at the same time providing access to specialist services for people in rural and remote areas who suffer greater morbidity and mortality from mood disorders. There is also a satellite clinical service where a psychiatrist is on-site as well as via telepsychiatry to enhance the service.

The Institute also conducts Rural “Roadshows” where education for professionals in the topic of mood disorders is conducted simultaneously with a public meeting open to consumers and the community which informs and supports the public. It is hoped that in this way it becomes easier for the public to recognise and seek help for their mood disorders.

A novel initiative of the Consumer and Community wing is a “Virtual Centre” where people will be able to access high quality information and resources on mood disorders and direction on how to find help.

The Institute is most happy to conduct its activities in conjunction with other services to enhance access for all people.

Recently we have become involved with that area of mental health service that lies between the consumer and the professionals. It includes counsellors, support workers, relationship counselling, outreach workers and even religious workers such as ministers, priests and pastors. As an NGO, we feel that we can be sufficiently flexible to take up such new challenges that demonstrate need and make response in a professional fashion. The “First Aid in Mental Health” Program which is a non-government outreach program directed at the general public education has identified a need in this area of the Mental Health Arena. Contact has been made between this program and our own organisation, to which we are responding by developing a

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program for such people and piloting it in the mid-west of New South Wales in conjunction with the people who piloted the First Aid Program so successfully.

Today I have highlighted for you that NGOs have a special place in mental health service provision. They can be flexible, independent and yet able to integrate with the government organisations. I have shown you that there are some services that NGOs can offer more effectively than governments, such as the “Barbie in the Park”, without the restraint of expensive overheads to prove what should be obvious, that they do good. I have shown you statistically that overall NGOs have been distracted by the high profile of the so-called “Seriously Mentally Ill”, a term described by the President of the RANZCP, Prof Philip Boyce, as a silly phrase that does not do justice to those who may suffer Depression and other mental Disorders. That as a result there is a clear need for NGO activity in the area of Mood Disorders. Finally, I have used the Black Dog Institute as a model of what an NGO can do in these areas and the need for others to be involved.